Psychosocial Interventions to Support Breast Cancer Patients Affected by Treatment-Related Hair Loss

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A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Doctor of Philosophy

Faculty of Health and Applied Sciences
University of the West of England, Bristol

January, 2017

Word count: 77, 581

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Acknowledgements

Firstly, I would like to thank my supervisors, Di Harcourt, Nicky Rumsey, Daryl O'Connor and James Brennan for giving me the opportunity to carry out this research and for their continued encouragement, support and guidance. I would also like to thank Paul White for his statistical help.

I am very grateful to Breast Cancer Campaign for funding the research. I would also like to thank all the participants; this research would not have been possible without them.

I would like to thank all the organisations, consultants, nurses who helped me with recruitment. I would particularly like to thank Breast Cancer Care and the staff at the Bristol Haematology and Oncology Centre for showing an interest in the research and for their assistance and support with recruitment.

Also, I would like to thank everyone at CAR, particularly the postgraduates for their continual encouragement and support.

Lastly, a huge thank you to my family and friends, particularly to my mum, dad and Chris for all their encouragement and endless support. I would not have been able to get to this stage without them.

Abstract

The psychosocial impact of cancer treatment is wide-ranging, including changes to appearance, such as hair loss. To date, there is limited published research on the provision of psychosocial support for breast cancer patients who are affected by chemotherapy-induced hair loss. The aims of the research were to explore what psychosocial interventions are currently available for women, whether they have been evaluated and whether they are meeting patients' needs in order to inform the best possible provision of care for women in this situation in the future. The Medical Research Council's (MRC) framework for complex interventions and the Appearance Research Collaboration (ARC) framework, which is a model of adjustment, guided the program of research. This is the first time that the ARC framework has been used with a breast cancer population. There were three overarching research questions which the program of research aimed to answer: To what extent are interventions effective at reducing distress associated hair loss? What are individuals' experiences of current interventions which aim to support them with their hair loss? Are any further interventions needed?

The first objective was to conduct a systematic review of the available evidence of the effectiveness of psychosocial interventions to support people affected by hair loss (Study 1). A systematic search yielded eight studies, reporting on five different interventions. Characteristics of the successful interventions included: intervention delivery soon after hair loss, information provision, individual based intervention; and an opportunity for individuals to express their concerns. However, since a number of interventions currently available for breast cancer patients have not yet been evaluated, it is unknown whether they offer any benefit.

One intervention currently freely available to breast cancer patients, but which has not yet been evaluated, is Breast Cancer Care's HeadStrong service. HeadStrong is a volunteer led service offering information and support in the use of head camouflage. A mixed methods approach was used to evaluate the HeadStrong service, employing parallel qualitative and quantitative approaches. In Study 2, 25 semi-structured interviews were conducted to explore women's experiences of this service. Thematic analysis identified three main themes: facing the challenges of hair loss, experiences of receiving support for treatment-related hair loss and meeting

unmet needs. A key contribution from this study is that it is the first qualitative study of women's experiences of the national HeadStrong service. In study 3, sixteen participants elected to participate in a pre-intervention, 2 week and 3 month follow-up to examine the short and long term impact of the HeadStrong service. A benefits of HeadStrong included improvements in self-reports of confidence in managing hair loss, using headwear to camouflage it and handling the reactions of others. Participants' quality of life, emotional well-being and fear of negative evaluation were found to reduce over time and appearance-related distress and depression were all poorer at 3 month follow-up. A synthesis of the findings from study 2 and 3 suggested the HeadStrong intervention can be important and helpful for breast cancer patients affected by hair loss, but it does not necessarily meet all their needs. The research has led to the development of a number of recommendations for the provision of care, including the HeadStrong session being tailored to individuals' needs. It was highlighted that there is still potential to develop a range of interventions for this patient group.

The final study in this program of research (Study 4) adapted Pennebaker and Beall's expressive writing intervention, to explore its feasibility for breast cancer patients with treatment-related hair loss and to investigate whether the timing of the intervention and the recruitment strategy was appropriate. Nine female breast cancer patients completed the baseline questionnaire and four participants completed all follow-up questionnaires. Reasons for declining to participate included; not having the time or having difficulty writing. It was found that the intervention in its present form was not feasible for patients newly referred for chemotherapy, which may have been a result of aspects of the intervention and/or aspects of the study design.

In conclusion, support needs vary between individuals and throughout their cancer journey; not all patients want the same support with their hair loss. The following recommendations are required in order to improve the provision of care to support this patient group; it is imperative that patients are equipped with strategies to help them to manage all aspects of hair loss and available interventions need to be tailored to individual's needs, rather than relying on one strategy, such as camouflage.

Chapter One

Introduction to the Research Area

1.1 Introduction

In 2006 and 2012 the charity Breast Cancer Campaign (now known as Breast Cancer Now) arranged for a group of leading breast cancer researchers to identify the limitations of current research into the pathophysiology, detection, treatment, prevention and psychosocial aspects of breast cancer. The aim of the analysis was to determine the gaps which, if resolved, could most benefit patients, and to draw the attention of researchers and funding bodies on the highlighted areas of research (Eccles et al., 2013; Thompson et al., 2008). As a consequence, Breast Cancer Campaign's Gap Analysis stated the need for rigorously evaluated psychosocial interventions to meet patients' support needs (Thompson et al., 2008).

One area in which there has been relatively little published research in recent years is the provision of psychosocial support for chemotherapy-induced hair loss. Instead, research has focused on medical approaches to reduce hair loss, although it still cannot be prevented. Research into patients' needs has highlighted a disparity between doctors' reports of perceived patient needs and patients' reports of their actual needs; patients have reported issues including the changes to their bodies and hair loss to be significant, whereas doctors considered appearance changes to be less important (Mulders, Vingerhoets & Breed, 2008). If health professionals have a better understanding of the impact of chemotherapy-induced hair loss for individuals, they may be better prepared to provide practical and emotional support (Roe, 2011). In essence, this is the rationale underpinning the direction adopted in the current program of research.

The aim of this introductory chapter is to provide a synthesis of the literature encompassing psychosocial aspects of breast cancer and chemotherapy-induced hair loss. It begins with a description of breast cancer and chemotherapy before exploring the hair loss literature, including the importance of hair and the effect of its loss on one's wellbeing. There is a discussion towards the end of the chapter of the current services and psychosocial interventions available for those affected by this condition.

Finally, the chapter ends with an overview of the research conducted within this thesis.

1.2 Breast cancer

Breast cancer is the most pervasive cancer in the UK, with around 49,900 people being diagnosed in 2011 (Cancer Research UK, 2015). Worldwide, 1.68 million women were diagnosed in 2012 and the female breast cancer incidence rates in the UK have increased by 72% since the mid-1970s (Cancer Research UK, 2015). Men are also affected, with around 350 in the UK diagnosed in 2011 (Cancer Research UK, 2015). However, for the purpose of this research the focus will solely be on women.

Many women who are diagnosed with breast cancer experience psychosocial distress (including anxiety, depression, body image concerns, low self-esteem, and social isolation) as a result (Helms, O'Hea & Corso, 2008). Moreover, a cancer diagnosis can have a profound psychological impact which can continue years after treatment has ended (Salmon, Clark, McGrath & Fisher, 2015). This highlights the importance of interventions to support patients throughout their cancer journey, including through the transition at the end of treatment and beyond.

1.3 Breast cancer treatment

Individuals with breast cancer may receive a range of treatments including surgery, chemotherapy, radiotherapy, hormone therapy and biological treatments. The combination of treatments received depends on individual circumstances including the type of breast cancer, size of the tumour, stage of the cancer and whether the cancer cells have receptors for particular cancer drugs (Cancer Research UK, 2014). Some individuals have neo adjuvant treatment whereby they undergo chemotherapy, radiotherapy or hormone therapy to help shrink the cancer in the breast, making it easier to remove during surgery or adjuvant treatment after surgery to help lower the chance of the cancer coming back (Cancer Research UK, 2014).

Chemotherapy involves the use of cytotoxic drugs to destroy cancer cells, which disrupts their growth (Cancer Research UK, 2014). There are a variety of

chemotherapy drugs available and it is quite common for a combination of around three drugs to be used to treat breast cancer. The National Institute for Health and Care Excellence (NICE) recommends that chemotherapy treatment for breast cancer should consist of four to eight cycles of a combination of drugs (Cancer Research UK, 2014). Chemotherapy regimens are cycles of treatment, with drugs administered daily for one or more days, followed by rest days, depending on the combination of agents and dosages used.

Unfortunately, these anti-cancer drugs cannot differentiate between cancer cells and normal cells, which results in a number of adverse side effects including but not limited to hair loss, loss of nails, fatigue and sickness (Cancer Research UK, 2014; Carelle et al., 2002). However, different combinations of drugs have different side effects. Chemotherapy is the cancer treatment most likely to cause hair loss (alopecia); complete hair loss is less likely with other types of cancer treatment (Cancer Research UK, 2014). The psychosocial disruption as a result of chemotherapy may impact on patients' perception of their ability to meet role demands and personal expectations (Buick et al., 2000). The psychological and functional impairment typically increases over the course of treatment and patients often report a decline in positive affect when treatment has finished (Buick et al., 2000).

The side effects of cancer treatment, body image distress and fear of recurrence can increase psychological distress (Helms et al., 2008; Henselmans et al., 2010; Mehnert, Berg, Henrich & Herschback, 2009). No two patients are the same in terms of their cancer or their needs (Fiszer et al, 2014; Independent Cancer Taskforce, 2015), due to disease factors, psychological or social variables, socio-demographic factors or expectations based on experiences of health (Armes et al., 2009; Boyes, Girgis, D'Este & Zucca, 2012; Snyder et al., 2009). This suggests that there needs to be a flexible approach to providing a variety of supportive interventions in order to meet women's varied psychosocial needs and to facilitate their adjustment to treatment-related hair loss.

1.4 Chemotherapy-induced alopecia

As outlined above, chemotherapy treatment causes a number of adverse side effects including hair loss. Alopecia is a Greek word meaning hair loss or baldness (Welsh & Guy, 2009) and for the purpose of this thesis the words hair loss and alopecia will be used interchangeably. The term alopecia is used to describe hair loss of more than 20% (McGarvey, Baum, Pinkerton & Rogers, 2001). Relatively little is known about the pathobiology of the human hair's response to chemotherapy (Botchkarev, 2003). However, research has revealed that chemotherapy-induced alopecia can occur in two different ways depending on the phase of hair growth (Yeager & Olsen, 2011). Hair follicles are more vulnerable to damage during the Anagen (rapid growth) phase; chemotherapy during this period weakens the hair shaft causing hair to break off or fall out spontaneously when an individual washes or brushes their hair (Batchelor, 2001; Yeager & Olsen, 2011). If chemotherapy agents enter cells during the Telogen (resting) phase, hair loss will be much slower and rarely involves more than 50% of scalp hair which, as a result, produces a level of hair thinning that is often less noticeable to others but still very distressing for the individual (Batchelor, 2001; Yeager & Olsen, 2011).

Hair loss can range from slight thinning to complete baldness (Randall & Ream, 2005) including hair loss from eyebrows, eyelashes, underarm, leg and pubic hair (McGarvey et al., 2001). The extent of hair loss depends on a number of factors including the type or combination of chemotherapy drugs, the dose and the phase of hair growth (see above) (Cancer Research UK, 2014; Roe, 2011). For example, part of a drug regime for breast cancer is Anthracycline therapy, which results in complete baldness in approximately 90% of cases (Ridderheim, Bjurberg & Gustavsson, 2003). It is common for hair loss to begin within one to two weeks after chemotherapy treatment starts (Münstedt, Manthey, Sachsse & Vahrson, 1997). In most instances, individuals' hair will re-grow, however, for some it is possible that their hair will remain patchy depending on the type and strength of chemotherapy drugs used (Cancer Research UK, 2014).

Hair loss can be a very distressing side-effect of treatment for women who have been diagnosed as having breast cancer and, for some, can be harder to cope with than the

loss of a breast (Freedman, 1994). Some women describe it as the most feared and traumatic side effect of chemotherapy (Batchelor, 2001; McGarvey et al., 2001). Many women play an active role in the decision-making process regarding their breast cancer treatment (Pozo-Kaderman, Kaderman & Toonkel, 1999) and some individuals refuse chemotherapy treatment as the prospect of losing their hair is too profound (Fawzy, Secher, Evans & Giuliano, 1995; Grevelman & Breed, 2005; Roe, 2011). To date, research on alopecia predominately focuses on the loss of hair from the head and face. Hilton, Hunt, Emslie, Salinas and Ziebland (2008) propose that this is because talking about hair loss from the wider body challenges the secrecy surrounding the fact that females do not usually have a naturally hairless body.

Hair loss requires individuals to adapt to an altered appearance (Ucok, 2005). People with chemotherapy-induced alopecia frequently experience depression and anxiety due to it being a constant reminder of the presence of cancer (Pickard-Holley, 1995; Williams, Wood & Cunningham-Warburton, 1999). The visual nature of alopecia can affect individuals' body image, self-confidence, social interaction and self-esteem (Williams et al., 1999). Rosman (2003) found that a group of women who experienced hair loss after chemotherapy expressed four common reactions – feeling unprepared, shocked, embarrassed and a loss of sense of self. Furthermore, Hilton et al., (2008) found that even though some individuals are given advice and suggestions on how to deal with bodily changes, they are unprepared for the reactions of others to their altered appearance.

1.5 Techniques to prevent or reduce hair loss

To date, most interventions for hair loss have taken a medical rather than social approach, focusing on lessening hair loss through the use of methods such as scalp cooling (Delamere, Sladden, Dobbins & Leonardi-Bee, 2008; Macduff, Mackenzie, Hutcheon, Melville & Archibald, 2003). Scalp cooling aims to prevent hair loss (Batchelor, 2001) by slowing down cellular metabolism and chemotherapy delivery to the scalp (Trüeb, 2009). The process of scalp cooling typically involves a patient wearing a gel-filled cap for approximately 20 minutes before starting their session of chemotherapy and continuing to wear it during chemotherapy and for 20 minutes after treatment has finished. The cap is stored in the freezer at -25°C for at least 12

hours before the patient wears it (Auvinen, Mähönen, Soininen et al, 2010), and is changed every 20 minutes to ensure that it remains at the necessary temperature (Collett, Al-Tameemi, Dunnill, Hussain & Georgopoulos, 2014). However, the effectiveness of scalp cooling is questionable. Six out of seven randomised trials found a significant advantage in the amount of hair preserved during chemotherapy with scalp cooling (Yeager & Olsen, 2011), however, the majority of these studies were from the 1970s and 1980s and as scalp cooling technology has progressed over time; these studies are outdated.

Moreover, concerns have been expressed that scalp cooling may prevent chemotherapy from reaching cancer cells (Randall & Ream, 2005) and could allow a protective area for cancer cells to develop in the scalp (Grevelman & Breed, 2005). Furthermore, scalp cooling is not 100% effective for everyone; one of the studies that reported a significant effect found that 48% of those who received scalp cooling still suffered hair loss (Ron, Kalmus, Kalmus, Inbar & Chaitchik, 1997). Dougherty (2006) highlighted that people with a larger amount of hair experienced moderate to severe alopecia, which is thought to result from their hair having an insulating effect and preventing the scalp cooling treatment from reaching the necessary low temperatures needed. Additionally, a number of patients report extreme discomfort and numbness associated with scalp cooling (Dougherty, 2006) as well as side effects including severe headaches (Katsimbri, Bamias & Palidis, 2000; Rosman, 2004), increased anxiety (Peck, Mitchell & Stewart, 2000), nausea and dizziness (Protière, Evans, Camerlo et al, 2002). Some patients are unable to continue with scalp cooling for the duration of their chemotherapy, as demonstrated in a study where only six out of fifteen participants were able to persevere with scalp cooling for all six cycles of chemotherapy (Macduff et al, 2003). Finally, scalp cooling does not address psychosocial needs related to an altered appearance and the impact of hair loss on one's quality of life, although, interestingly, Rosman (2004) found that women who maintained their hair through the use of scalp cooling felt that it actually made them less conscious of the fact that they had cancer.

1.6 Hair re-growth

Hair re-growth normally occurs within 1-2 months following chemotherapy ending, however, approximately 65% of patients will notice a change in the appearance of their re-grown hair compared with how it looked before chemotherapy (Batchelor, 2001), as it often lacks protein following treatment, leading to a change in texture (McGarvey et al., 2001). Also, re-grown hair may be curlier (Münstedt et al., 1997) or may be a different colour which a patient might perceive as making them look older, particularly if the re-grown hair is grey (Batchelor, 2001). These changes may impact on body image and self-esteem (Power & Condon, 2008). Patients may be advised to use special shampoos and to avoid dying their hair for six months until it has strengthened (Roe, 2011).

1.7 Social significance of hair

Hair can be seen to represent an individual's identity, personality, attractiveness, sexuality and femininity (Benjamin, Ziginskas, Harman & Meakin, 2002; Nolte, Donnelly, Kelly, Conley & Cobb, 2006). It has been said that hair is a woman's 'crowning glory' (Cash, 2001). Hair is a distinctive facial characteristic, so its loss makes it difficult to manipulate and alter one's appearance (Cash, 2001). "The expression 'bad hair day', is testimony to the psychological importance of hair loss" (Cash, 2001; p. 161). Hair is an integral part of human identity; it can provide an avenue through which a woman can express her identity (Freedman, 1994). As a result hair loss may have negative repercussions on a variety of aspects of quality of life (Freedman, 1994; Batchelor 2001; Lemieux, Maunsell & Provencher, 2008). Women who lose eyelashes and eyebrows can experience problems with identity and its effect on appearance can effect social interactions (Rosman, 2004). Suffering because of a loss of control of one's bodily appearance and self-presentation may be significant and for some women can actually be as debilitating as the illness itself (Ucok, 2005).

Hair is a sign of physical attractiveness (Kacar, Ozuguz1, Bagcioglu, Coskun, Polat, Karaca & Ozbulu, 2016). From an evolutionary psychology perspective, when choosing a mate, men and women see hair as a sign of good health and a sign of

sexual maturity (Muscarella & Cunningham, 1996). From a young age, women are socialised to develop an emotional attachment to their hair (Manning, 2011). The importance that society places on women's hair is both demonstrated and influenced by its portrayal in the media and the attention given to advertising hair products (Freedman, 1994). Specifically, advertisements encourage women to buy hair care products and to invest time in ensuring that their hair is long, thick and shiny, which epitomises healthy hair (Hielscher, 2013).

The cultural importance of hair has been documented in the literature for a number of years and a movie titled "Good Hair" demonstrated the sociocultural importance of hairstyle to African American women (Stilson, 2009). For example, research has highlighted that African American women have identified hair maintenance as an important barrier to engaging in exercise (Brown, 2009; Harley et al. 2009). The majority of Black African women invest a large amount of time and money into maintaining their hair, which often includes utilising hair extensions, wigs and hair straightening (Oyedemi, 2016). This suggests that culture may be an important factor and demonstrated that hair is an important symbolism across different cultures (Etcoff, 1999).

Given the social significance attached to hair and the distress associated with its loss (Hunt & McHale 2005), it is not surprising many women adopt a strategy to hide and camouflage their hair loss in order to cope (Rosman, 2004). Batchelor (2001) argues that the importance placed on hair has diminished in present western society with individual's becoming more accepting of people with physical disabilities; these shifting views should provide hope for women who lose their hair due to chemotherapy, as the changing perspectives will promote more acceptance of hair loss. However, 15 years later there is still a large focus on hair as a key aspect of idealised images of beauty, emphasised in media images and advertisements for hair products. As society places great importance on hair, it is not surprising that hair loss can have a significant impact on an individual's body image, self-esteem and quality of life, and can result in some feeling stigmatised.

1.8 Stigma of hair loss

Stigma is defined as "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society" (Brown, Macintyre & Trujillo, 2002, p. 50). Stigma is an important issue within health psychology, as certain conditions are stigmatised and the prevalence of these stigmatising conditions are increasing with a number of individuals having a stigmatising attribute/condition (Stablein, Hall, Pervis & Anthony, 2015). A stigmatised person "is reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p.3). Research has highlighted that the main concern for a stigmatised individual is that they will become the target of prejudice and discrimination (Crocker, Major & Steele, 1998). As a result of stigma, society labels an individual as different and as a result stigmatisation can lead to prejudicial behaviour, thoughts and actions (Zierler et al., 2000). According to Goffman (1963) there are two different types of stigma; 'discredited' and the 'discreditable'; individuals are discredited when their alopecia is visible and are discreditable when they hide their hair loss. Discredited individuals have to try to cope with social judgement such as staring and pointing, which can be very distressing and potentially lead to social isolation (Rosman, 2004). In contrast, discreditable individuals such as breast cancer patients with treatment-related hair loss face the challenge of whether to disclose their hair loss. Since this is potentially stigmatising information, they are faced with the decision of who should they let know that they have a stigmatising condition (Stablein et al, 2015; Rosman, 2004). Although Goffman's work on stigma is highly respected, a main critique of his theory is the helpless role it gives to people with a stigmatised condition, as it fails to acknowledge the resistance to being stigmatised that individuals can demonstrate (Carnevale, 2007).

The fear of being stigmatised is a common fear amongst women diagnosed with breast cancer (Deniffe & Gooney, 2011). As a result, some choose to wear wigs to camouflage their hair loss, but wigs themselves can become a symbol of stigma since they can, if obvious to the observer, convey the message that an individual has lost their hair. Although hair loss is seen as a stigmatised event, for many patients it is "the price to pay for being cured" (Rumsey & Harcourt, 2005, p109). Some accept

alopecia as an inevitable consequence of chemotherapy, whereby image-related concerns may be secondary to survival issues.

1.9 The use of headwear

Some individuals accept their hair loss as a result of chemotherapy and are happy and confident to embrace their baldness (Rosman, 2004), but many patients disguise or camouflage hair loss through the use of wigs, hats, and scarves. Research has found that 83% of people reported shopping for headwear prior to hair loss in an attempt to cope with their anxieties about it (Borsellino & Young, 2011). Women engage in a variety of camouflage behaviours; total camouflage were a wig is always worn, and partial camouflage when a wig is not worn in some situations (e.g. when at home). In contrast, banalisation is where individuals do not use any form of head camouflage.

Wearing a wig allows an individual to reclaim the image that they are used to (i.e. their normality) and so helps them to restore their sense of self (Ucok, 2005). Social relationships and the actual and imagined responses of others play a significant role in determining whether or not an individual chooses to engage in the use of headwear to hide their hair loss (Ucok, 2005). Looking 'normal' takes effort, and is usually done for the benefit of self and for the protection of others (Rosman, 2004; Williams et al., 1999). Some individuals feel it is important to hide their alopecia in order to protect their loved ones from the reminder of their cancer, but wigs themselves can become a symbol of the stigma of both breast cancer and hair loss (Rosman, 2004).

Wigs are available through the National Health Service (NHS), although women may have to financially add to the amount the NHS provides for a wig if they want greater choice and quality (Roe, 2011). There are two main categories of wigs; natural hair or those made from synthetic materials, each with pros and cons. Synthetic wigs are generally less expensive than those made from natural hair, they do not require as much styling and are easier to take care of (Roe, 2011; Yeager & Olsen, 2011), but some patients find both types of wigs to be hot or itchy and head scarves and turbans offer an alternative form of camouflage. Cotton is the preferred fabric for scarves and turbans as it is less likely to slip off a smooth scalp than other

fabrics (Yeager & Olsen, 2011). Moreover, despite a number of headwear options being available, for some people camouflage can bring its own problems in relation to issues of identity, over-reliance on the camouflaged image in social interaction and fears that the 'truth' will come out (Coughlan & Clarke, 2002). Many individuals consider wigs to be unnatural and, as a result, emphasise feelings of difference (Williams et al., 1999). Therefore, headwear is helpful to an extent but has a number of challenges of its own.

1.10 Impact of chemotherapy-induced alopecia on body image and distress

Cash, Melnyk and Hrabosky (2004) describe body image as an overall attitude towards one's body, which is influenced by investment and evaluation facets. Chemotherapy-induced hair loss puts people at risk of a disturbed body image as the greater importance they place on body image and appearance, the more likely they are to experience difficulty adjusting to breast cancer and all the bodily changes that go along with it and the side effects of treatment (White, 2000). A study by Choi et al. (2014) found that 55.3% of patients in their study were either 'quite a bit' or 'very much' distressed by their alopecia. Moreover, Kraus (1999) found that women who reported decreased bodily concerns demonstrated stronger self-concepts and identities than those who placed a high value on physical appearance.

Even though chemotherapy-induced alopecia is usually believed to be temporary, the negative emotional repercussions can continue even after hair has re-grown and women may continue to feel self-conscious and experience a persisting negative self-image (Borsellino & Young, 2011; Foster, Wright, Hill, Hopkinson & Roffe, 2009), including concerns around body image, specifically when the re-grown hair is different than before (as discussed in section 1.6) (Rumsey & Harcourt, 2005). A prospective longitudinal study that explored patients' self-concept and body image before treatment, during complete hair loss, and after hair re-growth, found that self-concept and body image were poorer during treatment and did not improve or return to pre-treatment levels when hair began to re-grow (Münstedt et al., 1997). Additionally, research has highlighted that women may experience persisting body image disturbances relating to their breast cancer diagnosis and treatment which can often continue once treatment has ended (Falk-Dahl, Reinertsen, Nesvold, Fossa &

Dahl, 2010; Hartl et al., 2003; Przezdziecki et al., 2013). This demonstrates that the impact of chemotherapy-induced alopecia can be long lasting, hair loss distress is not 'temporary', and psychosocial support needs to be freely available not only throughout the course of hair loss but remain accessible once hair has re-grown. Moreover, it has been highlighted that younger women diagnosed with breast cancer have more difficulty adjusting to hair loss than older women, with lowered overall quality of life ratings linked to concerns about body image, partner relationships, sexual functioning as well as less adaptive coping styles (Avis, Crawford & Manuel, 2004; Fobair et al., 2006). This may be because society tends to place more emphasis on younger women's appearance (Fiszer et al, 2014).

Boehmke and Dickerson (2005) found that the extent of negative effects which hair loss had on their body image was dependent on how women coped with their alopecia, with some women viewing baldness as a sign of pride and courage whilst others reported feelings of trauma and a loss of identity. Loss of hair from other parts of the body, not just the head, was reported to be distressing; women reported that loss of hair from their nose caused them to experience a runny nose, which led members of the public to perceive them as sick and suggested they should go home from work (Boehmke & Dickerson, 2005). This demonstrates the practical issues related to the function of hair and the impact of hair loss.

1.11 Adjustment to treatment-related hair loss

The terms adjustment, coping and adaptation are used interchangeably within the health psychology literature (Israelashvili, 2012). A number of definitions of adjustment have been outlined, with it often being defined as "the lack of poor adjustment" (Snyder & Lopez, 2008, p. 152). However, it is unclear from this definition, what is meant by poor adjustment and how the authors' differentiate between good and poor adjustment. Alternatively, Watson, Greer, Young, Inayat, Burgess and Robertson (1988) defined adjustment to cancer as "the cognitive and behavioural responses the patient makes to their diagnosis of cancer" (p. 203). Furthermore, this definition fails to acknowledge social aspects of adaptation and does not state what successful adjustment is (Brennan, 2001). A preferred definition of adjustment is "the processes of adaptation that occurs over time as the individual manages, learns from and accommodates the multitude of changes which have been

precipitated by changed circumstances in their lives" (Brennan, 2001, p. 2-3). Dealing with the consequences of receiving a cancer diagnosis and improving psychological adjustment have become recent priorities within healthcare practices (Raingruber, 2011).

The psychological adjustment to receiving a breast cancer diagnosis can have implications both in the short and longer term (Boinon et al., 2014). It is argued that there are two different adjustment responses: positive and negative response styles. A positive response is seen to have a beneficial effect, as opposed to negative response styles, which have detrimental effects (Watson et al., 1988). A limitation of the adjustment literature is that the focus of research has primarily seen adjustment as the end point of coping, as opposed to a process of change which can fluctuate over time (Brennan, 2001).

Within both the cancer and appearance literature, attention has been given to exploring the factors and processes that might facilitate adjustment. Within cancer research, the emphasis has been on the link between availability and perceived adequacy of social support and improved psychological adjustment. The social-cognitive processing model highlights that the expression of one's thoughts and feelings about cancer in a supportive environment may facilitate cognitive processing and psychological adjustment (Boinon et al., 2014). A positive correlation has been found between breast cancer patients who repress their emotions and high levels of distress (Iwamitsu et al., 2005). Specifically, emotional support is most highly correlated with psychological adjustment in cancer (Talley, Molix, Schlegel & Bettencourt, 2010).

1.12 Current policy around provision of care for breast cancer patients

In recent years the NHS has focused on ensuring that it is patient-led and aims to improve the quality of life of patients (Department of Health, 2005; DoH, 2011). Numerous cancer policy documents have highlighted that referral pathways and services are required to meet individuals' needs (DoH, Macmillan Cancer Support & NHS improvement, 2013; Macmillan, 2014). The National Cancer Survivorship Initiative (NCSI) recommends a holistic needs assessment, so that each individual's

support needs are met (Department of Health, Macmillan Cancer Support & NHS Improvement, 2013) and Breast Cancer Care (BCC) advocate that this assessment should include questions about body image and intimacy (BCC, 2014). It is recommended that all early and locally advanced breast cancer patients are offered prompt access to specialist psychological support (NICE, 2014). Also, patients should be provided with a written care plan which includes contact details for support services (NICE, 2009).

The All Party Parliamentary Group (APPG) on Body Image highlighted the significant impact which a negative body image can have on an individual (APPG, 2012). Recent steps have been taken by organisations such as Breast Cancer Care to ensure that current policy for the provision of care for breast cancer patients includes support for body image issues. Breast Cancer Care developed a policy report titled 'My body, myself' and a body image awareness campaign (BCC, 2014, www.breastcancercare.org.uk/body) including a short film of individuals talking about their experiences of body image after breast cancer. The campaign also encourages people affected by breast cancer to write letters to their body including their feelings about their body and what has helped them to cope with their feelings. The aim of the campaign is to raise awareness of the body image issues that breast cancer patients may experience and to highlight that BCC are able to provide information and support (BCC, 2014). Breast Cancer Care recommend that national and regional breast cancer guidelines should address body image, intimacy and sex as part of routine breast cancer care and secondly, that breast units should develop referral pathways to relevant services which can provide support and information around body image issues (BCC, 2014).

1.13 Support for cancer patients affected by treatment-related hair loss

Although hair loss is a very distressing side effect of treatment for many women with breast cancer, many patients and nurses are unaware of the existing support groups and services aiming to improve patients' psychological well-being (Manning & Dickens, 2007; Mills, 2000). Supportive care aims to treat the patient as an individual and improve their quality of life (QOL) by treating the symptoms of their illness and the side effects of treatment (Fiszer et al., 2014). Yet, despite the

recognition of the importance of support, to date it is relatively unclear what level of help and/or support patients require or expect in order to successfully manage their symptoms (Snyder, Blackford, Brahmer et al., 2010; Snyder et al., 2009). Results from a systematic review revealed that a large number of women with breast cancer perceive significant unmet needs throughout their cancer trajectory, with information and psychological needs being the most prevalent, and younger age being correlated with greater needs, particularly around body image concerns and sexuality (Fiszer et al., 2014). A greater understanding of the prevalence of the needs of breast cancer patients at different times along the cancer trajectory would enable health care providers to predict when women have particular needs and could guide the development of supportive care interventions (Fiszer et al., 2014). Therefore, this highlights the importance of needs assessment, rather than solely relying on distress outcomes, as not everyone who is distressed wants help. A number of needs assessments have been developed but unless they are implemented into routine care and are used for the purpose they are designed, they are unlikely to improve patient care and outcomes. It is imperative that needs assessments are only conducted by staff who are confident in doing so and that procedures and resources are in place so that if needs are identified, appropriate help and support is available and accessible.

At the outset of this PhD program, a search was conducted to explore what psychosocial interventions and supportive care are available for breast cancer patients, and to observe whether they are specifically set out to support those who are affected by treatment-related hair loss. This search found a range of interventions and approaches, from basic information provision to more structured interventions. These are now considered below.

1.13.1 Structured psychosocial interventions

A scoping exercise was conducted to explore what psychosocial interventions are currently available for breast cancer patients. It found that structured psychosocial interventions in this area include psycho-education (Golant, Altman & Martin, 2003), Cognitive Behavioural Therapy (CBT) (Tatrow & Montgomery, 2006) and social and emotional support (Banning, 2007). A link has been found between active problem solving and improvements in the quality of life of patients with cancer, as a

result psycho-education interventions are being developed and becoming increasingly appealing (Golant et al, 2003), specifically, patient education has been found to enhance symptom management and reduce feelings of helplessness (Fawzy, Fawzy, Arndt & Pasnau, 1995). CBT interventions have been found to help reduced cancer-related distress in breast cancer patients (Tatrow & Montgomery, 2006; Mundy DuHamel and Montgomery, 2003). These interventions have included beneficial components including hypnosis, relaxation and skills training. Since social and emotional support are two key contributing factors to successful adjustment in women who have received a cancer diagnosis (Spiegel, 1997), interventions which provide social and emotional support have been developed. However, none of these interventions have focused specifically on supporting women who are affected by treatment-related hair loss.

1.13.2 Social support

Social support is an aspect of supportive care which can reduce cancer-related distress (Simpson, Carlson, Beck & Patten, 2002; Smith, Herndon, Lyerly, Coan, Wheeler, Staley & Abernethy, 2011), facilitate adjustment to cancer and improve QOL (Leung, Pachana & McLaughlin, 2014). Women may receive support from a number of sources, including their family, friends and from within the National Health Care System (NHS). Women who perceive more accessible, better quality and appropriate support are thought to cope better, leading to improved psychological adjustment (Boyle, 2006; Friedman, Kalidas, Elledge et al, 2006; Jones, 2001). The stress-buffering model of support focuses on the perceived availability, quality and appropriateness of support (Cohen & Wills, 1985). Emotional/informational support and affectionate support/positive social interaction have been found to be more important in improving health related quality of life (HRQOL) after a diagnosis of breast cancer (Leung et al., 2014).

There are a number of widely used measures of social support that assess aspects such as patients' need for and use of it, for example the Social Support Questionnaire (SSQ) (Schaefer, Coyne, & Lazarus, 1981), the Sources of Social Support Scale (SSSS) (Carver, 2013) and the Supportive Care Needs Survey (SCNS-SF34) (Boyes, Girigis & Lecathelinais, 2009). Research has highlighted a number of problems with these measures, including their variability in terms of their length and

the nature (e.g. emotional, information, practical and negative support) and sources of support being evaluated (Heitzmann & Kaplan, 1988), making it difficult to draw meaningful comparisons between studies that have used different measures.

1.13.3 Role of specialist breast care nurses

The multidisciplinary team (MDT) is core to the standard structure of UK supportive cancer care (Whelan, Griffith & Archer, 2006). UK policy recommends that all women diagnosed with breast cancer should have contact with a Breast Cancer Nurse (BCN) for information and support (Anderson et al, 2006; Lamb, Allchorne, Sevdalis & Green, 2011; NHS Executive, 1996; NICE, 2002). A link has been found between the breast care nurse role and patients' overall well-being (Halkett, Arbon, Scutter & Borg, 2006). Breast care nurses are valuable members of the multidisciplinary breast cancer team and aim to meet patients' healthcare needs through psychosocial support, education and information (Ambler et al., 1999; Amir, Scully & Borrill, 2004; Arving, Brandberg, Feldman, Johansson & Glimelius, 2007) and by doing so can enhance the patient experience (Department of Health, 2007). They can positively influence support and care by providing information around side effects of treatment including hair loss and clinical trials (Campbell, Khan, Rankin, Williams, & Redman, 2006), as well as psychosocial support (Cruickshank, Kennedy, Lockhart, Dosser, & Dallas, 2008; Voigt et al., 2011), continuity of care and better identification of patients with psychological problems (Baildam et al., 2002) and are able to signpost patients to the relevant psychosocial care as and when required.

1.13.4 Information provision

Information provision is an important aspect of supportive cancer care (Husson, Mols & van de Poll-Franse, 2011) but many patients feel that the information they receive does not meet their needs (Power & Condon, 2008). Providing information which meets patients' needs, may help to improve health related quality of life (HRQOL), anxiety and depression (Husson et al., 2011). Unfortunately, standard, mass-produced written information is generalised and not tailored to patients' individual needs and, as a result, can cause confusion and may even increase levels

of anxiety and depression (Ong, Visser, Lammes et al, 2000; Manning & Dickens, 2007). Anxiety can inhibit information processing, so even when the information is of high quality patients may have difficulty understanding it (Griggs, Sorbero, Mallinger et al., 2007).

Research has highlighted that patients who had difficulties gaining their desired level of information can be less confident in their ability to deal with health-related issues (Arora, Johnson, Gustafson et al, 2002). Until relatively recently, patients would rely on their doctors and health professionals for information, however, the development of Cancer Information and Support Centres (CISCs), telephone lines, web-based information services and government-funded initiatives have offered an opportunity to improve patient access to a wide variety of information (Manning & Dickens, 2007; Smith, Dickens & Edwards, 2005).

A small number of studies (now somewhat dated) suggest that information about side-effect management and self-care strategies can have a positive value (Ream & Richardson, 1996), yet a systematic review consisting of 57 articles highlighted that between 6-93% of patients report being unsatisfied with the information provided throughout their cancer journey from health professionals (Harrison, 2009. In addition to information provided by health professionals, the provision of information often becomes the responsibility of families, friends and support groups or helplines (Manning & Quigley, 2002). Borsellino and Young (2011) highlight how information can help patients prepare for hair loss (i.e. promote anticipatory coping) by rehearsing thoughts and behaviours (such as practicing responses to people's questions or having headwear available and feeling confident in using it). However, as evidenced above, information provision does not necessarily meet all patients' needs.

1.13.5 Online information and support groups

Cancer support groups and charities including Breast Cancer Care and Macmillan Cancer Support offer information specifically on chemotherapy-induced hair loss, including booklets, online resources and telephone helplines. Moreover, in recent years a number of online discussion forums have been developed, for example Macmillan's forum (https://community.macmillan.org.uk/cancer_types/breast-

cancer/discussions), Breast Cancer Care's online forum (https://forum.breastcancercare.org.uk/), and Cancer Research UK's online forum (https://www.cancerresearchuk.org/about-cancer/cancer-chat/). Forums enable patients to share experiences and offer support to one another. However, despite some patients finding online forums helpful, others may find them distressing if they read about someone's negative experience, or feel that others are doing better than they are i.e. upwards and downwards comparisons are at play. Upward comparisons are when an individual compares themselves to others who are in a better situation, whereas downward comparisons are with individuals who are in a worse situation (Peterson & Ritz, 2010). This further emphasises the importance of individualised information and support based on an individual's need.

A number of barriers to accessing face-to-face support have been highlighted by cancer patients, some of which include time constraints and travel barriers. Online support, including forums, offers an alternative means of accessing support (Lieberman et al., 2005; Owen et al., 2005). They may be appealing to those that suffer from social anxiety, as individuals can be accessed from their own home or any other place of their choice, and may be more confident doing so rather than accessing face-to-face support which some may find anxiety provoking (Morahan-Martin & Schumacher, 2003). An important consideration is ensuring the safety of individuals who access online support. Although online forums tend to have facilitators who regularly check the content of forums and chat rooms, it is much harder to identify those in need of support and to provide that support, compared to individuals receiving face-to-face support.

1.13.6 Camouflage-based interventions

The search conducted at the outset of the PhD found several organisations offering camouflage-based interventions for breast cancer patients experiencing treatment-related hair loss. Out of all the available interventions (see section 1.13.1 for an overview of the types of interventions), HeadStrong and Look Good Feel Better (LGFB) are most widely available in the UK and therefore these two interventions are considered in more detail below.

1.13.7 HeadStrong

The UK-based charity Breast Cancer Care offers a volunteer led service called 'HeadStrong' (www.breastcancercare.org.uk/HeadStrong). Many of the volunteers have had cancer themselves; however this is not a requirement. A session may therefore offer social support as the volunteer can share their experiences with the individual. The volunteers provide information and advice to cancer patients on using headwear to camouflage chemotherapy-induced alopecia (Breast Cancer Care, 2011). The HeadStrong service is advertised through Breast Cancer Care's website and in oncology departments. A one-to-one session with a volunteer provides advice on scalp and hair care, from diagnosis until after treatment has finished. During the session, the volunteer demonstrates how to wear a selection of headscarves and hats and provides details of where they can be purchased, if wanted. Most individuals only attend one HeadStrong session, although they can attend as many as they wish.

Breast Cancer Care have designed their own user surveys, which HeadStrong volunteers distribute to patients, to ask them about their experiences of the service. However, this is not a rigorous evaluation and patients may feel obliged to leave positive comments, especially if the volunteers hand out the user surveys and ask for them to completed and returned to them at the end of the session. Currently, little is known about the extent to which HeadStrong meets individuals' psychosocial needs. Without evaluations of large services such as HeadStrong, it is impossible to know whether the service offers any benefits to patients and if they do what those benefits are. Also, evaluations of services can enable service users to feedback suggestions and recommendations to service providers for how the services can be enriched.

1.13.8 Look Good Feel Better

Look Good Feel Better (LGFB) (www.lookgoodfeelbetter.org) originated in America in 1988 from a collaboration between the Cosmetic Toiletry and Perfumery Association (CTPA) and the American Cancer Society. Now freely available in the UK, LGFB aims to improve the self-esteem and quality of life of people undergoing cancer treatment, through the use of complimentary group and self-help beauty sessions (Cosmetics, Toiletries & Fragrances Association, 2015). The LGFB program includes beauty professionals volunteering to teach small groups of people

with cancer how to use makeup, wigs, and skin and nail products in an attempt to improve how they feel about their appearance and reduce feelings of stigmatization (Look Good Feel Better, 2014). The LGFB service is advertised through cancer information centres which are often located in oncology departments. At the end of the session, individuals are given a 'goodie bag' including various make-up products. LGFB is similar to the HeadStrong service as it focuses on the use of camouflage to cover hair loss including the loss of eyelashes and eyebrows. Numerous articles describe the LGFB service (i.e. Taggart, Ozolins, Hardie, & Nyhof-Young, 2009; Roark, 2008; Kendrick, 2008), however, only one study has evaluated the service: a pilot study found that participants reported a significant improvement in self-image, social interaction and anxiety after attending LGFB (Taggart et al., 2009). Further research would consolidate these findings. However, a critique of LGFB is that it is provided in a group setting, as opposed to one-to-one. This has a number of implications. While a group setting offers an opportunity for social support and to hear the experience of other patients, it may not suit everyone and has the potential for social comparisons to be made that increase rather than reduce distress. LGFB focuses solely on the use of make-up to camouflage hair loss, it does not provide any emotional support (although attendees may feel this is provided through contact with other patients), and has potential to reinforce appearance ideals and inadvertently make people feel like they have to use make up to camouflage their hair loss, rather than embracing the loss of their eyebrows and eye lashes.

Despite a number of charities offering information, face-to-face and online support, patients are reporting that their information and support needs are not being met (Fiszer et al, 2014; Power & Condon, 2008). To the best of the researcher's knowledge there are only two widely available services which focus on treatment-related hair loss in the UK, which are HeadStrong and Look Good Feel Better (LGFB). To date, it is unclear what benefit, if any HeadStrong and LGFB offer to women affected by treatment-related hair loss.

1.14 The theoretical framework for this research

It is imperative that condition-specific models of susceptibility to distress are available for cancer survivors, to ensure that support is tailored to those most likely to benefit (Kaiser, Hartoonia & Owen, 2010). A number of cancer models/frameworks have been developed for cancer patients, including Fuerstein, Todd, Moskowitz, Bruns, Stoler, Nassif and Yu (2010) who have developed an evidence-based model which provides a framework to help cancer survivors return to work. Gauthier et al (2012) explored the use of the Communal Coping Model (CCM) in relation to the social context of cancer pain, suggesting that people catastrophize to express distress and prompt support. Also, it has been suggested that hope theory may act as a guiding theoretical framework to explain and promote positive coping with cancer treatment (Germann, Leonard, Stuenzi, Pop, Stewart & Leavey, 2015). Naus, Ishler, Parrott and Kovacs (2009) proposed a cancer survivors adaptation model which highlights adaptation over time through goal appraisal and change. These models are currently in their early stages of development and piloting, and to date have not been widely adopted and tested.

A number of theories have been developed which can be used to explain individual differences in adjustment to an altered appearance, such as that resulting from cancer treatment (Thompson & Kent, 2001). Some models have attempted to explain appearance issues within a specific condition, however, White's (2002) cognitive behavioural model is one of few to be proposed in relation to cancer. White suggests that it is important to consider the importance that an individual places on their appearance/part of their body that has been affected by cancer and related treatment. However, to date, White's model has not been tested and ultimately there is currently a lack of models specifically around an altered appearance in cancer.

As highlighted earlier in the chapter, not everyone who loses their hair through cancer treatment is equally affected by appearance-related distress (see section 1.9), with some people adapting positively. However, it is unclear why this is. As there are a lack of theories specific to body image and hair loss in cancer, the wider altered appearance/visible difference literature was considered to explore a possible theoretical framework to guide the research in this PhD. The ARC framework was

chosen as it is a model of adjustment which allows the identification of factors which contribute to 'resilience' and positive adjustment (see figure 1) and it enables the identification and clarification of factors which have the potential to be amenable to change through psychosocial support and intervention (ARC, 2009). The framework is believed to make predictions about individual susceptibility to distress (Rumsey & Harcourt, 2012). An overview of the ARC framework is provided below. This is the first time that the framework has been used with a breast cancer population.

The ARC framework was developed as the result of a research program which sought to explore the variation in adjustment to disfiguring conditions, specifically the psychosocial factors and process which contributed to successful adjustment (ARC, 2009). Within the ARC framework, the process of adjustment to an appearance concern is theorised as having three main features. The first is the predisposing factors such as demographic characteristics, disease/treatment factors; visibility of an individual's altered appearance and the media. The media can be seen as an important predisposing factor given the importance that it places on an individual having healthy hair (Tiggemann & Kenyon, 1998). Understanding of their influence is important, however these factors are less amenable to change via interventions compared with cognitive and behavioural aspects of the framework (ARC, 2009).

Intervening cognitive processes are the second feature of the framework, believed to contribute to the difference between good and poor adjusters to appearance concerns (ARC, 2009). There can be a variation in the way a person perceives their own looks, whether it is in a positive or negative light (Sarwer & Crerand, 2004). Some of the ways in which appearance can be made more salient and prone to negative evaluation include social comparison processes and positive or negative experiences of social interactions (i.e. staring, pointing) (Green & Sedikides, 2001). In support of the important role of intervening factors, Cash (2003) argues that body image investment concerns the degree to which an individual places importance on maintaining their appearance and the degree to which appearance is central to their self-worth, whereby those with high motivational salience and high self-evaluative salience (i.e. those who place high importance on appearance and see it as a key

aspect of their self-worth) are thought to have more difficulty adjusting to an altered appearance.

The third aspect of the ARC framework is the experienced effect of appearance concerns, for example social anxiety and avoidance behaviours. Although considered as outcomes in the ARC framework, it is acknowledged that these factors can also influence the psychological setting for the intervening cognitive processes described in the paragraph above (ARC, 2009). Therefore, the outcomes can influence the intervening cognitive processes, and vice versa.

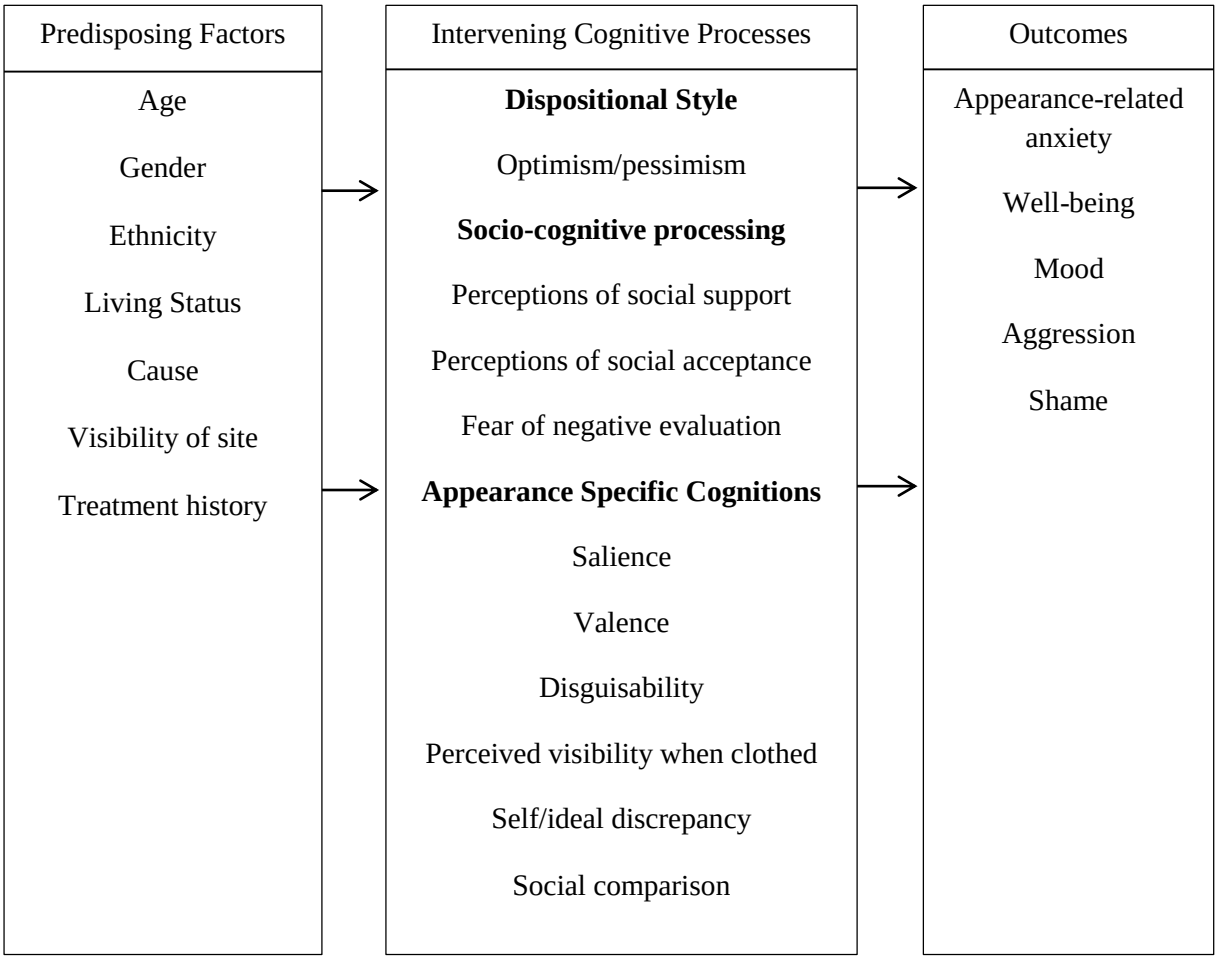


Figure 1. The Appearance Research Collaboration (ARC) (2009) research framework. Figure in Clarke, Thompson, Jenkinson, Rumsey, and Newell. (2013). CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety due to Visible Difference. Figure 3.5, p. 35. (Reproduced with copyright permission from Wiley-Blackwell).

1.15 The link between the ARC framework and the hair loss literature

By identifying the factors and processes which promote successful adjustment, researchers are able to then focus on the factors which are amenable to change, which can inform the development of interventions to support breast cancer patients who are affected by treatment-related hair loss. Women with breast cancer typically receive a variety and combination of treatments (see section 1.3), which can lead to unpreventable hair loss for many of those undergoing chemotherapy. However, the severity and extent of hair loss is not a consistent predictor of adjustment (Rumsey & Harcourt, 2004). Along with age, the significance society puts on hair and hair loss status; are all factors that are unchangeable through interventions and considered as predisposing factors to appearance-related distress in breast cancer patients affected by hair loss.

As discussed earlier in this chapter, there are a number of intervening cognitive processes that can effect an individual's adjustment to their treatment-related hair loss. As a result of hair loss, many individuals wear wigs and head scarves to disguise hair loss (Kent and Thompson, 2002). However, head wear can become a symbol of stigma, highlighting that the individual has lost their hair (Crocker et al, 1998), which can lead individuals to fear being negatively evaluated by members of the public (a discussion of stigma can be found in section 1.8). Fear of negative evaluation is therefore an appropriate intervening variable in the ARC model when relating it to hair loss. As discussed earlier, White (2000) highlighted that chemotherapy-induced hair loss can put women at greater risk of a disturbed body image if they place a higher value on appearance. It is important to remember that despite hair loss often being seen as a short term problem which will disappear once an individual's hair starts to re-grow, unexpected problems with hair re-growth such as hair being a different colour and/or texture can lead to women continuing to feel self-conscious and experience a persisting negative self-image (Borsellino & Young, 2011). Another important intervening factor is self-esteem, there is thought to be a link between higher self-esteem and a better body satisfaction (Wardle et al., 2002).

Furthermore, treatment-related hair loss can lead to a number of outcomes including a negative impact on an individual's quality of life (Leung et al, 2014); including

their confidence and even appearance-related distress (Helms et al, 2008). Also, individuals with chemotherapy-induced alopecia can experience anxiety and depression for a number of reasons, for example hair loss can serve as a reminder of an individual's cancer (Pickard-Holley, 1995; Williams et al, 1999).

In summary, the ARC framework of pre-disposing factors (in this thesis these include demographic variables, hair loss status, treatment history) and moderating factors (cognitive/thought processes including importance placed on appearance, self-esteem and fear of negative evaluation) may determine psychosocial adjustment to treatment-related hair loss as indicated by relevant outcomes (e.g. appearance-related distress) (See Figure 2).

A guiding theoretical framework for this research has been developed based on the ARC (2009) framework.

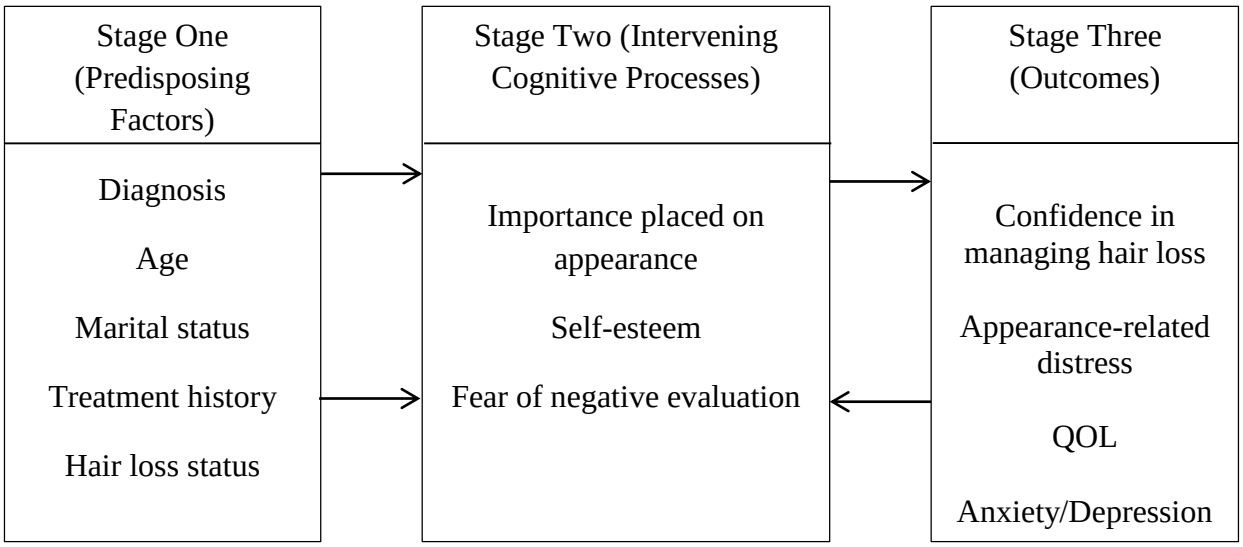


Figure 2. The guiding theoretical framework, informed by the ARC (2009) framework, in Clarke, Thompson, Jenkinson, Rumsey, and Newell. (2013). CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety due to Visible Difference. Figure 3.5, p. 35. (Reproduced with copyright permission from Wiley-Blackwell).

1.16 Research questions

As a result of the scoping exercise, it has become apparent that interventions such as HeadStrong and LGFB are available to women affected by hair loss during or after

chemotherapy, but it is unclear what service users' experiences of their services are and whether their needs are being met through existing interventions. Therefore, this PhD thesis aims to answer the following research questions:

1. To what extent are interventions effective at reducing distress associated hair loss?
2. What are individuals' experiences of current interventions which aim to support them with their hair loss?
3. Are any further interventions needed?

In order to answer these research questions in a rigorous manner, the MRC framework for complex interventions (outlined in chapter 2) was used to guide the research, alongside the ARC framework (outlined above). The ARC framework helped to inform the particular constructs deemed relevant and the selection of measures, whereas, the MRC framework informed the choice of a series of individual studies within the research program. For example, the initial phase of the MRC framework advises that relevant theory is explored to ensure the best choice of intervention. Therefore, the first objective was to conduct a systematic review of previous research that has evaluated the effectiveness of interventions to support people who have experienced hair loss. The findings of this review were then used to inform the second stage of the research which was to evaluate the HeadStrong service, in order to gain an insight into individuals' experiences of the service and to explore whether further interventions were required. This work was guided by the first phase of the MRC framework which highlights the importance of identifying the components of an intervention. The second phase of the MRC framework highlights the importance of describing the components of an intervention and developing a protocol. Therefore, the findings from the HeadStrong evaluation informed the decision to explore the feasibility and acceptability of an RCT of an existing expressive writing intervention that has not previously been used to support women affected by cancer-related hair loss (see chapter 6). Figure 3 demonstrates the structure of the thesis and different stages of the research.

In keeping with the recommendations of the MRC framework, the first study in this research program was, therefore, a systematic review of current interventions.

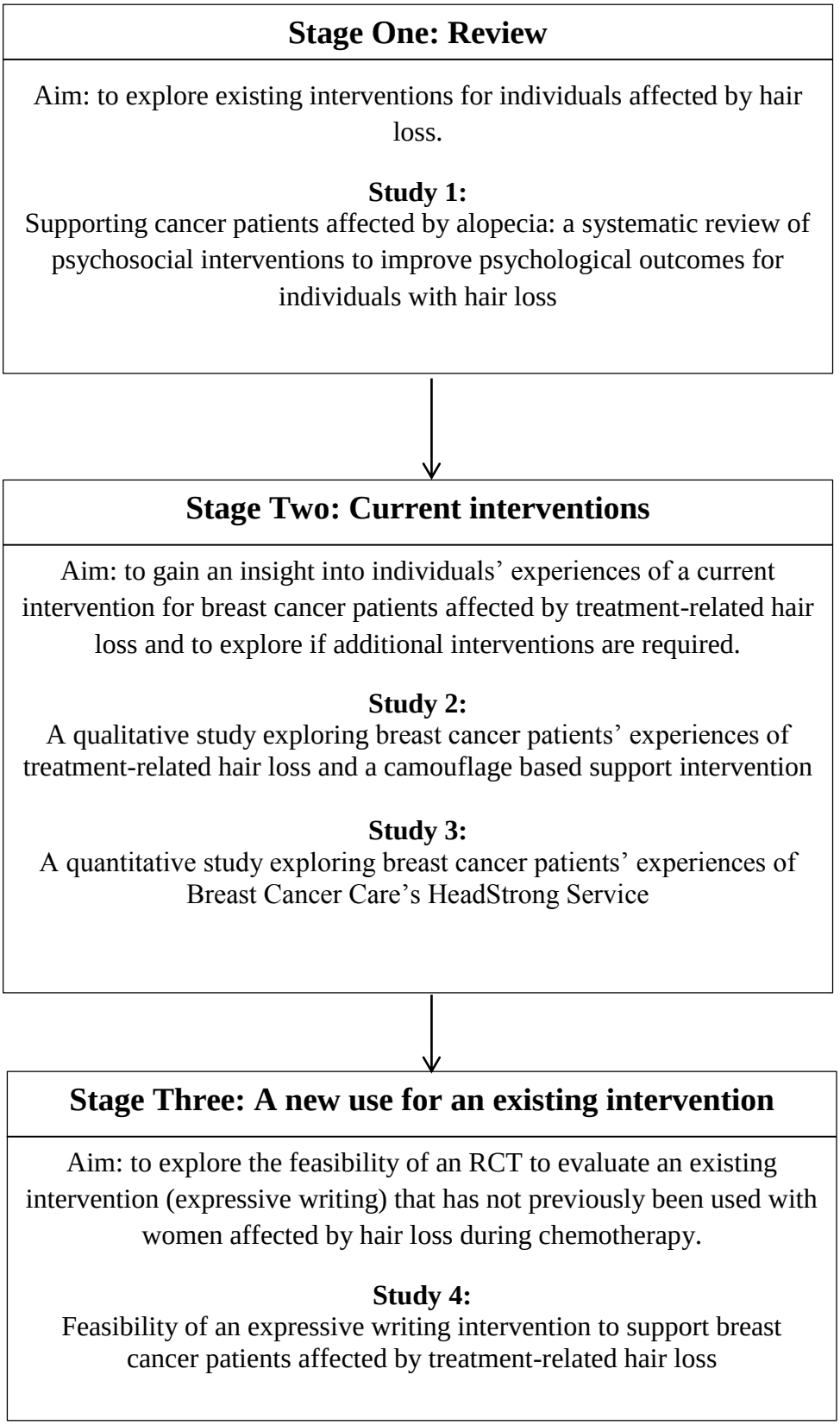


Figure 3. The structure of this thesis, including the stages of the research and individual studies.

1.17 Conclusion

Hair loss presents those affected with a variety of significant challenges. It is difficult to prepare individuals for chemotherapy-induced alopecia as the experience is different for everyone and individuals' psychosocial needs vary (Independent Cancer Taskforce, 2015). Some people adjust to an altered appearance due to cancer treatment with relative ease, whilst others find it more difficult. Medical interventions available for chemotherapy-induced alopecia, such as scalp cooling, are not always effective and do not address patients' psychosocial needs. As highlighted above, there are a number of freely available support services (e.g. NHS wig service, HeadStrong, Look Good Feel Better) for breast cancer patients who are affected by treatment-related hair loss. However, these services tend to focus on disguising or covering up hair loss and offer very limited psychosocial support, and a scoping exercise has revealed no published evaluations of the NHS wig service and HeadStrong, so the benefit they offer to patients is unknown. Therefore, it is still important to explore what psychosocial interventions are currently available for patients, whether they have been evaluated and whether they are meeting patients' needs in order to inform the best possible provision of care for women in this situation in the future.

1.18 Summary of the key points in this chapter:

- Currently there is limited published research into the provision of psychosocial support for breast cancer patients affected by chemotherapy-induced hair loss.
- An appraisal of the adjustment, social support and stigma literature has helped to explain the prevalence of appearance-related distress that women with breast cancer can experience as a result of treatment-related hair loss.
- This is the first time the ARC framework of factors and processes influencing adjustment to an altered appearance has been used in research with a breast cancer population.
- There are three main research aims within this thesis;

- To explore the effectiveness of psychosocial interventions aiming to improve psychosocial outcomes and appearance-related distress for people affected by hair loss due to chemotherapy
- To gain an insight into service users' experiences of current interventions
- To explore whether additional interventions are required.

1.19 The next stage of the research

It is evident that the impact of treatment-related hair loss can be diverse and extremely distressing for individuals' affected by treatment related hair loss, however, little is currently known about the psychosocial support available for individuals affected by hair loss or whether the available interventions have been evaluated. The following chapter discusses the findings from a systematic review which explored the available psychosocial interventions for individuals' affected by hair loss.

Chapter Two

Supporting Cancer Patients Affected by Alopecia: A Systematic Review of Psychosocial Interventions to Improve Psychological Outcomes for Individuals with Hair Loss

2.1 Introduction

Alopecia and its corresponding psychosocial problems have been reported in the literature for a number of decades (McGarvey et al., 2001; Williams et al., 1999). However to date, we know little about the psychosocial support currently available for patients affected by hair loss, nor whether these interventions have been evaluated. As a result, it is unclear how successful they are in meeting individuals' needs and helping them to manage their distress. Lemieux, Maunsell and Provencher (2008) conducted a literature review to explore the effects of alopecia on quality of life outcomes for breast cancer patients, and suggested that rigorous evaluations of interventions for cancer-related hair loss are still needed (Lemieux et al., 2008). From a scoping exercise and discussions with experts in the field, it became apparent that there is still a paucity of research in this topic area, and no evidence (from searching the Campbell Collaboration, Cochrane, NIHR Centre for Reviews and Dissemination (CRD) and Database of Abstracts of Reviews of Effects (DARE) databases) that previous attempts have been made to conduct a systematic review of the evidence currently available.

This is therefore the first systematic review to explore the effectiveness of psychosocial interventions in this area.

2.2 Aim

- To explore the effectiveness of psychosocial interventions for individuals affected by treatment-related hair loss.

2.2.1 Identification of the research question

This review was seeking to answer the following questions:

- What types of psychosocial interventions for patients experiencing hair loss have been evaluated?
- Are these interventions effective in reducing patients' distress?
- What are the characteristics of effective interventions?

2.3 Method

2.3.1 Rationale for inclusion/exclusion criteria

Booth and Fry-Smith's (2004) PICO model (**P**opulation, **I**ntervention, **C**omparison, **O**utcome) was used to guide the focus of the literature selection criteria (cited in Centre for Reviews and Dissemination, 2009). The **P**opulation were defined as adults (>18 years) who were experiencing clinical hair loss (it was not limited to cancer patients since it became apparent, when conducting a literature search and a scoping exercise in chapter one, that few interventions solely for breast cancer patients exist). Children and adolescents were excluded from the review, since the cognitive changes, developmental and health trajectories facing these groups mean they have specific and differential intervention needs to those of adults (Holmbeck, 2002); and because it was important to relate the findings to adults with breast cancer in the rest of the thesis. Interventions and studies with patients with terminal cancer were excluded, as the psychosocial issues facing these patients differ from those with a good prognosis, who should hopefully regain pre-cancer quality of life and continue with a normal life trajectory (Downey & Engelberg, 2010). Patients with trichotillomania (a disorder whereby an individual has an uncontrollable urge to pull their own hair out) were also excluded as this is more of a behavioural issue, and it is believed that these patients have different interventional needs to those who lose their hair as a consequence of treatment or a genetic or inherited condition.

Whilst acknowledging that randomised control trials are the gold standard for scientific rigour and can help to reduce selection bias and increase internal validity

(Blackwood, O'Halloran & Porter, 2010; Bottomley, 1997; Feneck, 2009), it was decided that a sensitive search strategy and an inclusive approach to synthesising data on a range of psychosocial **I**nterventions and study designs was appropriate, making no assumptions about the nature and type of study design that may affect the outcomes. Any psychosocial intervention specifically designed to target patients experiencing clinical hair loss was sought.

The **C**omparison with the intervention could be either a passive or active control group or pre and post intervention. Considering the relevance of **O**utcome measures to the development of the search strategy, this review focused on both quantitative and qualitative studies as long as they included psychosocial outcomes (i.e. quality of life, self-esteem, body image, appearance concerns). Lemieux et al (2008) informed the decision to use broad aspects of QOL as the outcome.

2.3.2 Summary of the inclusion criteria

- Adults (>18 years) who are experiencing clinical hair loss.
- Psychosocial interventions to support patients affected by clinical hair loss.
- Comparison with an active or passive control or a pre and post intervention comparison.
- Outcome evaluation using a quantitative or qualitative measure of psychosocial outcomes i.e. quality of life, self-esteem, body image or appearance concerns related to hair loss.
- Published in the English language.

2.3.3 Exclusion criteria

- Hair loss due to ageing
- Studies of children/adolescents <18 years of age
- Patients diagnosed with a terminal illness
- Patients with trichotillomania

2.3.4 Search protocol

Electronic searches were conducted on the following databases: Allied and Complimentary Medicine Database (AMED), Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index (BNI), Campbell Collaboration, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, Embase, Medline, PubMed, PsychINFO, Science Direct, Science Citation Index, UK Pubmed Central. For each database specific MeSH terms were identified for the broad terms; hair loss (for example: alopecia, hair$) + psychosocial intervention (for example: psycho$ intervention, social$, exercise, social support, cognitive behave$) + quality of life (for example: quality of life, QOL, body image, appearance, self-esteem) and were entered as search terms (see appendix 1 for a list of databases and search terms used). Prior to conducting the systematic review, a meeting was held with a colleague with expertise in the topic area, in order to identify potential hair loss and psychosocial intervention terms. No limit was set on publication date; this was to remain consistent with the inclusive nature of the review. An initial search was carried out in February 2012 and then again in June 2014, to capture any subsequent papers that had been published.

The process of article selection is demonstrated in the Quorum Flow Chart (Altman et al., 2001) in Figure 4. During stage one, ineligible and duplicate articles were eliminated and the remaining abstracts were reviewed independently by two reviewers in stage two. Full copies of papers were retrieved for the relevant articles and these were then independently reviewed by the same two reviewers during stage three, according to the literature selection inclusion criteria. To aid with this final process, a Data Extraction table (see table 1) detailing the inclusion criteria was devised for both reviewers. Elements of the Effective Public Health Practice Project (EPHPP, 2010) quality assessment tool combined with elements from the Consolidated Standards for the Reporting of Clinical Trials (CONSORT) statement described by Altman et al. (2001) were used to extract data from the studies. Any disputes concerning the inclusion of a paper were reviewed by a third reviewer, with experience in conducting systematic reviews.

Alongside electronic searches, ‘grey’ searches were also conducted, including hand searches of relevant articles and the journals in which the papers that had met the

review's inclusion criteria had been published. Experts in the field who had published relevant articles (i.e. Biondo & Collins, 2003; Fox, 2003; Roark, 2008) proposing the benefits of psychosocial interventions were contacted to see whether these interventions had since been evaluated.

2.3.5 Assessment of the scientific quality of the evidence

For the purpose of the review, scientific quality was defined as "the extent to which a study's design, conduct and analysis have minimised selection, measurement and confounding bias" (Agency for Healthcare Research and Quality, 2002, p. 2). Due to the variable nature of study designs included, the assessment of scientific quality was based on the Effective Public Health Practice Project (EPHPP) tool for assessing quantitative studies. Alternative tools including the Cochrane Collaboration Risk of Bias Tool (CCRBT) were considered, however, it was decided that the EPHPP would be more appropriate as studies have shown it to have better inter-rater agreement in both individual domain scoring and final grade assignment compared to the CCRBT (Armijo-Olivo, Stiles, Hagen, Biondo & Cummings, 2012). Additionally, Spencer, Ritchie, Lewis and Dillon's (2003) framework was used to assess the quality of qualitative studies.

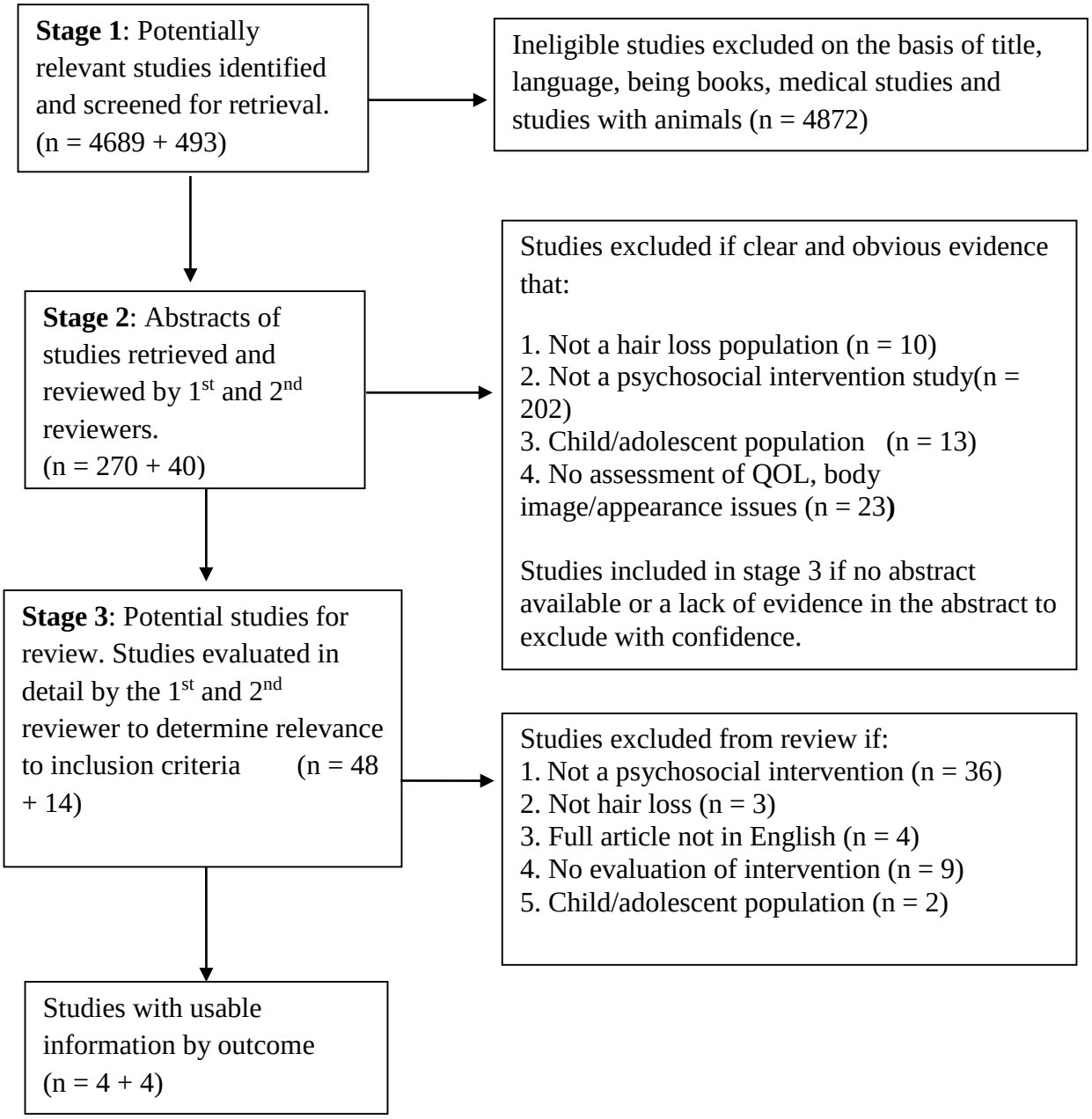


Figure 4. Quorum Flowchart. Numbers in brackets refer to citations identified by electronic database and citations by other sources (grey searches).

2.4. Results

This section discusses the results of the systematic review, specifically the types of interventions included, their effectiveness and the quality of their evaluations.

2.4.1 Systematic literature review

The Quorum diagram (see Figure 4) demonstrates the results of the initial database search (4689 abstracts) and the addition of abstracts from the grey search, which included articles added from bibliography checks and expert referrals (493). Articles were excluded because they were not written in English, were animal or medical studies, or were book chapters. The remaining 310 abstracts were read by two independent reviewers.

Abstracts were excluded if they were not a hair loss population (10), not a psychosocial intervention (202), involved children (13) or if there was no assessment of an aspect of QOL including body image/appearance concerns (23). There was general agreement between reviewers on which abstracts met the inclusion criteria. Disagreement occurred because a number of abstracts were not clear whether the study was an intervention, or lacked information about evaluation. A noteworthy point is that, in many studies, QOL or body image was not a primary outcome and was therefore not highlighted in the abstract. Due to the limited information available, it was decided to include all the studies where agreement could not be reached in the next stage of the review, in an attempt to provide a thorough review of all the evidence available. Therefore when abstracts could not be excluded with confidence, full papers (62) were retrieved and reviewed by two independent reviewers.

From these full papers, studies were excluded if they were not a psychosocial intervention (36), not a hair loss population (3), provided no evaluation of the intervention (9), the full articles were not available in English (4) or the population were children/adolescents (2). A total of 8 articles (4 of which were obtained from grey searches) were retained, reporting on 8 different interventions.

It is relevant to note at this stage that the interventions described below were excluded on the basis that they described services that had not been evaluated:

- Roark (2008) described the ‘Look Good…Feel Better’ program which offers a free cosmetic workshop to women undergoing chemotherapy.

- Ehmann, Sheehan and Decker (1991) explored the entrepreneurial role of oncology nurses and incorporated the development of a patient education program and booklet, along with professional education sessions.
- Fox (2003) looked at the benefit of a web-based news group for individuals with alopecia universalis. The aim of the study was to assess themes of discussion rather than to evaluate the web-based news group as an intervention.
- Kalabokes (2011) described the National Alopecia Areata Foundation as a support group.
- Biondo and Collins (2003) proposed a group psychological intervention for women with hair loss.
- Clarke and Evans (1990) designed an interactive TV program, available in waiting rooms, to offer information to patients.
- Fawzy, Secher, Evans and Giuliano (1995) described the Positive Appearance Centre, designed to support patients in managing the cosmetic side effects related to their diagnoses and treatment.
- Vandegrift (1994) described the development of an oncology alopecia wig program.

The following interventions were excluded as they did not meet all the inclusion criteria for this review: -

- Both Reinfold (1960) and Sandok (1964) lacked details of the intervention, its duration and who delivered it. In addition, Reinfold (1960) included participants under the age of 18 and Sandok (1964) did not include any detail of outcome measures.
- A hypnotherapeutic management intervention by Willemsen, Vanderlinden, Deconinck and Roseeuw (2006) was not included in the systematic review as it included participants under the age of 18 years.

- Willemsen and Vanderlinden (2008) provided details of the hypnotherapeutic intervention and examples of individual participant cases but no evaluation.

Table 1. Systematic review data extraction table

Citation	Intervention	Study Design	Participant Selection, Response Rate, Descriptive Statistics	Instrument/Measures	Data Analysis	Findings	Effect size	*P*
McGarvey et al (2010)	**Computer-imaging program** (HAAIR) **Timing** Newly diagnosed cancer patients **Delivered by:** Clinical nurse specialist/ research team **Process evaluation** With normal samples, recovered cancer pts and HCP's **Fidelity** Good **Replicability** Good	RCT **Type of control** Usual care **Measures** Baseline (T1) Following hair loss (T2) 3 month follow-up (T3)	Convenience sample of female cancer patient with current diagnosis of breast, ovarian, lung, blood, melanoma with chemotherapy treatment associated with alopecia **Treatment received** No details **Total n in study:** 25 (intervention) 20 (control) **Response rate/attrition** T1 & T2 97.5% completed measures. 1 pts dropped out at T3- 95% completed all 3 assessments/ 1 **Mean age** 51.7 (intervention) vs. 50.9 (control) **Ethnicity** 76% white/Caucasian (intervention) 83.3% white/Caucasian (control) **SES** Demographically representative **Degree of hair loss** Complete hair loss 60% (intervention)	**Name** Brief Symptom inventory (BS1-18) **Description** 18-items measuring general psychological distress **Name** Importance of Hair questionnaire (IHQ) **Description** 20-item self-rating scale **Name** The Brief Cope **Description** 24-items measuring various coping methods. Items coded into either active or avoidant coping. Qualitative data	**Baseline group** **Comparison** Yes: BSI-18- at baseline more pts in intervention not expressing Clinical levels of Psychological distress. **Intention to treat analysis** No	**Qualitative feedback**: pts found HAAIR system easy to use and the educational rules useful.100% pts found it enjoyable or glad they used it. Virtually trying on wigs and changing hair styles was not as exhausting as in real life. **BSI-18:** No significant interaction between time of visit and intervention group. No sig differences between groups. **IHQ:** T2 significant decline in distress from baseline in both groups. At T3 hair loss distress continued to decrease in intervention group. No sig interaction between treatment and time (p = 0.079) **Brief Cope:** Pts had higher	Statistics power not optimal at 0.75 for testing a treatment effect size	Sig level was set at p = 0.05

			65%(control) almost 40% (intervention) 35% (control)	obtained through ended questions.		active than avoidant coping styles (p <0.001). Coping styles did not change significantly over time. Avoidance coping positively correlated with hair loss (p = 0.328, p = 0.032) and GSI (*p* = 0.667, *p* < 0.001)		
Willemsen et al (2011)	**Hypnosis** Duration of session: 1 hour Sessions include discussions on various topics. Next is a 40-minute manual- based hypnosis session. First two sessions focused on learning hypnotic relaxation and on learning self-hypnosis. From the third session patients received a variety of suggestions during hypnosis to improve self-esteem. Patients received a self-hypnosis CD and were asked to perform exercises on a daily basis.	Pre-test & post-test cohort study **Type of control** No control **Measures** Baseline (T1) end of hypnosis treatment (T2) 6 months follow- up (T3)	Convenience sample of patients referred for AA willing to attend a psychosomatic dermatology consultation. **Treatment received** No details **Total n in study:** 24 **Response rate/attrition** 3 pts dropped out: 1 due to lack of motivation. 2 due to failure to concentrate while listening to self- hypnosis audio tape. **Mean age** 41.95 (SD 13.79) **Ethnicity** no detail **SES** no detail **Degree of hair loss**	**Name** The Toronto Alexithymia scale (TAS-20) **Description** 20-item self-report scale **Name** The Symptom Check list (SCL-90) **Description** Evaluates a broad range of psychological problems and symptoms of psychopathology. **Name** SF-36 (version 2.0) **Description** Assesses health	**Baseline group** **Comparison** No **Intention to treat analysis** No	Hypnosis intervention had significant effect at T1, T2 & T3. Improvements at T2 were maintained 6 months later. **SCL-90:** Improvements found at T2 & T3 compared to T1. Significant decrease (*p*= 0.001) in total SCL-90 scores and subscale scores measuring anxiety, depression and sensitivity. Improvements in psychological well-being persisted 6 months after treatment. **SF-36-HRQOL:** 4	1%= small, 6% moderate 14% large for partial eta squared 0.2-= small, 0.5 = moderate, 0.8 = large for cohen's d	Sig level was set at p = 0.05

						HRQOL		
	Timing Newly referred to Dermatology	30-49%= 14% pts	related quality of life.			parameters, 1 for physical (p=0.01) and 3 for mental		
	clinic for AA	50-74% = 14% pts 75-99% = 33% pts	**Name**			HRQOL (p=0.001) demonstrated pts continued to report a better		
	Delivered by:	100% = 39% pts	Skindex-17			QOL 6 months post treatment.		
	Research team		**Description**			**TAS-20:** significant		
	Training of deliverer		A dermatology specific			improvement from baseline, significant decrease		
	No details		HRQOL instrument.			in alexithymic		
	Process evaluation					characteristics at T3.		
	No details					Post hoc pairwise comparisons		
	Fidelity					showed moderate to large effect for TAS-20, SCL-90 and for most SF-36 mental QOL scores at T2 % T3 compared to T1.		
	No details							
	Replicability							
	Good							
Nolte et al (2006)	**Videotape Intervention (Best Look Forward)** 45 minute video presenting make-up techniques and suggestions for hair and head pieces. Videotape viewed at either home or clinic.	RCT **Type of control** Standard care **BI Measured** Pre, prior to the 3rd course of chemo and post intervention after **Treatment received** Chemotherapy 100% no other details **Total n in study:** 68 (intervention) 68 (control) **Response rate/attrition**	Opportunity sample of Gynaecological patients with stage 0, 1, 2, 3,	Body Cathexis/ Self-Cathexis Scale (BSCSC) **Description** Two components: Items related to 46 body parts and functions. Asked to rate feelings on a 5 point scale.	**Baseline group** **Comparison** No **Intention to treat analysis** No	Small but significant (p= 0.045) change in body image at course 3 but no change in self-esteem. No intervention effect found for either body image (p= 0.74) or self-esteem (p= 0.57).	No mention of effect size	Sig level p = 0.05

	Timing After hair loss had been established **Delivered by:** Gynaecological Oncology Staff **Training of deliverer** No details **Process evaluation** Evaluated by oncology nurses for appropriateness of content **Fidelity** No details **Replicability** Good	4th course of Chemo	No details **Mean age** 57.7 **Ethnicity** 93% Caucasian **SES** no detail **Degree of hair loss** No details	Single score derived from mean score of the 46-body items. Second component: 55 items that represent a sampling of various conceptual aspects of self.		Qualitative feedback: all except 3 pts reported videotape to be helpful. One person thought the videotape should be provided earlier. Four pts found the makeup portion of the video unhelpful. All pts reported they would recommend it to other women experiencing hair loss. **Negative effects** None stated		
Taggart et al (2009)	**Look Good Feel Better Workshops** Cosmeticians teach skin care, make-up techniques and wig and hair alternatives. 2 hour free sessions **Timing** Median time since diagnosis 7.5 Months **Delivered by:** Look Good Feel Better staff	pre, post-test **Type of control** No control **BI Measured** Pre, post workshop and by telephone 2-4 weeks later	Purposive sample of pts enrolled in 12 workshops **Treatment received** No details **Total n in study:** part A 18 in questionnaire stage, 3 interview stage; part B 10 in questionnaire stage, 7 in interview stage **Response rate/attrition** No details	**Name** Part A: The Negative self-Concept Scale (NSC) subscale of Derriford Appearance Scale (DAS) **Description** High scores indicated lower self-image **Name** Part A: The Social Self-Consciousness	**Baseline group** **Comparison** No **Intention to treat analysis:** No	**Quantitative Data: Part A: Self-image**: significant (p< .005) improvement immediately post workshop but not long-term. **Part A: Social Interactions**: Statistically sig reduction in self-consciousness scores (p <.01) **Part B: Anxiety**: significant	No mention of effect size	Sig level set at p = 0.05

Training of deliverer

No details

Process evaluation

Pilot study

Fidelity

No details

Replicability

Good

Mean age

Not enough detail (11 were 45 to 64)

Ethnicity

Not enough detail (47% Canadian born)

SES demographically representative

Degree of hair loss:

No details

of Appearance (SSC) subscale of the DAS

Description

Explored avoidance behaviours, distress in social situations and feeling misjudged due to appearance

Name

Part B: State-Trait Anxiety Inventory (STAI) state subscale

Description

Completed pre and post workshop. Scores range from 20 (lowest anxiety) to 80 (highest anxiety).

Name

Part A & B: Qualitative-semi structured telephone interviews

Description

Interviews lasted 10-20 minutes and were conducted 2 to 4 weeks

reduction in anxiety scores ($p < .01$)

Part A: self-image: pts fell into two categories 1) feeling workshop had minimal impact on self-image 2) those feeling it had a positive impact.

Part A: Social interactions: 3 major themes; usual routine, no differential treatment; positive impact.

Part A: social support: Women felt comfortable surrounded by other women with cancer but did not necessarily feel the workshops , were a source of social support.

Part B:Anxiety: 3 major themes: sources of anxiety, workshop experience, workshop outcomes; people. Workshops resulted in reduced anxiety, satisfaction

			post workshop with women who had completed the questionnaires.		with workshop content and experience.		
Roberts et al (1997)	**Support Group Intervention** Uses standard group therapy techniques to provide psychological support. Psychoeducational techniques incorporated information provision and problems solving. 6 topics were included. Duration of session: 90 mins **Timing** 11 less than 2 yrs since diagnosis, 3 more than 2yrs since diagnosis **Delivered by:** Oncology social workers **Training of deliverer:** Experts **Process evaluation** No detail **Replicability**	Cohort **Type of control** No control **Measures** Pre & post test	Opportunity sample of Breast, Gynaecological cancer, Leukaemia, Lymphoma, Marfan's syndrome, Melanoma **Treatment received** 9 completed therapy 2 under observation 3 chemotherapy **Total n in study:** 14 originally **Response rate/attrition** 3 completed 3 or fewer sessions and and were eliminated **Mean age** 29.7 (SD 3.56) **Ethnicity** 12 white, 1 Native American, 1 African American **SES:** no detail **Degree of hair loss:** No detail	**Name** The Profile of Mood states (POMS) **Description** 65 items or symptoms **Name** The Cancer Rehabilitation Evaluation System (CARES) **Description** 45-item scale with 5 subscales. **Name** The Ways of Coping Checklist (WCCL-R)	**Baseline group** **Comparison** No **Intention to treat analysis:** No	Significant improvement found on subscales of fatigue (p =.072), confusion(p = .058) and in total mood (p = .080). **WCCL-R**: no sig changes in coping mechanism. **CARES**: significant change on the medical interactions subscales (p = .031) **Qualitative data**: four major areas of helpfulness identified Concerns about appearance were addressed by group members on introduction to a member wearing a hat and pts began to share experiences of baldness.	No mention of effect size	Sig level set at p = .10 due to small sample size

	Good			**Description** 68-item to assess the use of coping strategies in response to specific stressors.		
Salonen et al (2011)	**Individual face to face support** Intervention focused on providing support and information according to individual needs. Duration: 1 hr **Timing** 6 months after breast cancer Surgery **Delivered by:** Trained nurse/Physiotherapist **Training of deliverer:** No detail **Process evaluation:** **Fidelity** Good **Replicability** Good	Quasi-experimental two-group design. Trained nurses gave numbers to pts and those with even number were assigned to the intervention group. **Type of control** Usual care **Measures** Intervention group: 2 weeks after intervention. Control group: 6 month after surgery	Breast cancer patients admitted for treatment and/or follow up to an oncology clinic in Finland. **Treatment received** Breast cancer surgery, chemotherapy, radiotherapy, hormone therapy. **Total n in study:** 204 (112 intervention group, 92 control group) **Response rate/attrition** Originally 359 gave informed consent: 120 received telephone intervention as 61 dropped out, 108 received usual care as 70 discontinued the study and so 202 received either face-to-face support or usual care. **Mean age** Control: 57.7 **Ethnicity** no details	**Name** Ferrans and Powers Quality of Life Index-Cancer Version (QLI-CV) **Description** Measures satisfaction with various domains and the relevant importance of each domain to the individual. Each part consists of 33 items **Name** The European Organization for Research and	**Comparison group** No	Women with better body image were aged > 55, ($p < 0.001$) Women who had no chemotherapy ($p < 0.001$) or hormone therapy ($p < 0.01$) had a better body image than women who received chemotherapy or hormonal therapy as adjuvant therapy.

			SES: most women had vocational education and were employed **Degree of hair loss** No detail	Treatment for Cancer Breast Cancer- Specific Quality of Life Questionnaire. (EORTC QLQ-BR23) **Description** Consists of 23 items		
Zannini et al (2012)	**Aesthetic care program** Explored the perceived effects if an aesthetic care program for Italian women affected by chemotherapy-induced alopecia. Study investigated what ways cultural factors influence a women's choice of camouflaging chemotherapy-induced alopecia with a wig. **Timing** 10 women in active chemo 10 women in follow-up **Delivered by:** Oncologist, social workers, sociologists, hairdressers **Training of deliverer** Interview training **Replicability**	Qualitative study using IPA **Type of control** No control	Convenience sample of 20 Sicilian women who had suffered or who were suffering from chemotherapy-induced alopecia who had participated in an aesthetics program **Treatment received** 100% had received chemotherapy **Total n in study:** 20 **Response rate/attrition** No detail **Mean age** 53 **Ethnicity** no details **SES** demographically representative **Degree of hair loss** Selection of women who had suffered or were suffering from chemotherapy-induced alopecia	**Name** Interpretative Phenomenological analysis **Description** IPA was used as it recognises the central role of the analyst in making sense of the personal experiences of pts.	**Baseline group** **Comparison** No	**Seven themes emerged from the analysis:** Reactions to cancer: anger, incredulity and the desire to fight. Chemotherapy and it's collateral effects are acknowledged as unavoidable. Even if it's expected, alopecia is experienced as a traumatic event that challenges a women's femininity. The ambivalent perceptions of the hair cutting/ shaving 'rite'. The wig is positively perceived because it camouflages the baldness and reduces the 'sick

	Good					aspect' of a women affected by chemotherapy- induced alopecia. The wig is worn mostly for others, out in public, but in some cases women wear it also for themselves. Hair re-growth presents the visualisation of the healing process
Amiel et al (2009)	**Beauty Care in Hospitals** Evaluated programmes: simple beauty care delivered by a cosmetician in the hospital; beauty care provided by a socio-aesthetician (a cosmetician who had done extra training); image advice; image advice and socio-aesthetics service. Gustave Roussy Cancer Institute (IGR) created the image advice and socio-aesthetics.	Retrospective Qualitative study using direct observation and semi-structured interviews. **Type of control** No control **Measures** Qualitative analysis **Timing** No specific details	convenience sample of professional service providers working in a hospital where cancer patients are treated, professionals, patient users treated for Cancer **Treatment received** No detail **Total n in study:** 6 Professional service providers 11 Health professional 60 Patient users (40 main survey) (20 complementary service) **Response rate/attrition** Not reported	**Name** Direct observation and semi-structured interviews **Description** To explore psychopathological dimensions of body deterioration and the relationship between the patient and the beauty care service.	**Baseline group** **Comparison** No **Intention to treat analysis:** Not reported	**A number of themes were identified:** Perceptions of physicians & nurse. Experiences and perceptions of patient users. Cancer and treatment-related changes. Psychological investigation of the cancer-and treatment-related effects.

Delivered by: A Sociologist delivered survey. A Clinical psychologist delivered the complementary service. **Training of deliverer** No detail **Process evaluation** No detail **Replicability** Good	**Mean age** 53.18 (main survey) 48.75 (complementary service) **Ethnicity** No details **SES** No details **Degree of hair loss** No detail	Beauty care How they managed to find out about the beauty care and how frequently they used it. Identifying services offered. Relationship with professional care provider. Benefits perceived by the users and expectations. Characteristics of beauty care. Patient user expectation. Value of services provided.

2.4.2 Types of interventions

The articles included in the systematic review reported on three different types of interventions; 4 focusing on behavioural techniques to camouflage hair loss (Taggart et al, 2009; Amiel et al, 2009; McGarvey et al., 2010; Nolte et al, 2006), 3 providing psychological support (Zannini et al, 2012; Roberts et al, 1997; Salonen et al, 2011) and 1 based on hypnosis (Willemsen et al, 2011).

Details of the interventions and the theoretical basis behind their development (if available) are described in table 2.

Table 2. Description and theoretical basis of interventions included in the systematic review

Citation	Intervention	Description	Theoretical Basis
Nolte et al (2006)	***Best Look Forward' Videotape'*** 45 min videotape viewed at home or at clinic	45 min videotape with real patients presenting make-up techniques, hair/ head piece solutions. Presents info in a positive, uplifting but realistic Manner	Evidence of effectiveness in video modelling in facilitating clinical decision-making, reducing anxiety and physiologic arousal.
McGarvey et al (2010)	***Computer-imaging program (HAAIR.*** Individual 60-90 min session at clinic.	Pts facilitate photograph being taken, 4 images of pts faces were displayed on the screen, optional images available for pts to choose from i.e. individual with bald head, wearing different wigs/hair styles	To determine whether a single session of HAAIR would help prepare patients in advance of hair loss and elicit anticipatory coping. Could the program desensitise patients to hair loss as well as educate them about alopecia.
Willemsen et al (2011)	***Hypnosis*** one-to-one 1 hour session. 1 introductory session followed by 10 individual sessions.	Sessions include discussions family or work stress, quality of sleep, feeling ashamed, low self-esteem. Next is a 40-minute manual based hypnosis session; first two sessions focused on learning hypnotic relaxation and learning self-hypnosis; from the third session patients received a variety of suggestions during hypnosis to improve self-esteem. Patients received a self-hypnosis CD and were asked to perform exercises on a daily basis.	To explore whether hypnosis would improve psychological outcomes.

Taggart et al (2009)	***Look Good Feel Better Workshops*** 2 hour, free, product neutral workshop, 8 times a month.	Cosmeticians and hair alternative specialists teach about skin care, make-up techniques and wig and hair alternatives.	Helping women manage the appearance-related side-effects of treatment to improve a women's self-image and social interactions whilst providing social support.
Roberts et al (1997)	***Group Support intervention*** Incorporation of psychoeducational techniques. 90 minutes sessions over the course of 6 weeks.	Standard group therapy techniques to provide psychological support; establish group cohesion and emphasise the universality of young adult problems. Psychoeducational techniques incorporated information provision, problem solving and stress management. Six topics of discussion included; health, loss of physical well-being, concern about children, problems with relationships, financial and vocational concerns; feelings of unattractiveness.	Evaluated the effectiveness of intervention in reducing psychological distress and enhance coping skills and quality of life of participants.
Salonen et al (2011)	***Individual face-to-face support*** Focus on providing support and information based on individual needs. Delivered 6 months after breast cancer	Intervention was provided by physiotherapist. Teaching and information given about illness, education on general health, support and counselling on physical functioning and guidance, counselling on stress related problems, opportunity for participants to ask questions, opportunity for participants to talk about their feelings, providing information	Based on Ferran's conceptual model of QOL, comprising of health and functioning, socioeconomic, psychological and spiritual; and family. Based on individualistic ideology.

	surgery. Duration: 1 hour.	about support groups and rehabilitation services in the area.	
Zannini et al (2012)	***Aesthetic care program*** Qualitative study using Interpretative Phenomenological Approach	Study investigated what ways cultural factors influence a women's choice of camouflaging her chemotherapy- induced alopecia with wigs.	Trying on wigs and different hair styles can help patients develop anticipatory coping and these programs are forms of emotional and psychological support. Program provides info provision.
Amiel et al (2009)	***Beauty Care in Hospitals*** Qualitative study	Evaluated programs: simple beauty care delivered by a cosmetician in the hospital; beauty care provided by a socio-aesthetician by a cosmetician who had extra training; image advice and socio-aesthetics service Gustave Roussy Cancer Institute (IGR) created the image advice and socio-aesthetics	Cancer patients offered more and more access to beauty care in hospital. Evaluated beauty care as a supportive care and as a service providing comfort.

Taggart et al's (2009) cosmetic/beauty care program ('Look Good Feel Better') was designed to help individuals manage the appearance related side effects of treatment, aiming to improve self-image and social interactions. Amiel et al (2009) evaluated four different aesthetic programs, delivered either by a cosmetician, socio-aesthetician (the authors failed to state exactly what a socio-aesthetician is), image advisor or an image advisor combined with a socio-aesthetics service.

Nolte et al's (2006) videotape intervention consisted of real patients presenting make-up techniques and hair/head piece solutions. The aim of the video was to reduce anxiety and promote decision making. In contrast, McGarvey et al's (2010) computer-imaging program enabled individuals to see what they would look like with a bald head and wearing different wigs and headwear.

Zannini et al (2012) aimed to help individuals develop anticipatory coping and also offer forms of emotional and psychological support. Roberts et al's (1997) intervention used standard group therapy techniques to provide psychological support, plus psycho-educational techniques including information provision to reduce distress and enhance coping skills. Salonen et al's (2011) face-to-face intervention, delivered by a physiotherapist, provided support and information based on the participants' individual needs, and an opportunity for participants to talk about their feelings. Willemsen et al's (2011) intervention used hypnotherapy for general relaxation and ego strengthening.

Nolte et al's (2006) videotape intervention was a single 45 minute session and McGarvey et al's (2010) computer-imaging program was a single 60-90 minute session. The hypnosis intervention (Willemsen et al, 2011) consisted of an introductory one hour session followed by 10 x 1 hour sessions. Look Good Feel Better workshops (Taggart et al, 2009) were provided eight times per week and lasted for two hours; participants included in the evaluation had attended at least one session. The group support intervention (Roberts et al, 1997) consisted of 6 x 1 hour sessions, and the individual face-to-face support intervention (Salonen et al, 2011) was for one hour (no details of number of sessions provided). The mode of delivery included one-to-one interventions (Nolte et al, 2006; McGarvey et al, 2010; Willemsen, 2011, Salonen et al, 2011) and group support (Roberts et al, 1997).

2.4.3 Scientific quality

To assess the scientific quality of the studies, the EPHPP tool was used as a guide to assess the quantitative studies and Spencer et al's (2003) framework was used for assessing the qualitative studies. The following sections summarise the scientific quality of the papers included in the systematic review.

All the interventions were described; however some papers provided more details and clarity than others. Within psychological research, there have been discussions around the importance of replicating research in order to confirm the reliability of findings (Francis, 2012; Simons, 2014). To enable the replication of research studies, it is important that researchers document the process involved in their research. However, the ability to replicate both the interventions and studies within the systematic review ranged from poor (Amiel et al, 2009), where the authors had provided no information regarding the psychosocial element of the intervention and provided no interview schedule, to good, where manuals or materials were referred to (Nolte et al, 2006; Roberts et al, 1997; McGarvery et al, 2010; Taggart et al, 2009; Zannini et al, 2012; Salonen et al, 2011), interview schedules used in qualitative studies or a clear description of the elements of the intervention were provided (Roberts et al, 1997; Willemsen et al, 2011).

It is important that a researcher has a sound theory and an evidence-based understanding of their topic of enquiry, in order to identify the outcomes of an intervention (Bos, Schaalma & Pryor, 2008). The theoretical basis underpinning the choice and design of the intervention within the review were generally weak. Only Salonen et al, (2011), Roberts et al (1997) and Nolte et al (2006) described the theory or model which guided their interventions and none of the interventions were underpinned by a model of body image.

Positive aspects of the reporting of the studies included providing a detailed description of the timing (all included studies did this, except for Amiel et al, 2009 and Roberts et al, 1997), duration (except for Zannini et al, 2012 and Amiel et al, 2009), mode of delivery and who delivered the intervention. Interventions were provided pre and during treatment (McGarvey et al, 2010; Nolte et al, 2006; Taggart et al, 2009) and post treatment (Salonen et al, 2011, 6 month after cancer surgery;

Willemsen et al, 2011 at 6 months follow-up). In Zannini et al's (2012) study, half of the participants were currently receiving treatment and half had completed it. Details of who delivered the interventions were generally provided but details of any specific training given to the intervention deliverers were lacking, with the exceptions of Zannini et al (2012), Roberts et al (1997) and McGarvey et al (2010) who stated that the clinical nurse specialist and research team delivering their intervention were trained in delivering it. With regards to settings, interventions were delivered in hospitals (McGarvey et al, 2010; Taggart et al, 2009; Zaninni et al, 2012; Amiel et al, 2009; Salonen et al, 2011) or clinics (Willemsen et al, 2011; Nolte et al, 2006; Roberts et al, 1997).

2.4.4 Participants

All of the studies provided details of how participants were selected and recruited. Purposive or convenience sampling techniques were utilised (i.e. recruitment from hospitals or clinics by nursing or research staff). Amiel et al (2009) and Zaninni et al (2012) were the only two studies to specifically acknowledge that their participants were not a representative sample of the population of individuals receiving beauty care/aesthetic care in their hospitals.

Half of the studies provided response and attrition rates, the exceptions being Nolte et al (2006) (videotape intervention), Taggart et al (2009) (Look Good Feel Better workshops), Zaninni et al (2012) (aesthetic care) and Amiel et al (2009) (beauty care in hospitals). Salonen et al's (2010) response rate was 56% (originally 359 gave consent and 202 completed the study), there was a 79% response rate for Roberts et al (1997) (14 originally and 3 dropped out), 80% for Willemsen et al (2011) (24 originally and 3 dropped out) and McGarvey et al (2010) reported a 97.5% response rate at T1 (baseline) and T2 (following hair loss) and 95% at T3 (3 month follow-up). Of the studies which provided response rates, only Willemsen et al (2011) reported participants' reasons for dropping out (1 participant for lack of motivation and 2 for not concentrating during self-hypnosis).

All studies provided demographic characteristics of the participants (although Taggart et al (2009) provide very limited details), with the most common detail

being age (mean age ranged from 29.7 to 57.7 years). Most papers reported ethnicity (most participants were Caucasian) and socio-economic status (SES).

Disease characteristics for the studies including cancer patients were outlined well, including degree of hair loss, type and stage of cancer, time since diagnosis and treatment received (as appropriate). The studies varied widely with regards to their sample of patients; two studies included a mix of cancers (McGarvey et al, 2010; Roberts et al, 1997), one study only recruited patients with alopecia areata (with more than 30% hair loss), alopecia totalis or alopecia universalis (Willemsen et al, 2011), one study (Nolte et al, 2006) only included patients with gynaecological cancer, Salonen et al (2011) only included breast cancer patients and three studies included patients experiencing chemotherapy but did not state the type of cancer that participants had (Taggart et al, 2009; Zaninni et al, 2012; Amiel et al, 2009).

Only four studies reported the treatment which participants were receiving; all those in Zaninni et al (2012) and Nolte et al (2006) had only undergone chemotherapy, those in Salonen et al (2011) had undergone breast cancer surgery, chemotherapy, radiotherapy and/or hormone therapy and those in Roberts et al (1997) were at various treatment stages (nine had completed therapy, two were under observation (the authors failed to provide specific details of what stage the patients were in their treatment journey when being observed), three were receiving chemotherapy).

2.4.5 Design

Study designs varied from randomised control trials (RCTs) (McGarvey et al, 2010; Nolte et al, 2006); pre and post-test cohort studies (Willemsen et al, 2011; Taggart et al, 2009; Roberts et al, 1997), quasi-experimental design (Salonen et al, 2010) to qualitative studies (Zaninni et al, 2012; Amiel et al, 2009). Of the two studies employing an RCT design, both used a usual care group as the control and provided details of what constituted ‘usual care’.

The studies had varying follow-up times. Willemsen et al (2011) measured outcomes 6 months post intervention, McGarvey et al (2010) had outcomes at 3 months post intervention, Taggart et al (2009) measured outcomes 2-4 weeks post intervention and Salonen et al (2011) two weeks after intervention. However, it is possible that 2-

4 weeks post intervention is not long enough to determine whether the intervention is effective in the long term.

2.4.6 Outcome measures

Of the six quantitative studies, a variety of body image, appearance satisfaction and quality of life (QOL) measures were used, assessing a variety of components including psychological distress, physical appearance satisfaction, self-acceptance, avoidance behaviours, appearance-related distress in social situations, feeling misjudged due to appearance, and importance of hair. One study reported on measures designed specifically for hair loss (McGarvey et al, 2010) and 2 used measures designed particularly for cancer patients (Salonen et al, 2010; Roberts et al, 1997). Nolte et al (2006) designed their own body image measure specifically for gynaecological patients. The remaining studies used a variety of widely-used measures (for example State-Trait Anxiety Inventory, Profile of Moods Status) to assess psychosocial outcomes in addition to body image or QOL.

The measures were well described in most cases but the detail about their psychometric properties was inconsistent and generally weak. Therefore, it is difficult to determine whether they actually assess the constructs that the researchers were interested in. The majority of studies reported reliability data (except for Taggart et al, 2009) but none reported the specific content, face and predictive validity of measures and only Roberts et al (1997) commented on validity, acknowledging that without a control group there was a possible threat to internal validity.

2.4.7 Methods of data collection and analysis

Data collection and analysis were well reported and appropriate for the design of most studies. The majority that used comparison groups (apart from Nolte et al, 2006) tested for differences in baseline demographics, and Salonen et al (2011) also tested for baseline differences in treatment variables between the intervention and control group. When positive effects were found, only McGarvey et al (2010) and Willemsen et al (2011) reported effect sizes. Roberts et al acknowledged that not having a control group was a limitation of their study.

Of the two qualitative studies, Zaninni et al (2012) used Interpretative Phenomenological Analysis (IPA) to analyse their interviews and highlighted a number of limitations of their study: three different researchers were involved and interviews were conducted by the individuals who designed the aesthetic care program, which could have led to a reporting bias. Amiel et al (2009) failed to state the specific approach they used to analyse their interviews and observations, stating that 'conventional methods' were used (Amiel et al 2009; p.840).

2.4.8 Conclusions and considerations of adverse effects

All of the studies provided a clear summary of their findings which were justifiable and discussed in relation to past evidence. However, very few had used theory from the body image and psychological literature, despite hair loss being highlighted as having an impact on self-reported distress and body image. The majority of studies highlighted limitations, discussed their implications and suggested how these may be rectified in future research. None of the studies reported negative effects from participating in the intervention or comparison group.

2.4.9 Generalisability of findings (external validity)

Most studies addressed external validity but only when discussing the study's limitations. The majority of authors acknowledge that biased, opportunistic sampling, lack of a control group and small sample sizes (which resulted in data with low statistical power) limited the generalisability of their findings.

Small sample sizes are typical of research exploring sensitive topics such as hair loss and its impact on psychosocial outcomes. However, published studies often fail to discuss their recruitment strategies, making it difficult for other researchers to know which strategies are effective and which are not (i.e. Jennings et al, 2014). Some of the current studies highlighted recruitment as being difficult, with total sample sizes as low as 14 (Roberts et al, 1997), and as a result it is difficult to be confident that the effectiveness of the intervention has been tested. Exceptions include Nolte et al (2006) (68 intervention group, 68 control group) and Salonen et al (2010) (112 intervention group, 92 control group) which had relatively large sample sizes in their intervention and comparison groups, allowing for effectiveness to be evaluated.

Moreover, Amiel et al (2009) had a rather large sample size (77) for their qualitative study. Within qualitative research, a researcher generally collects data until saturation has been reached (O'Reilly & Parker, 2013). It has been argued that the more similar (homogeneous) participants are in a sample with regard to their experiences, the sooner saturation will be reached (Guest, Bunce & Johnson, 2006). Guest et al (2006) postulates that a larger sample size is often required if a sample is heterogeneous, the quality of the data is poor and the research questions are vague. As the participants in Amiel et al's (2009) study were a combination of service users, service providers and health professionals, a larger sample size would be expected due to the heterogeneity of participants.

Three studies excluded individuals on the basis of issues of mental health or due to physical co-morbidities (McGarvey et al, 2010; Nolte et al, 2006; Willemsen et al, 2011). McGarvey et al (2010) and Nolte et al (2006) excluded those with prior experience of cancer or alopecia. Nolte et al (2006) also excluded individuals who had a history of disfiguring surgery, drugs, disease or radiotherapy. Willemsen et al (2011) excluded those who had received local Alopecia Areata (AA) treatment in the preceding four weeks, systematic AA treatment in the preceding six months or psychopharmacological treatment or psychological counselling in the previous six months. Despite the fact that many authors reported that they refined inclusion criteria to reduce confounding factors, they failed to acknowledge the limited generalisability of their findings to the many individuals who do not meet the inclusion criteria.

2.4.10 Which interventions work, how well, for whom and in what settings?

The effectiveness of the eight different interventions was mixed. A noteworthy point is that given the small sample sizes of some studies, the effectiveness of the interventions cannot be accurately tested. Four showed improvements in either all or some of their measures, two studies found only a very small improvement in body image (Nolte et al, 2006) or distress over hair loss (Salonen et al, 2011). In the qualitative studies, Zaninni et al (2012) and Amiel et al (2010) both reported that the majority of participants found the beauty and aesthetic care to be beneficial.

Zaninni et al's (2012) aesthetic care intervention and Amiel et al's (2009) beauty care intervention will be addressed first. Zaninni et al (2012) explored the perceived effects of an aesthetic care program for Italian women affected by chemotherapy-induced alopecia. Using IPA of semi-structured interviews it was found that wigs were perceived positively due to their ability to camouflage hair loss and reduce the 'sick aspect' of women affected by chemotherapy-induced alopecia. Amiel et al's (2009) intervention of beauty care in hospitals found that physicians and nurses were unable to distinguish between beauty care and socio-aesthetics. The beauty care was found to be a 'morale booster' and was a good learning experience.

The quantitative evaluations found small improvements: Nolte et al's (2006) single session videotape intervention targeting patients with gynaecological cancer and established hair loss had only a small significant change in body image after the third course of chemotherapy, but no interaction effect between intervention and time. In Salonen et al's (2011) individual face-to-face intervention for breast cancer patients, a small clinical difference was found between groups in terms of sexual functioning and distress associated with hair loss. However, there was no follow-up in these two studies, so they were unable to determine their benefits in the longer term.

McGarvey et al's (2010) computer-imaging program found a significant decline in hair loss-related distress in both groups from baseline, and this distress continued to decrease in the intervention group at 3 month follow-up. However, no significant interaction was found between intervention and time. In Taggart et al's (2009) study of 'Look Good Feel Better' workshops, a significant improvement in self-image was found immediately after the workshop but not long-term. A significant improvement was also found in self-consciousness, anxiety, fatigue, confusion and total mood in Roberts et al's (1997) group support intervention.

Willemsen et al's (2011) ten session hypnosis intervention over a six month period found improvements at the end of hypnosis and at follow-up compared to baseline on the symptom checklist-90 (SCL-90), with significant decreases on the anxiety, depression and sensitivity subscales. Improvement in psychological well-being persisted six months after the intervention. Significant improvements were also found on the Skindex-17 (a dermatology specific health related quality of life measure), particularly on the physical and mental health QOL subscales.

Furthermore, participants continued to report better QOL 6 months after the intervention.

To summarise, it remains difficult to establish which elements of the interventions were beneficial in terms of psychosocial outcomes to the individuals experiencing hair loss. A summary of the key features of these interventions can be found in table 3. Specifically, they were delivered immediately or soon after hair loss/or cancer diagnosis and included hypnosis, promoting and providing information around the use of head wear and make up to camouflage hair loss, information provision, a trained professional delivering the intervention, individual intervention, and an opportunity for individuals to express their concerns.

Table 3. Summary of the key features of the interventions included in the Systematic Review

Citation	**Timing**	**Sessions**	**Setting**	**Mode of delivery**	**Delivered by & to whom**	**Content**	**Intervention components improvements found**
McGarvey et al (2010)	Immediately after diagnosis	1	Hospital	One-to-one	Clinical nurse specialist, also a cancer survivor	Computer takes pts photo, optional images are available for pts to choose i.e. bald head, diff wigs/hair styles	Less hair loss distress after intervention.
Willemsen et al (2011)	Newly referred to Dermatology Clinic	10	Outpatient clinic	One-to-one	Research team to patients with AA referred to clinic	1.Discussion on family or work stress, quality of sleep, feeling ashamed, low self-esteem. 2. Hypnosis sessions: learning hypnotic relaxation, learning hypnosis sessions. 3. Variety of suggestions to improve self-esteem.	Significant improvements in psychological well-being. Better QOL reported 6 months post hypnosis intervention.

						4. Pts asked to perform self-hypnosis twice a week	
Nolte et al (2006)	Immediately after hair loss has been established	1	Clinic	One-to-one	Gynaecological oncology staff	1.Video presenting make-up techniques and suggestions for hair and head pieces 2. Info provision	Small but significant change in body image after the fourth course of chemo
Taggart et al (2009)	Median time since diagnosis 7.5 months	No details provided	Hospital	One-to-one	Look Good Feel Better team to cancer patients	Cosmeticians and hair specialists teach pts about skin care, make-up techniques and wig and hair alternatives	Significant improvements to self-image post intervention, reduction in self-consciousness and sig reduction in anxiety score.
Roberts et al (1997)	11pts less than 2yrs since diagnosis, 3 pts more than 2	6	Clinic	Group	Oncology social workers to cancer patients	1. Psychological Support 2. Psychoeducational techniques	Overall improvement on mood scores. Overall helpfulness of program identified for universality of shared

	yrs since diagnosis					including info provision, problem solving, stress management 3. Discussion on anxiety about health, loss of physical wellbeing, concerns about children, problems in relationships, financial and vocational concerns, feelings of unattractiveness	experiences, therapeutic group support & receiving information.
Salonen et al (2011)	6 months after breast cancer surgery.	1	Clinic	One-to-one	Trained nurse and physiotherapist to patients admitted to Oncology Clinic for treatment and/	1. Teaching and providing info about illness. 2. Giving instructions for home exercises. 3. Offering concrete support	87% of women reported the intervention to be beneficial to them. 83% felt the individual support had helped them. 85% felt the opportunity to talk had helped them.

		or follow up who had breast cancer surgery 6 months ago.	and counselling in physical functioning and providing guidance about how to use upper limbs. 4. Giving general health education. 5. Counselling on stress related problems. 6. Giving women a chance to talk about their feelings and a chance to ask questions. 7. Providing info about rehabilitation and support groups in area.	Women in the intervention group were more upset by hair loss than those in the control group- however half pts in both groups did not answer this question.

Zannini et al (2012)	Active chemotherapy & follow-up	1	Hospital	One-to-one	Oncologist, social workers, sociologists, hairdressers to patients suffering from treatment-related hair loss	1. Perceived effects of aesthetic care program. 2. What cultural factors influenced women's choice of camouflage.	Wigs considered best way to camouflage baldness & make women feel stronger. Wigs worn mainly for others or for women themselves. Hair re-growth presents visualisation of recovery
Amiel et al (2009)	No details	1	Hospital	One-to-one	Sociologist & clinical psychologist to professional service providers, health professionals & patient users treated for cancer	Evaluated: 1. Simple beauty care delivered by cosmetician in hospital 2. Beauty care provided by socio-aesthetician 3. Image advice 4. Image advice and socio-aesthetics service	Ability to ask questions to socio-aesthetician they could not ask usual hairdresser. Beauty sessions as a distraction from treatment. Helped pts accept side effects of treatment. Beauty care as form of advice & psychological support

2.5 Discussion

2.5.1 Summary of main results

The overall efficacy of the interventions in this review was poor; if they were evaluated in an adequately powered way then the research and conclusions that can be drawn from it would be stronger. Most interventions were of short term duration and evaluation follow-up, with the longest follow-up being six months. Therefore, their effectiveness in the longer term is unknown. One indication of the effectiveness of an intervention would be to include long term outcomes. This is particularly important, given the duration of hair loss. Despite their limitations, some of the positive aspects include the benefits of the interventions being delivered immediately or soon after clinical hair loss, providing an opportunity to express emotions, delivery by a trained professional and on an individual basis.

Combinations of the elements of the EPHPP tool and the consort statement provided criteria for assessing the quality of the studies. Most followed the guidelines for presenting and including criteria to indicate methodological rigour i.e. most reported on selection procedures, demographic characteristics, recruitment responses and attrition rates. The interventions were generally described in detail, including information about who delivered the intervention and where.

2.5.2 Internal validity

Internal validity refers to how well a study was conducted (i.e. research design, how the variables were measured) (Huitt, Hummel & Kaeck, 1999). Studies lacked details of the training that individuals delivering the interventions received, but they did evaluate their success in doing so according to the research protocol. It is important that interventions are manualised, so that interventions delivery can be standardised and improved which is particularly important if interventions are to be implemented into practice (Orford, 2008).

Three of the studies (Nolte et al, 2006; McGarvey et al, 2010; Salonen et al, 2011) increased internal validity by comparing the intervention with control groups. A number of studies incorporated several components within a complex intervention and did not include a method for determining which elements were successful and

which were not, which is essential if the intervention is to be incorporated into routine care for patients. In order to improve the effectiveness of interventions, it is important to know 'what it is that works', i.e. whether it is specific active ingredients or the intervention techniques themselves (Abraham & Michie, 2008). The effect of the interventions may have been diluted by the inclusion of participants without disturbance in body image or appearance concerns, as evidenced by data from pre-intervention baseline measures. This is supported in the literature, whereby some individuals are proud of their bald heads (Boehmke & Dickerson, 2005) and are happy to show them in public by engaging in 'banalisation' (Rosman, 2004).

2.5.3 External validity

External validity refers to the extent to which a study's findings can be applied to other people or settings (Huitt et al., 1999). A number of the studies did not adequately consider the influences of selection biases on the generalisability of findings, and those that included participants undergoing (or who had completed) a variety of treatments did not consider their subsequent cumulative impact on appearance as an independent variable. The one study that did consider age as an independent variable (i.e. Salonen et al, 2011) found that younger participants were more dissatisfied with their body image than older participants, supporting Avis et al's (2004) research that younger women diagnosed with breast cancer have more difficulty adjusting than older women. Identification of the characteristics of those dropping out of studies would provide important information for researchers and health care professionals about the characteristics of those patients who are likely to use the intervention and those who are not. A noticeable and unreported selection bias across all studies was the predominant recruitment of white/Caucasian participants.

Immediacy of intervention delivery appeared to be a feature of success, which may reflect that body image and appearance concerns are a priority for individuals experiencing hair loss and therefore need to be addressed during the early stages of treatment. However, longitudinal designs are important in order to assess whether any benefits of help with negative emotional repercussions of hair loss persist after hair has begun to re-grow (Borsellino & Young, 2011; Münstedt et al., 1997).

2.6 Conclusions

This review has applied a systematic strategy that identified only a small number of evaluated psychosocial interventions for individuals experiencing hair loss. The aim of the review was to comment on the current state of the research in this area, its scientific quality and areas of success that might inform future intervention design and evaluation. While the number of interventions included was small, this does not reflect the total number of interventions and sources of support that are available. This is demonstrated by the studies which were identified but did not meet the systematic review inclusion criteria. The quality of the small amount of research in this area is mixed, with some good research of reasonable scientific quality but some poor, with significant methodological limitations. Despite promising indications of key features that might benefit participants (namely the importance of early intervention and opportunities to express feelings and concerns), at present no definitive conclusions can be made.

2.7 Implications for future provision of care

It is essential that as part of routine care, breast cancer patients are aware of and have access to support, to help them to manage their treatment-related hair loss. It is imperative that health care professionals are aware of interventions which are currently available, so they can signpost patients who are affected by treatment-related hair loss to the relevant services and support organisations. However, before promoting services and interventions to breast cancer patients, it is important that they are evaluated in order to ascertain whether they offer any benefit to patients.

2.8 Implications for future research

It is essential that authors are clear about which are the most relevant outcomes in this area, as it would help to guide the selection of well-validated measures, intervention design and evaluation. Future interventions should recruit participants who are clinically homogenous i.e. similar disease severity or duration or both, so clinically meaningful outcomes can be used to direct clinical practice. Identifying patients in need of psychosocial interventions by screening for appearance and body image concerns could increase intervention effect, and large scale longitudinal

studies are required that allow for evaluation of small effects and the possibility that body image distress fluctuates over time. Furthermore, prospective studies need larger sample sizes to be statistically powerful, and should include usual care control groups as the efficacy of the current psychosocial interventions for hair loss remains uncertain. A noteworthy point is that during the systematic review process a number of interventions which focused on camouflage and covering hair loss (i.e. behavioural strategies) were identified, however they had not been evaluated and so were not eligible for inclusion within this review, demonstrating that a systematic review can be limiting. Since a number of interventions currently available for breast cancer patients have not yet been evaluated, it is unknown whether they offer any benefit to patients or not.

Whilst the PICO search strategy tool is regarded as a fundamental tool and has been widely used in quantitative systematic reviews, even being adopted by the Cochrane Collaboration (O'Connor, Green & Higgins, 2008), research has started to question its suitability as a strategy for qualitative evidence synthesis (Cooke, Smith & Booth, 2012). Specifically, 'Comparison' is not usually part of a qualitative research questions and combining 'Population' and 'Intervention' as specified by PICO are more likely to retrieve quantitative studies. A suggestion for future mixed method systematic reviews would be to consider using an additional search strategy tool to PICO, such as SPICE (Setting, Perspective, Intervention, Comparison and Evaluation) (Booth, 2006) or SPIDER (Sample, Phenomenon of interest, Design, Evaluation and Research type) (Cooke et al, 2012) which would increase the chances of retrieving qualitative studies.

The findings of this systematic review were used to inform the further studies within this thesis, including an evaluation of Breast Cancer Care's existing HeadStrong service. HeadStrong is currently freely available to breast cancer patients, but has not yet been evaluated and so it is not known what benefit the service offers. The next stage of this program of research therefore sought to gain an insight into patients' experiences of HeadStrong and to evaluate the service.

2.9 Summary of the key points in this chapter:

- This is the first systematic review to examine the evidence of the effectiveness of psychosocial interventions to support people affected by hair loss.
- Aspects of the effective interventions in the review included: being delivered immediately or soon after hair loss had begun, offering an opportunity to express emotions, being delivered on an individual basis and by a trained professional.
- The quality of research in this area is mixed, with some research of reasonable scientific quality but some poor, with methodological limitations.
- Implications of the review include the need for researchers to be clear about which outcomes are relevant, in order to help guide the selection of well validated measures. Prospective future studies need to include a control group and adequate sample sizes to provide statistical power to detect any effect of interventions. A number of interventions currently available have not been evaluated and as a result were not eligible for inclusion in the Systematic Review.

2.10 The next stage of the research

The next chapter discusses the methodology and methods employed in this program of research. A challenge throughout has been around recruitment. The challenges faced are discussed in the following chapter, along with the steps taken in attempt to overcome them. A key aspect in this research has been patient and public involvement (PPI) input.

Chapter Three

Methodology

3.1 Introduction

The aims of this thesis were to explore and evaluate current psychosocial interventions for breast cancer patients who are experiencing treatment-related hair loss and to inform the provision of psychosocial support for this patient group in the future. This chapter begins with a discussion of the MRC framework for the development and evaluation of complex interventions followed by a justification for the selection of methods used, describing the debate surrounding qualitative versus quantitative approaches (deemed the 'paradigm wars' (Bryman, 2006)), in order to appreciate the epistemological and methodological issues involved in designing and conducting health psychology research. 'Paradigm peace' (Bryman, 2006) and the emergence of mixed methods are then discussed. Finally, the chapter discusses the importance of service user involvement in research, including how it has been a key aspect throughout the thesis.

3.1.1 The use of the MRC framework for complex interventions in this thesis

Guidelines set out by the Medical Research Council (MRC, 2000; 2008), which guide researchers through a process of developing, evaluating and implementing complex interventions, was adopted for this research. An advantage of following a framework is that it helps with the selection of appropriate research methods to develop and evaluate the effectiveness of complex interventions (Evans, Stone, Manthorpe & Higginson, 2013). The 2008 MRC framework highlights four phases of intervention development: development, feasibility/piloting, evaluation, and implementation (De Silva et al, 2014). It acknowledges that the process of moving through each of the four stages may not always be linear, and although RCT designs are the most robust method to reduce bias, the MRC (2008) guidance argues that it is important to use the best and most appropriate methods to fit the particular research area under consideration. This may result in an evaluation of an existing service being conducted before an RCT (Evans et al, 2013). A pragmatic approach to the choice of evaluation methods is encouraged by the framework (Craig & Petticrew, 2013). To date, the MRC framework has been widely used by researchers to inform

study designs evaluating the effectiveness of complex interventions for a variety of health conditions (i.e. Barley, Haddad, Simmonds, Fortune, Walters., et al, 2012; Dugdale, Elison, Davies, Ward & Dalton, 2016; Eveleigh, Blencowe, Mills & Blazeby, 2011; Lakshman, Griffin, Hardeman, Schiff & Ong, 2012; Murchiea, Hannaforda, Wykeb, Nicolsonc & Campbell, 2007).

Although the initial 2000 MRC framework has been found to be highly influential, a number of limitations have been highlighted, one being that it is based on similar phases which are used to evaluate new drugs (MRC, 2008). Also, there is a lack of guidance regarding how to evaluate complex interventions, this is a key limitation as it is important that researchers understand how and why interventions have a particular effect and which part has the greatest impact on outcomes (De Silva et al, 2014). While the 2000 MRC framework recognises that healthcare evaluations consist of a number of complex interacting components, it does not consider the context in which the intervention is delivered. For example, it is important to consider the social and geographical context in which an intervention is delivered, as an intervention may be beneficial in one setting and not in another (Craig et al. 2008). Acknowledging these limitations, the revised MRC (2008) guidance placed more emphasis on the development phase, in order to better understand the research area, the context and the components of the intervention, and the link between the research areas and outcomes (Evans et al, 2013). In this thesis, and in an attempt to minimise any limitations of this research, the revised 2008 MRC framework was used in conjunction with the ARC framework which has been discussed in chapter 1.

The first stage (development) of the MRC framework involves reviewing previous research to identify whether an intervention may have a desired effect, and providing evidence for its possible success (MRC, 2008). The development stage also includes identifying the components of the intervention, typically by employing qualitative methods such as interviews (Blackwood et al, 2010). During the feasibility/piloting stage, the information gathered in the development stage is used to develop the intervention and study design, and to explore the feasibility of the intervention and its acceptability to participants (MRC, 2008). In the evaluation stage, any possible barriers or problems with the randomised controlled trial can be highlighted, before the intervention is implemented into practice (Evans et al, 2013).

Within this program of research an exploration of psychosocial interventions to support patients affected by hair loss was conducted through a systematic review (the development stage of the framework; see chapter 2), followed by feedback from women who had accessed an existing service (the development stage) (see chapters 4 and 5). This information helped to design a feasibility study of an RCT (feasibility/piloting stage) to explore the feasibility and acceptability of an expressive writing intervention that has not previously been used with this patient group (see chapter 6).

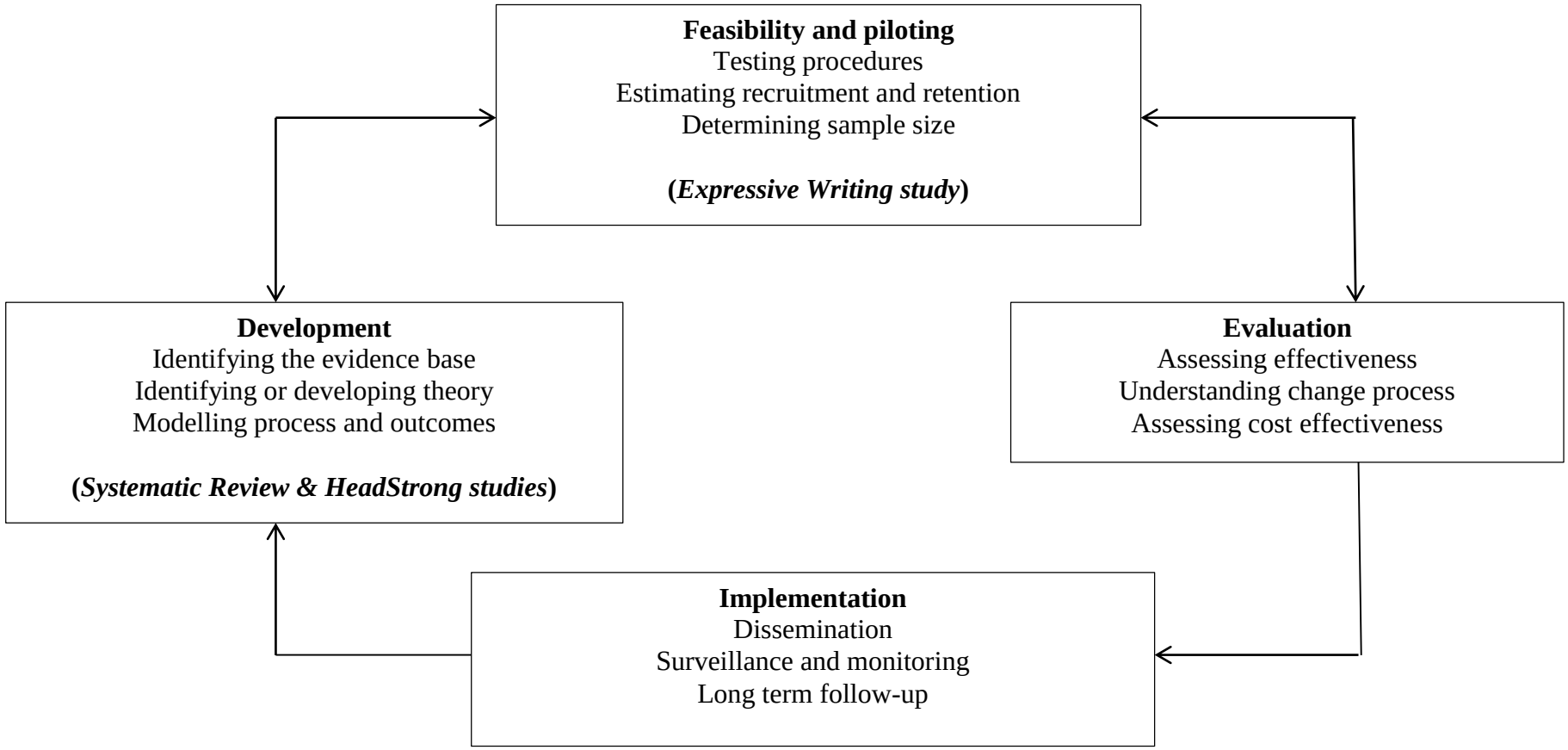


Figure 5. The guiding MRC framework (Craig, Dieppe, Macintyre, Mitchie, Nazareth & Petticrew, 2008). (First produced by the British Medical Journal (2008), 25(337): 980. Reproduced with copyright permission from the BMJ Publishing Group).

3.2 Epistemology and choice of methods in this thesis

It has been argued that the choice of methods used should predominantly be influenced by each study's research questions and not by methodological and epistemological considerations alone (Kelle, 2006). The research questions highlighted in chapter one are best answered by both quantitative and qualitative methods. The paradigms and world views that underlie both approaches to research are reflected in different origins about the nature of reality (ontology) and knowledge (epistemology) (Gelo, Braakmann & Benetka, 2008), as well as in terms of the methods used to collect and analyse the data (Chamberlain, 2000). Quantitative data analysis requires the transformation of data into a numerical form, while qualitative data involves interpretation of the meaning of data collected (Hayes, 2000; Smith, 2003). Also, qualitative approaches tend to be more inductive than quantitative (Hayes, 2000; Pope & Mays, 1995).

3.3 'Paradigm war'

The term 'paradigm war' has been coined in the literature to refer to the debate about quantitative and qualitative research at the epistemological level, specifically from a perception of these being distinct and competing paradigms (Bryman, 2006). Both approaches have a number of weaknesses; qualitative methods' weaknesses include the findings not being generalisable as they are unique to the participant group being studied, and since the research is subjective in nature the findings can be influenced by the researcher's personal biases (Johnson & Onwuegbuzie, 2004). The weaknesses of quantitative methods include its rigidity of focusing on hypothesis or theory *testing* as opposed to *generation*, which can result in the researcher missing out on important aspects of the phenomenon being studied (Johnson & Onwuegbuzie, 2004).

Psychology has traditionally been led by a positivist paradigm believing in a single reality and objective research (Stevenson and Cooper, 1997). This 'scientific' approach is underpinned by experimentation with a reliance on quantitative research methods seeking to prove or disprove hypotheses. According to quantitative approaches, social and psychological phenomena have an objective reality, whereas

qualitative methods consider reality as socially and psychologically constructed (Gelo et al, 2008). Whilst the scientific principles such as measurement and hypothesis testing are suitable in many instances, they fail to consider social processes and the influence of the researcher on the research process (Murray & Chamberlain, 1998). These limitations have led to the acceptance of qualitative research methods, which recognise that knowledge is a result of an interaction between the data being generated and the researcher (Pidgeon, 1996). In recent years, the National Health Service (NHS) in the UK has placed increasing emphasis on the provision of care that considers and is informed by the needs and experiences of patients (Department of Health, 2006a). This requires different research questions being asked and, as a result, the value of qualitative methods has been increasingly recognised within health research.

When deciding which methods to employ, an important consideration is who the stakeholders are and the types of data they would value. In this case the key stakeholders are breast cancer patients affected by treatment-related hair loss (service users), who have taken part in the research with an understanding that the findings could potentially inform service provision; research funders (e.g. Breast Cancer Campaign); and the range of health professionals involved in service delivery. Healthcare organisations operate with limited resources and as a consequence the focus is often on addressing the needs of the majority of a given population, rather than concentrating resources on an individual level, therefore quantitative research is favoured over qualitative research as it allows the researcher to generalise the findings to a specific population.

Despite qualitative research helping to provide detailed understandings of a topic that has previously not been researched, it does not set out to be generalisable. In contrast, quantitative research uses large samples to enable generalisation of research findings. Within mainstream psychology, quantitative methods are the dominant method (Alise & Teddlie, 2010); however, over the years there has been increased recognition of the limitations of the positivist paradigm (Murray & Chamberlain, 1998; Silverman, 2000). The phrase ‘paradigm peace’ has been coined in the literature to refer to quantitative and qualitative research no longer being regarded as incompatible and to promote the use of mixed-methods research (Bryman, 2006).

Johnson and Onwuebbuzie (2004) have argued that "mixing methods frequently results in superior research" (p.14) as it incorporates both the strengths of qualitative and quantitative research methods.

3.4 Mixed methods

Mixed methods research has been defined as "the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches for the broad purposes of breadth and depth of understanding and corroboration" (Johnson, Onwuegbuzie & Turner, 2007, p. 123). The past decade has seen a rapid increase in health research using mixed methods (Tariq & Woodman, 2010; Yardley & Bishop, 2015; O'Cathain, Murphy & Nicholl, 2007), identified as the employment of both qualitative and quantitative methods (Brannen, 2005).

The current research was primarily 'bottom up' as it began with the questions that needed investigating. Given the applied nature of those questions, the mixed methods literature with its emphasis on real world enquiry was appealing and considered in detail before deciding to use this approach throughout the thesis. The value of mixed methods or the 'third paradigm', as it has been coined, has received increasing attention and is now viewed by some to be on an equal level with quantitative and qualitative research (Daigneault & Jacob, 20014; Small, 2011). A common rationale for conducting mixed methods research is the idea of generating complementarity data in order to reveal different dimensions of a phenomenon and to enrich understandings of the multi-faceted, complex nature of the social world (Moran-Ellis et al., 2006). The term 'complementarity' is used to describe the process and outcome when different data sets are used to address different but complementary aspects of a research project (Brannen, 2004). An important aspect of mixed methods research is the integration of the two methods during analysis and interpretation (Tariq & Woodman, 2010).

Denscombe (2008) has outlined four key characteristics of mixed methods; qualitative and quantitative methods are used within the same research, the research design outlines the sequencing and priority given to the qualitative and quantitative

aspects of data collection and analysis, an account is given of the way in which qualitative and quantitative aspects of the research relate, with an emphasis on the way in which triangulation is used, and finally, pragmatism is the philosophical underpinning for the research.

This thesis takes the view that quantitative and qualitative approaches provide complementary information in order to offer a more comprehensive understanding of breast cancer patients' experiences of treatment-related hair loss and their psychosocial support needs. Qualitative and quantitative methods address fundamentally different research questions, however, mixed methods research can overcome the weaknesses of qualitative and quantitative methods by complementing the strengths of each other and provide a synthesis, whereby the outcomes of different studies lead to an integrated understanding of the phenomenon being explored (Fetters, Curry & Creswell, 2013; Lee & Rowlands, 2015).

It is important to highlight the philosophical challenges around mixed methods research; given the epistemological differences between quantitative and qualitative approaches, an essential element of mixed methods research is that the integrity of each component is maintained (Bishop, 2015; Morse, 2003). Pragmatism is viewed as "the philosophical partner to mixed methods research" (Denscombe, 2008, p.273) which offers a way of approaching the challenges associated with mixed methods (Bishop, 2015; Bryman, 2006; Dures, Rumsey, Morris & Gleeson, 2011; Morgan, 2014). Pragmatic approaches acknowledge that there are fundamental epistemological differences between quantitative and qualitative approaches; however, these methods are seen as complimentary (Bishop, 2015). Working with a pragmatic approach "does not ignore the relevance of epistemology but it does reject the 'top down' favouring of ontological assumptions at the expense of conducting practical and useful research" (Morgan, 2007, p.68). Maxcy (2003) argued that pragmatists focus on achieving richer experience, gaining functional knowledge and considering the impact of research on practise.

3.5 Designs for mixed methods research

It is important that the design for mixed methods research is driven by the research questions (Tashakkori & Teddlie, 2010). When trying to answer the question regarding how and when to combine quantitative and qualitative methods, a popular approach is develop typologies of mixed methods designs (Bishop, 2015); to date, more than 15 designs have been published (Creswell & Plano Clark, 2011). Although the names of these designs differ, they can be characterised according to whether they merge the qualitative and quantitative data in a concurrent way, or have the qualitative or quantitative data build on or extend the other type of data in a sequential way (Creswell, Plano Clark & Garrett, 2008).

Creswell and Plano Clark (2011) propose six designs for mixed methods research: explanatory, exploratory sequential, convergent parallel, transformative, multiphase and embedded designs. Both explanatory and exploratory designs are sequential, with the first component being completed before the second is started; within exploratory designs, the qualitative component is usually completed first, whereas the quantitative component is completed first in explanatory designs. Embedded designs are concurrent, as the quantitative and qualitative components are carried out at the same time (Creswell & Plano Clark, 2011). According to Bishop (2015) the transformative design is where one of the designs discussed above are selected and are enclosed within a transformative framework. For example, quantitative data is collected and analysed, followed up with quantitative data collection and analysis, whereas an example of a multiphase design is where a qualitative study informs a quantitative study which then informs a mixed methods study. The convergent parallel design (also known as the triangulation design) is well used within mixed methods research (Kettles, Creswell & Zhang, 2011), whereby different but complimentary data is obtained on the same topic (Morse, 1991). A concurrent triangulation design was adopted for the research as it was the most appropriate in answering the research questions. For example, for the HeadStrong studies (study 2 and 3), in order to answer two overarching research questions, it was deemed necessary to conduct two simultaneous but independent studies with different samples, the data was then triangulated. Additionally, to explore the feasibility and

acceptability of an expressive writing intervention (study 4), quantitative and qualitative data was obtained.

Morse (1991) highlighted the relationship between the various components in a mixed methods study by using capital letters for the principal method and lowercase for the complementary method. The sequence of the methods is depicted by an arrow (e.g. qual → QUANT represents an initial qualitative study guiding a primarily quantitative study). A criticism of the priority-sequence model is that it neglects the option of attributing equal priority to both methods and using them simultaneously rather than sequentially. Morse (1991) highlighted the concurrent use of both methods by using a plus sign (e.g. QUAL+quant depicts a quantitative study conducted alongside the priority qualitative study). This is an evolving field and Johnson and Onwucgbuzie (2004) recognised the possibility of new and alternative combinations emerging in the future.

There are strengths and limitations of sequential and concurrent designs. Specifically, with sequential designs it is easier to maintain the integrity of each method and to evaluate each method as one study is completed before the next begins, whereas concurrent designs encourage the researcher to mix qualitative and quantitative more closely, making it difficult to bear in mind the fundamental assumptions, strengths and limitations of each approach (Bishop, 2015). However, concurrent designs may be more appealing to researchers as they may find it easier to make strong links between qualitative and quantitative components than in sequential designs (Bishop, 2015). Study 2 and 3 are two independent studies which both explore the HeadStrong study at the same time but with two different samples. Figure 6 demonstrates the concurrent triangulation design for the HeadStrong evaluation (studies 2 and 3), demonstrating that equal priority was applied to both qualitative and quantitative data, study 2 used qualitative data collection and analysis, whereas study 3 used both quantitative and qualitative data collection and analysis. The findings for both studies, were collected and analysed simultaneously (see chapters 4 and 5) before the results were combined for interpretation.

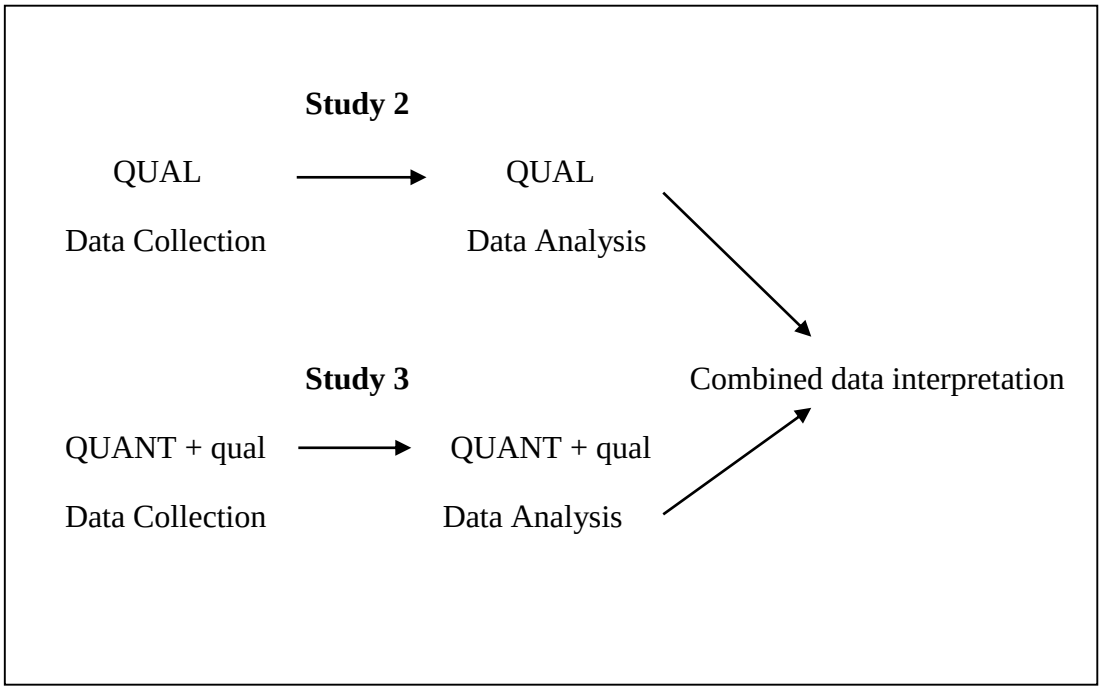


Figure 6. Visualisation of the concurrent triangulation design for the HeadStrong study

There are at least 4 phases in the research process in which quantitative and qualitative components of mixed methods research might be integrated; sampling, data collection, data analysis, and interpretation (Yardley & Bishop, 2015). Creswell, Plano Clark, Gutmann and Hanson (2003) postulate that, when conducting mixed methods research, it is important that researchers consider 4 particular aspects; the sequence of methods, priority given to the methods, integration and theoretical perspective.

The following section discusses how these four points were addressed in relation to this thesis:

1) The sequence of methods

The first stage of the research in this thesis involved conducting a systematic review, the second stage included studies using qualitative (semi-structured interviews) and quantitative (questionnaires) methods, while the third stage utilised quantitative and qualitative data (a QUANT + qual study). In stage 2, inductive qualitative and deductive quantitative methods were used in the evaluation of HeadStrong (a service

for cancer patients affected by hair loss). Individuals' qualitative accounts of their experiences of chemotherapy-induced hair loss and of the HeadStrong service were analysed alongside quantitative data from questionnaires that were developed to explore how common these experiences were amongst a larger sample. The main research question at this stage was 'What are individuals' experiences of the HeadStrong service which aim to support them with their hair loss? And are any further interventions needed?' Quantitative measures were best suited for this as it maximised the study's internal validity. Since the findings of these studies indicated a need for additional, alternative interventions in this area, a feasibility study of an expressive writing study was carried out. This was primarily quantitative, but with a qualitative aspect via open ended questions, which were included to obtain acceptability data alongside feasibility data, that would inform future decisions about any further development and evaluation of an expressive writing intervention with this patient group.

A particular consideration when designing this research was that some participants in the quantitative HeadStrong study and expressive writing study may want to reflect on their personal experiences and may feel that ticking boxes on a questionnaire does not fully represent their unique experience. To address this, the questionnaires included open questions so that participants could expand on issues raised and provide any further information, if they wished.

Full details of recruitment for each study can be found in the relevant chapters later in this thesis.

2) Priority given to each method

While some researchers have argued that a mixed methods approach can mean that qualitative research becomes secondary to quantitative (Denzin & Lincoln, 2005), others highlight that qualitative research can be highly prominent within a mixed methods research project, to the extent that a project can be qualitatively driven (Creswell et al., 2003). Therefore, in order to ensure this thesis was grounded in breast cancer patients' actual experience, semi-structured interviews were chosen as this qualitative method is particularly well equipped to gain rich accounts of people's individual experiences.

Questionnaires were used during the HeadStrong service evaluation and for the expressive writing study, to allow for a focused examination of specific variables enabling comparisons within and across data sets (specific details of the methods used are included in the individual study chapters).

3) Integration

A main concern with mixed methods is that there is often insufficient detail regarding how methods are mixed (Bryman, 2006). One way to integrate the quantitative and qualitative findings in any mixed methods study is to analyse the two data sets separately and to then compare, contrast and combine the data and findings during a second stage of analysis (O'Cathain et al, 2007). There are two points at which qualitative and quantitative data are integrated in this thesis. First, the qualitative and quantitative findings from the HeadStrong service evaluation through semi-structured interviews and questionnaires were analysed in parallel, which is common in health research (Őstlund, Kidd, Wengström, & Rowa-Dewar, 2011). The results were then reported simultaneously. Second, findings from across the thesis are synthesised in the final chapter of this thesis.

The findings were triangulated using a composite analysis technique (Yardley & Bishop, 2007), the data was collected and analysed using either qualitative or quantitative methods, to preserve the integrity and unique contribution of each methodological approach. Wagner et al. (2012) argue that the aim of triangulation in mixed methods is to seek agreement across quantitative and qualitative methods, so that the conclusions can verify each other. A challenge is that the findings from different methods can sometimes appear to contradict each other. However, Creswell et al (2008) suggest this can actually result in a deeper understanding of a complex phenomenon, and contradictory findings using a concurrent design may even be viewed as uncovering new theories.

The first point of integration was the analysis of interviews of women's experiences of hair loss and the HeadStrong service and the identification of areas to take forward in the expressive writing study. Analysis needed to be flexible to be able to capture the detail of participants' experiences which could be expected to be highly variable, reflecting the variability of the impact of treatment-related hair loss. A

number of methods of analyses were considered for the qualitative aspect of study 2; thematic analysis was selected as the most appropriate method as it can provide a rich and detailed description of the data (Braun & Clarke, 2006). Themes can be generated either inductively (i.e. are data driven) or deductively (i.e. are driven by theory) (Braun & Clarke, 2006). The thematic analysis employed in this research was primarily inductive. Thematic analysis aims to remain close to the data and is therefore grounded in the experience and words of those who participate in the research. Also, it can summarise key features, including similarities and differences of a large data set (Hayes, 2000), which is useful in this case when a main aim of the research was to gain an insight into participants' experiences of the HeadStrong service and their support needs (further details can be found in the following qualitative HeadStrong chapter). Thematic analysis uses constant comparative analysis processes and each interview was analysed using the six stages of thematic analysis as outlined by Braun and Clarke (2006) (see chapter 4 for details).

The analytic process generated a detailed and rich description of each interview transcript which led to the identification of the key aspects of individuals' experiences of treatment-related hair loss and their psychosocial support needs. These key aspects informed the decision to explore the feasibility of an expressive writing intervention. The ARC framework, along with the findings from the systematic review, the qualitative and quantitative HeadStrong evaluation, and the existing hair loss and expressive writing literatures informed the choice of standardised psychological measures and open ended questions that were used in the expressive writing intervention feasibility study.

4) Theoretical perspective

Only recently has theoretical perspective been discussed in the mixed methods research design literature (Creswell et al., 2003; Greene, 2008). The theoretical perspective reflects the researcher's belief that knowledge is both constructed and based on the reality of the world we experience and live in (Morgan, 2007). It also reflects the researcher's personal stance towards the topic they are studying (Creswell et al., 2003), which for the purposes of this thesis is breast cancer patients' experiences of treatment-related hair loss and their psychosocial support needs. A pragmatic approach was taken as the researcher believed that despite there being

fundamental epistemological differences between quantitative and qualitative approaches, these methods can be complementary when used together to gain an insight into a particular phenomenon (Bishop, 2015). In line with Creswell and Plano-Clarke, a pragmatic approach was deemed to be appropriate when solving practical problems in the 'real world' (Creswell & Plano Clark, 2007, p. 20-28). A critique of mixed methods research can be found in section 7.6.1.

3.6 Recruitment challenges in psycho-oncology research

This section discusses recruitment challenges often faced by researchers working in psycho-oncology and psychosocial interventions, including the challenges of Randomised Controlled Trials (RCTs), the role of healthcare professionals and possible ways of overcoming barriers to recruitment. These were considered, at length, in the planning of each study. The specific recruitment challenges for each individual study, and the steps taken in an attempt to overcome them, are discussed in the subsequent chapters.

3.6.1 Barriers to recruitment

There are numerous barriers to recruitment, some of which include fear of the unknown regarding taking part in research and concerns around the potential costs including those associated with travel (Redmond, 2014). Age has been highlighted as a consistent barrier to recruitment, with older patients frequently being underreported in psycho-oncology studies (Jennings et al., 2014). A common barrier to recruitment of RCTs is patient preferences for a specific condition and not wanting to be randomised with the chance of receiving the alternative condition (Kaur et al., 2013). Recruitment to psycho-oncology research may be hindered by the prospect of discussion of a sensitive topic (Jennings et al, 2014) or by stigma surrounding mental health (Schain, 1994). However, there is limited research regarding barriers to recruitment and alternative strategies specifically in psycho-oncology (Jennings et al, 2014; Northouse et al., 2006). Jennings et al (2014) conducted a clinical trial of a sexual health intervention for female anal and rectal cancer survivors. Despite targeted recruitment, 53% of the eligible individuals approached declined to participate. Under-recruiting can question the study's

feasibility, which can hinder advancing knowledge and improving care (Jennings et al, 2014). It can also limit the statistical power of the study to detect an effect (Baum, 2002), which may result in clinically relevant differences being reported as statistically non-significant, possibly resulting in an intervention being abandoned before its true value has been established (Treweek et al, 2013). Also, the external validity may be threatened as the sample may be less representative of the population (Brown, Fouad, Basen-Engquist & Tortolero-Luna, 2000).

3.6.2 Specific challenges in Randomised Controlled Trials (RCTs)

Recruitment to trials within cancer research continues to be a particular challenge. The annual recruitment of cancer patients to the NIHR Clinical Research Network portfolio of cancer studies highlights that adult participation is around 18.3% of cancer cases in the UK (NIHR Cancer Research Network, 2013). A study of 114 multicentre trials found that less than a third achieved their original target (n=38; 31%), and more than half had to be extended (n=65; 53%) (McDonald et al., 2006).

Randomised controlled trials (RCTs) are highly regarded as the most powerful research method when evaluating health interventions (Feneck, 2009; Ross et al., 1999; Rothwell, 2005). Random allocation aims to ensure that participants have similar baseline characteristics, demonstrating that differences following an intervention can be attributed to the intervention and not to an unknown factor (Blackwood et al, 2010). Therefore, a RCT design was deemed appropriate to test the effectiveness of an expressive writing intervention, however, it was important to test the feasibility and acceptability of the design and intervention before any attempt was made to conduct a large RCT (see chapter 6).

RCTs are not an appropriate method for use in all research situations, especially those investigating psychosocial aspects of health, as they may create a self-selecting sample bias. Individuals may be motivated toward one particular treatment condition, and therefore, not want to take part in research which could potentially result in them being randomised to receive an alternative treatment and opposing condition (Kienle, Glockmann, Schink, & Kiene, 2009; Town, Abbass, & Hardy, 2011).

Several systematic reviews have highlighted a number of issues which RCTs need to address in order to successfully recruit a sufficient number of participants; they must aim to answer a research question with a clear protocol and low impact data collection (Campbell et al., 2007; Ross et al., 1999), employ dedicated research staff (Campbell et al., 2007; Ross et al., 1999) and use proven effective recruitment strategies (Treweek et al., 2010). Many difficulties with recruitment have been reported, including a lack of interest in the study purpose, the patient's degree of illness or fatigue, lack of patient's perceived benefit from the study, insufficient time, the complexity of the study, unwillingness to be randomised into the experimental versus control group, demographic and socio-demographic factors, or competing trials (Northouse et al., 2006). Yet, these issues are not unique to cancer studies. There are also organisational challenges within hospital settings including the need to allocate health professionals to help with recruitment and there being fewer eligible patients than expected (Donovan et al., 2014).

3.6.3 Influence of healthcare professionals on recruitment

Very few studies have considered how the process of recruitment occurs, or the potential influence that recruiters can have on recruitment (Donovan et al., 2014). For example, how patients are informed about a RCT and how health professionals present study information to them is pivotal. Donovan et al (2014) highlighted that doctors reported difficulty in relation to their joint role as clinician and recruiter; some felt that patients may not really be suitable for participation despite meeting eligibility criteria and, as a result, were uncomfortable recruiting them. Nurses felt conflicted between their roles as carers, patient advocates and recruiters/researchers, expressing discomfort about bothering patients with information about RCTs or making their own clinical judgements about a patient's suitability for research. This meant that many patients were not told about the study or given the opportunity to participate (Donovan et al., 2014). Lemieux et al. (2014) reviewed 985 cancer trials from a single breast cancer-specialised institution and found that at least one cancer trial was only proposed to 33.1% of all eligible patients. One of the suggested reasons for this is that health professionals may believe participation in a clinical trial or therapy may be too risky based on a patient's age, especially if they are an

older adult (Daugherty, Ratain, Grochowski et al., 1995). Training health professionals and researchers to ensure they have a thorough understanding of the RCT design and how to randomise patients fairly could help recruitment (Donovan et al., 2014).

3.6.4 Challenges of recruitment into psychosocial intervention studies

It is not always possible to find out why patients do not take part in studies for which they are eligible. Sears et al (2003) found that the majority of individuals who chose not to take part in their study did so through passive refusal; individuals were either unreachable after multiple call attempts or did not return baseline questionnaires after multiple reminders. Boonzaier et al., (2010) explored recruitment issues specific to psychotherapy and advanced cancer when evaluating a couples' intervention for women with metastatic breast cancer and their partners. The majority of women were contacted by letter because of the significant time gaps between appointments but only 9 out of the 88 couples who were sent letters expressed an interest in taking part. Recruitment also took place through the treatment team and community support agencies, which led to four women registering interest in the study, two couples consenting and taking part in the initial interview and one couple completing the whole study. Reasons for declining included not needing the study; being unwell; too busy and unable to travel to take part.

Psychotherapy studies with higher consent rates have recruited from multiple hospital sites, over a number of years, using multiple recruitment methods. For example Kissane et al (2006) recruited from seven hospital sites over a 6 year period, for their family focused grief intervention, suggesting that resource-intensive processes and a potentially long period of time is required to recruit sufficient sample sizes. However, clinical services often do not have sufficient research resources available to enable them to recruit participants this way without significant research funding. Also, many people diagnosed with cancer adjust to their diagnosis over time without an intervention (Stommel, Kurtz, Kurtz, Given & Given, 2006), so patients invited to participate in psychosocial intervention studies may not feel it is

enough of a priority for them to spend time and energy taking part (Schofield et al., 2008).

Boonzaier et al (2010) suggest that patients with cancer might not take part in research because the intervention offered may not be what they want. Sherman et al (2007) found that cancer patients cited medical information and health promotion as their most prominent motivations for attending an intervention, whereas only a small percentage identified emotional support as a motivator. It can be difficult to encourage people diagnosed with cancer to access psychological support services if they have not had previous exposure and understanding of such services (Redman, Turner & Davis, 2003). An additional factor to consider is that individuals who have received a cancer diagnosis and cancer treatment may experience a lack of confidence in seeking support (Foster et al., 2015), this may be due to the side effects of cancer treatment and the impact which it has on an individual's appearance, which may lead to a negative influence on their confidence and self-esteem (Helms et al, 2008). Boonzaier et al (2010) suggest that future studies need to consider how to approach patients about the value of psychological services, prior to attempting recruitment to a specific intervention. This highlights the importance of involving patients through PPI in setting agendas for what research is actually conducted (considered in more detail later in this chapter).

Gatekeeping by health professionals has previously been identified as a recurring issue amongst psychosocial studies (Duncan & Cumbia, 1987; Schofield et al, 2008). Educating health professionals regarding the value of the intervention and ensuring recruitment is broader than just clinical referrals appear to be the main strategies for overcoming this difficulty (Boonzaier et al, 2010). Also, patients may attend a large number of medical appointments and treatment can be burdensome, and they may therefore consider the additional commitment of taking part in research to be too much (Boonzaier et al, 2010). However, taking part in intervention-based research does not necessarily involve additional appointments.

It has been proposed that future research may benefit from collecting information about why women do or do not participate and what types of support they would like, for example through qualitative research using focus groups or screening patients using questionnaires to identify specific unmet needs (Boonzaier et al,

2010). One of the aims of this research program was to highlight any unmet needs that women with breast cancer may be experiencing in relation to their treatment-related hair loss. For example, the interview schedule for the HeadStrong study asked participants about any unmet needs and recommendations for how the HeadStrong service could be improved. A discussion around identifying unmet needs can be found in chapter 7.

3.6.4.1 Attrition

It is also important to consider the issues around keeping participants engaged in studies once they have consented. Attrition due to illness is an important factor (Northouse et al., 2006). All longitudinal studies experience attrition, however, significant attrition over the course of a study may result in biased findings and can increase study costs (Neumark, Stommel, Given & Given, 2001). Previous research has highlighted that attrition in longitudinal studies can vary from 16% to 50%, depending on the population studied (McMillan & Weitzner, 2003). Reasons for attrition may include death of the participant, the demands of the illness and treatments, the requirements or duration of the study, lack of time, loss of interest, participant frustration at not being randomised into the desired group and lack of contact with the research team (Cooley et al., 2003; Pruitt & Privette, 2001).

3.7 Methods to enhance recruitment and reduce attrition

It remains relatively unclear why some studies recruit better than others, however, ways to enhance recruitment and reduce attrition have been suggested including prior consideration of enrolment strategies and reasons for potential decline, the way in which sensitive topics are presented by the research staff and including health professionals in recruitment (Jennings et al, 2014). Also, conducting pilot and feasibility studies is useful in confirming the effectiveness of one's recruitment strategy (Cope, 2015; Loscalzo, 2009). Jennings et al (2014) propose two strategies that could help to improve the feasibility of psycho-oncology clinical trials: the researcher having greater knowledge of participant interest and consistent reporting of recruitment strategies and barriers encountered. These strategies were adopted for the expressive writing study in this thesis, where the recruitment strategy involved

the researcher attending the breast clinics in order to speak to eligible patients directly about the research. Also, the health professionals and charities who helped with recruitment fed back information from patients regarding their reasons for not wanting to participate in the study. These strategies were advantageous and they enabled the researcher to identify barriers to recruitment, make changes as appropriate and comment on the suitability of recruitment strategies employed.

Additional methods to improve recruitment and reduce attrition include telephone reminders (McDaid, Hodges, Fayter, Stirk & Eastwood, 2006; Nystuen & Hagen, 2004), incentives including financial ones (Free, Hoile, Robertson & Knight, 2010; McDaid et al., 2006), newsletters and mail-shots to encourage non-respondents (Campbell et al, 2007). Yet, despite telephone reminders and financial incentives both being used and accepted by many researchers as a legitimate recruitment tool, some may consider them a form of coercion (Treweek et al, 2013). Jennings et al (2014) suggest that allowing extra time to provide information and build rapport with patients could potentially increase willingness to participate. They found that individuals were more willing to consider participation when health professionals broached the study with them prior to being approached by the researcher, or were approached in the privacy of a clinic room. Considerably more women consented when approached in clinic, as opposed to by letter, since approaching patients in a clinical setting provides the opportunity to build rapport and address directly any concerns they may have (Jennings et al., 2014). Sending participants an introductory letter under the letterhead of the physician showing their support of the research has also been found to promote recruitment (Sears et al., 2003). Additionally, an important factor is maintaining healthcare professionals' engagement with the recruitment process. Enrolment can increase rapidly when the researchers contact referring physicians to get renewed commitment to the study (McNees, Dow & Loerzel, 2005), send monthly enrolment reports to referring physicians and research staff and make weekly visits to the site where recruitment is taking place (Sears et al., 2003).

Initiatives such as 'It's Ok to Ask' (National Cancer Research Network, 2015) encourage patients to request research participation since evidence suggests involvement can improve health outcomes, which may influence recruitment.

However, this puts the onus on the patient to contact the researcher during a time which can be extremely distressing for the patient, for example close to diagnosis and/or treatment decision making and treatment, and when they may already feel overloaded, such that the thought of taking part in research could be too much. Additionally, if patients have little experience or understanding of research or psychology then they may fear the unknown, demonstrating the importance of researchers taking the time to explain what would be involved in participating in the research and directing them to further information (e.g. including the following link in participant information sheets: http://www.nbt.nhs.uk/research-and-innovation/our-research/take-part-research). Moreover, it is important to actively recruit patients after they have agreed to be contacted or expressed a willingness to consider participating, since patients do not actively seek information about research (Puts et al. 2009; Townsley et al, 2006). This further demonstrates that researchers need to be active rather than relying on patients taking the lead in making contact with them.

3.7.1 Patient and public involvement (PPI)

In the UK, researchers (particularly those conducting NHS research) are increasingly being encouraged to involve service-users and patients in their research (Cotterell et al, 2010; Department of Health, 2006a). PPI refers to those who use, have used, or are eligible to use health and social care services (Beresford, 2005). Service users can offer a unique perspective based on their own experiences of living with illness which is different from that of clinicians and academics (DoH, 2005). There is an increasing emphasis on the importance of users of health and social care participating in decisions regarding their care (Maslin-Prothero, 2003; Rise et al., 2013) and it is logical that this extends to their involvement in determining research agendas and priorities.

The National Health Service (NHS) Research and Development established INVOLVE in order to promote service user involvement in research and evaluation (Beresford, 2007). Research has highlighted that including service users can generate new knowledge, resulting in a change to the research design and/or the way it is carried out (Cotterell et al., 2010). Specifically, including service users in the initial

stages of research is critical as they have the freedom to influence the aims and methods (Brett, Staniszewska, Mockford et al, 2010), including helping with the wording of questionnaires, and the content, face validity and appropriateness of measurement tools (Brett et al., 2010; Oliver & Buchanan, 1997).

The Cancer Reform Strategy highlighted user involvement as an implicit component of good cancer service commissioning and delivery (Department of Health, 2007). Cancer network partnership groups are regional organisations in the UK, consisting of cancer patients and health professionals working together to help improve cancer care (Attree, Morris, Clifton, Hinder & Vaughan, 2009). An evaluation of the work of these cancer networks highlighted that the service users involved had influenced cancer care in a number of different ways, for example the assessment, implementation and review of surgical services for upper gastro-intestinal patients (Attree et al., 2009). Moreover, user engagement has been found to be essential in maintaining ethical standards and the welfare of participants in research (Wright, Corner, Hopkinson & Foster, 2007).

Despite there being an emphasis on involving service users in cancer services and research, little research has actually focused on the impact which involvement has on the service users themselves (Cotterell et al., 2010) and there is a need for more structured approaches to reviewing the investments made in supporting the involvement of service users in research (Morrow, Ross, Grocott & Bennett, 2010). A study by Cotterell et al (2010) found that service users feel positive about being involved in influencing services or research and it has also been reported that service users can benefit from therapeutic gains, improved self-esteem and confidence from the research process (INVOLVE, 2012).

There is a general assumption that the effects of service user involvement are beneficial, however, concerns include financing service user time, issues with service user benefits and payments, and a need for training and support (Beresford, 2013; Brett et al., 2012; Pollard & Evans, 2013). Also, previous research has highlighted that people affected by cancer can hear distressing things when engaged in work with cancer professionals (Cotterell et al, 2010; Gray, Fitch, Greenberg, & Shapiro, 1995) and may lack objectivity (Wright et al., 2007) which can be a limitation of including PPI in research. Moreover, as service users might not be

familiar with the complexity of the research process, such as ethics, they may have unrealistic expectations regarding what can be achieved and how long research takes (Wright et al., 2007). This could slow down the research process and may be very frustrating and stressful for the service user; however, it is possible to overcome this limitation with appropriate support i.e. from the research team by explaining the different stages and timescales involved in research (Stevens, Wilde, Hunt & Ahmedzai, 2003).

3.7.2 Patient and public involvement (PPI) in this thesis

There are a number of different ways that patients and members of the public can become involved with different stages of the research cycle (see figure 7), for example, they can help to develop research questions, review research materials, join advisory groups and help to disseminate research findings (INVOLVE, 2012). Throughout this program of research, there have been two sources of PPI; a novice patient user representative from the Network Breast Site Specific Group of the Avon, Somerset and Wiltshire Cancer Network (ASWCN) and a number of advisors from Breast Cancer Care. An advantage of using a novice user representative is that, over time, users can become 'professionalised' which can weaken their representativeness (Wright et al., 2007). A user representative from ASWCN, who has personal experience of breast cancer and treatment-related hair loss, was able to bring her own unique perspective to this research. Following INVOLVE (2012) guidance, the research team met with the user representative to talk about the research and explore each party's expectations and understanding of service user involvement in it. The researcher met with the user representative regularly throughout the program of research in a setting of her choice which was easily accessible for her. She was consulted during the planning stages of the research and played an active role in 'the designing and managing' aspect of the research cycle (see figure 7) which involved reviewing the written materials (i.e. invitation letters, information sheets, consent forms, questionnaires, debrief sheets) used in studies 2 (chapters 4 and 5) and 3 (chapter 6), which has previously been highlighted as a benefit of engaging service users in research (Brett et al., 2012).

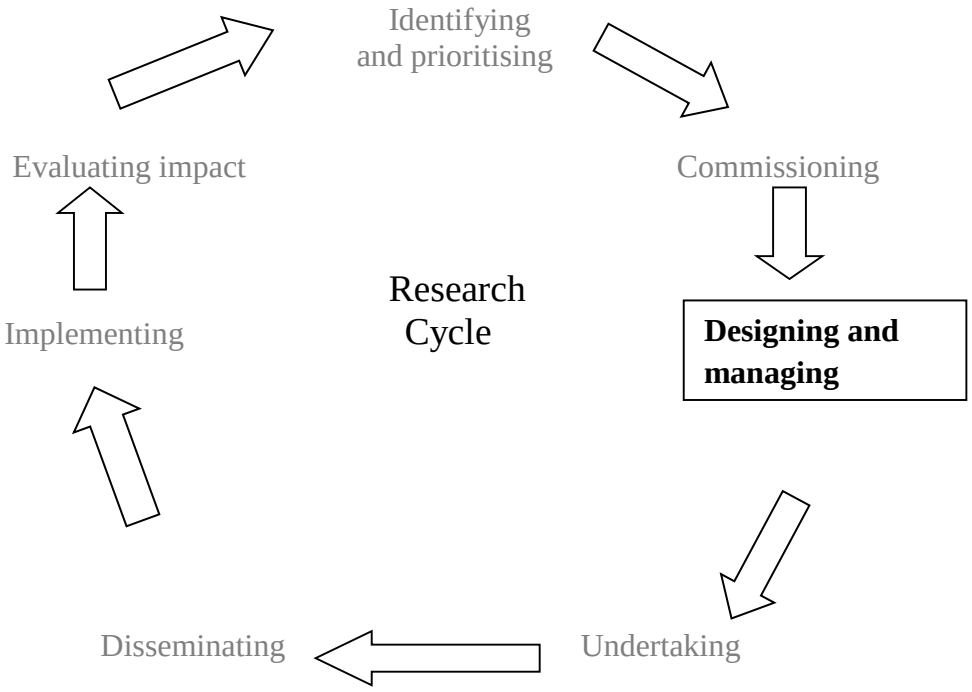


Figure 7. Diagram taken from INVOLVE (2012), depicting service user involvement at the designing and managing stage of the research cycle. (First produced by INVOLVE (2012), p.31. Reproduced with copyright permission from INVOLVE).

In order to prevent some of the negative aspects of including service users in research highlighted above, Department of Health (2006b) policy and guidelines on reimbursement and payment for service users were followed. The user representative was happy to be contacted via email and was sent paper copies of any materials to read ahead of face-to-face meetings to discuss her feedback. INVOLVE (2012) advise that it is good practice to offer payment to user representatives involved in research. Payment for the user representative's time was included within the PhD research budget and this was discussed before the user representative agreed to take on the role. The user representative was paid for the time she spent reading and providing feedback on the materials for each of the studies, she was reimbursed for her travel expenses, and refreshments were provided at each meeting. Previous research has found that receiving payment and being treated hospitably can help users feel valued, which is associated with a sense of empowerment (Hanley, 2005).

The researcher ensured that the information and details given to the user representative were appropriate for a lay person and that the research process involved in each of the individual studies was clearly outlined. Since user representatives may find the experience of PPI potentially distressing, the user representative was asked if she was still happy to act as a user representative prior to each meeting and was informed that she could withdraw at any time if she no longer wanted to be involved. She was also provided with a list of support charities that she could contact if needed.

Breast Cancer Care's advisory group 'Voices' (www.breastcancercare.org.uk/get-involved/volunteer-us/become-breast-cancer-voice), consists of hundreds of people from around the UK with experience and expertise of being diagnosed and treated for breast cancer. Prior to involving Voices, approval was granted from Breast Cancer Care. Working with Voices involved liaising with members through Breast Cancer Care staff and corresponding via email rather than speaking to them personally. Members of Voices were also involved in the 'designing and managing' stage of the 'research cycle' where they provided in-depth written feedback on the materials for studies 2 and 3.

3.8 Summary

A mixed methods research design was adopted for this research, as both qualitative and quantitative methods were used to answer the research questions. A mixed methods approach is frequently utilised within health psychology research due to its flexibility and appeal to a variety of stakeholders. In order to answer the research questions outlined in chapter one, the separate analyses from the different stages of the research were integrated. A detailed discussion of the different epistemological approaches has been provided in this chapter, including a justification for using a pragmatic approach.

Discussions of the challenges to recruitment, particularly within psycho-oncology research have been provided. In order to enhance recruitment for this research, an in-depth literature search was carried out to explore methods which have been successfully implemented in previous research. Also, service user involvement was

incorporated throughout the different stages of the research (further details of service user involvement for each study can be found in the subsequent chapters).

3.9 Summary of the key points in this chapter:

- The MRC framework for the development and evaluation of complex interventions was used in this research; it stresses the importance of rigorous reviews, of establishing the need for any new intervention and careful acceptability and feasibility work before trials are conducted to evaluate their effectiveness.
- Given the applied nature of the research questions a mixed methods approach was adopted within this thesis.
- A concurrent triangulation design was adopted for the HeadStrong service evaluation; equal priority was given to the qualitative and quantitative studies which were conducted simultaneously.
- An embedded design was adopted for the expressive writing study, as the quantitative and qualitative components were carried out at the same time.
- PPI was important throughout this research program and a patient representative from the Breast Site Specific Group of the Avon, Somerset and Wiltshire Cancer Network (ASWCN) and a number of advisors from Breast Cancer Care's Voices patient group were involved throughout.

3.10 The next stage of the research

The following chapter discusses the findings from an evaluation of one of the most widely available nationwide support services for those affected by hair loss in the UK. It is the first study to be conducted of HeadStrong which is a freely accessible service offering information and support around scalp care and in the use of headwear (scarves etc) to camouflage hair loss.

Chapter Four

A Camouflage Based Support Service

4.1 Background

Support services currently available for breast cancer patients who are affected by treatment-related hair loss tend to focus on information and advice around scalp care and behavioural-based camouflage techniques such as the use of wigs and headscarves. However, many of these interventions have not yet been evaluated and as a result were not included in the systematic review earlier in this thesis (chapter 2). One of the most widely available nationwide support services for those affected by hair loss in the UK is HeadStrong (www.breastcancercare.org.uk/HeadStrong), which is a freely accessible service offering information and support around scalp care and in the use of headwear (scarves etc.) as an alternative to wigs to camouflage hair loss. It is important to acknowledge that additional services do exist (a discussion of these services can be found in chapter 1). However, Look Good Feel Better (LGFB) and HeadStrong are the only two services which are widely available in the UK. As discussed in chapter 2, LGFB has already been evaluated (see Taggart, 2009). However, to the best of the researcher's knowledge, to date, HeadStrong has not been evaluated.

HeadStrong is funded by the charity Breast Cancer Care and is provided through volunteers across the UK at 24 different centres. HeadStrong centres normally offer appointments one day per week, but appointment availability varies across sites. A HeadStrong session is usually provided as an hour-long, one-to-one session, but patients are welcome to bring a family member or friend along to the session. Most patients only attend one HeadStrong session but they can attend more than once, if they wish.

Breast Cancer Care has developed their own brief questionnaire which they ask individuals to complete after attending a HeadStrong session. According to the charity, this has indicated high levels of patient satisfaction with the service. However, this is a satisfaction survey which is useful for audit purposes rather than a rigorous research evaluation, and, to date, these findings have not been published. It

remains unclear how successful HeadStrong is in helping women manage their distress in relation to treatment-related hair loss. It is important that services such as HeadStrong are evaluated so that health professionals can signpost breast cancer patients to services that they are confident will be beneficial. In conclusion, there is still a need for rigorously evaluated psychosocial interventions to support patients facing the challenges and emotional impact of treatment-related hair loss. As HeadStrong is a freely accessible national service for breast cancer patients, it was considered important to explore patients' experiences of the service and to see if it offers benefits in helping them to manage their feelings towards hair loss.

Specifically, the study aimed to address the following research questions:

- What are individuals' experiences of the HeadStrong service which aims to support them with their hair loss?
- Are any further interventions needed?

4.2 Aim

The aim of the service evaluation was to explore users' experiences of the HeadStrong service and its effectiveness, specifically its impact on appearance-related distress, concern about hair loss, psychological well-being and confidence in managing the personal impact of the situation.

4.3 Method

4.3.1 PPI involvement

As outlined in chapter 3, a patient user representative from the Network Breast Site Specific Group of the Avon, Somerset and Wiltshire Cancer Network (ASWCN) who was an advisor throughout this research, read over the participant information sheet, consent form and semi-structured interview schedule and questionnaires to check that the materials were appropriate for breast cancer patients, and provided suggestions on how the materials could be improved to make them more accessible for patients (see appendices 2, 3, 4).

4.3.2 Design

This evaluation of a current intervention was driven equally by quantitative and qualitative methodology. As there is no known research that concentrates specifically on the HeadStrong service, it was important that this research highlighted which aspects of psychosocial support for chemotherapy-induced hair loss are important to individuals (see figure 8). It was important to use mixed methods research to overcome the weaknesses of qualitative and quantitative methods (as discussed in chapter 3) by complementing the strengths of each other and providing a synthesis, whereby the outcomes of the qualitative and quantitative studies would lead to an integrated understanding of the participants' experiences of the HeadStrong service.

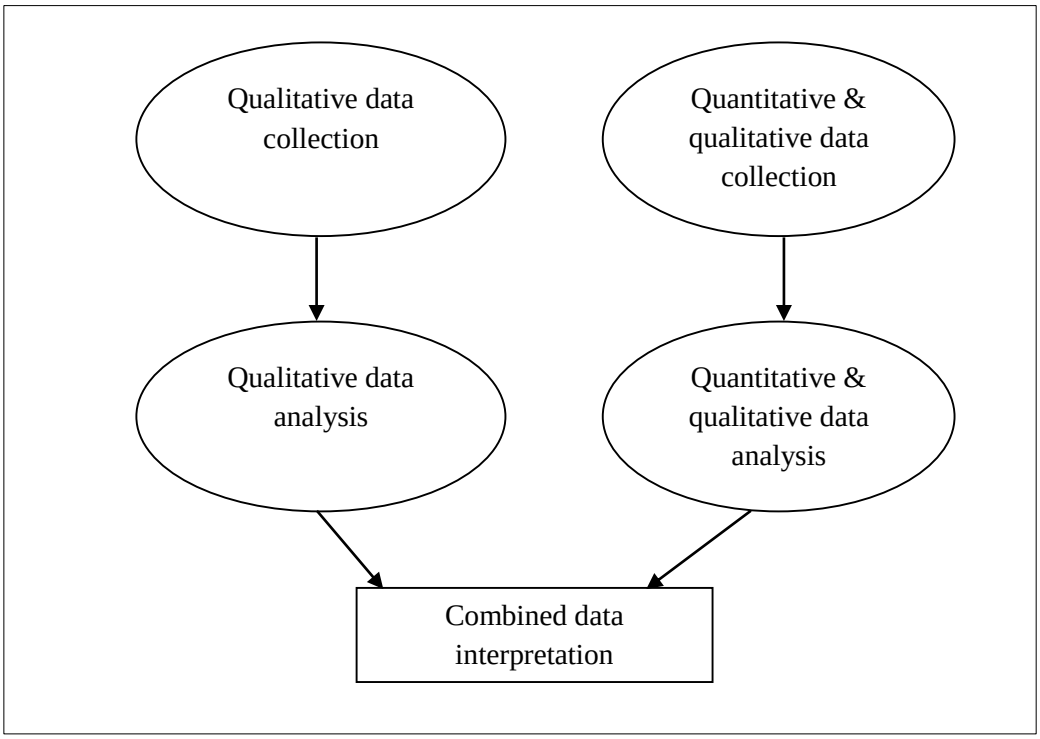


Figure 8. HeadStrong service evaluation

Whilst the aim of the qualitative study was to explore patients' experiences of the HeadStrong service, the quantitative element evaluated its effectiveness. Different participants were included in the qualitative and quantitative studies, so that the study did not become burdensome and time consuming for participants. Also,

participants in the quantitative study were women, who were accessing HeadStrong at the time, this was important so that the study could follow participants over a three month period, through their hair loss journey. Whereas participants in the qualitative study, were women who had experienced hair loss, who had used HeadStrong in the past and were able to reflect on their experiences of hair loss and of the HeadStrong service. The quantitative study was informed by the ARC (2009) framework (previously outlined in chapter 1), which demonstrates the importance of pre-disposing factors (demographic variables, hair loss status, treatment history) and moderating factors (importance placed on appearance, self-esteem and fear of negative evaluation) in determining psychosocial adjustment to treatment-related hair loss as indicated by relevant outcomes (QOL, appearance-related distress, anxiety, depression, confidence in managing hair loss).

The following section will discuss the qualitative study which explored breast cancer patients' experiences of treatment-related hair loss and a camouflage based support service.

4.4 Research questions:

- What were service users' experiences of hair loss?
- What were service users' experiences of the HeadStrong service?

4.5 Method

The current study used telephone interviews to explore women's experiences of treatment-related hair loss and of the HeadStrong service. The interviews lasted between 20 and 90 minutes. Although telephone interviews may have a number of limitations including restricted development of rapport and being a less natural encounter (Gillham, 2005; Shuy, 2003), they have been shown to be useful when conducting research into sensitive topics. Participants have been found to be more confident and open when speaking over the telephone, as opposed to being face-to-face with the interviewer (Trier-Bieniek, 2012). Also, telephone interviews are

advantageous when looking to recruit participants from wider geographical locations (Irvine, 2011), which was the case in the current study.

4.5.1 Recruitment strategy

Purposive sampling was most appropriate given that a specific population, i.e. individuals who had attended HeadStrong within the last 6 months, were the focus of the research. Recruitment was through the charity Breast Cancer Care, who posted out 50 letters (see appendix 5) to a selection of people across the country who had attended a HeadStrong session in the previous 6 months, and had indicated that they would be happy to be contacted regarding future research. 50 letters were posted in the first instance and depending on the response rate, more letters would have been posted had saturation not been reached from the 25 interviews which were conducted. This 6 month time period was selected as a longer period of time can effect an individual's accuracy when reflecting on their experiences. The selection process included a member of staff from Breast Cancer Care randomly selecting every 5th person from their database, which included a list of individuals who had attended HeadStrong in the previous 6 months. The researcher designed the study in discussion with Breast Cancer Care and it was agreed that the charity would contact potential participants in order to adhere to ethical guidance and data protection. The charity also promoted the study to its Body Image Advisory Group, which consists of patients, health professionals and body image experts who are campaigning for the provision of care for breast cancer patients to include support for body image and intimacy concerns. Three of the participants were patient representatives on the Body Image Advisory Group. It is important to acknowledge the possible implications of including participants from the Body Image Advisory Group. In particular, women who are sufficiently motivated to become involved with a group aiming to improve care around appearance-related issues for women with breast cancer may have particularly strong views on the subject which may differ to those who are not motivated to join such a group. This was not a problem, given that a qualitative approach was being used so the aim was not to involve a representative sample, but rather to gather views from women with a range of experiences and who were all in a position to discuss the topic from their own, individual perspective.

The letters included an information sheet, a consent form and a pre-paid envelope for individuals to return their consent form to the researcher if they wished to be interviewed about their experiences. If individuals had any questions or queries about the study they could contact the researcher via telephone or email before deciding whether or not to consent to take part in the study. The researcher then contacted those who wanted to take part, to arrange a convenient date and time for the interview to take place.

4.5.2 Sample characteristics

Twenty five women elected to participate – a sample size appropriate for thematic analysis (Guest et al, 2006). In this study, cases were compared at the individual level. Names of participants have been changed for confidentiality. Mean age of participants was 51 (range = 34-68 years) and all of the participants described themselves as White. The interviews were conducted during April and May 2013, with participants being between 4 and 13 months post diagnosis (mean 8 months) at the time of the interview. All of the participants had received or were currently undergoing chemotherapy at the time of the interview and had experienced or were currently experiencing hair loss. Participants were from a variety of geographical locations across the country (see table 4 for participants' demographic details). The inclusion criteria for the study was that participants were over the age of 18, had received a breast cancer diagnosis, were receiving curative cancer treatment and had attended a HeadStrong session within the last 6 months. The exclusion criteria included individuals under the age of 18, who were receiving palliative care and who could not speak fluent English.

Pseudonym	Age	Ethnicity	Date of Diagnosis	Type of treatment received	Experience of hair loss	Employment	Location	Marital status
Emma	50	White	Oct-12	Chemotherapy & Surgery	Yes	Full time work	England	Partner
Sophie	56	White	Sep-12	Chemotherapy, Lumpectomy, Mastectomy	Yes	Full time work	Wales	Married
Claire	64	White	Dec-12	Chemotherapy, Radiotherapy, Surgery	Yes	Retired	Edinburgh	Divorced
Emily	55	White	Aug-12	Chemotherapy, Radiotherapy, Surgery	Yes	Starting new job soon	On the Wirral	Married
Debbie	43	White	Mar-12	Chemotherapy, Radiotherapy, Surgery	Yes	Part time work	England	Engaged
Penny	48	White	Sep-12	Chemotherapy, Radiotherapy, Surgery	Yes	Full time work	England	Married
Katie	50	White	Aug-12	Chemotherapy, Radiotherapy, Surgery	Yes	Full time work	Newcastle	Partner
Nicola	61	White	Sep-12	Chemotherapy, Radiotherapy, Surgery	Yes	Retired	Merseyside	Married
Polly	60	White	Nov-12	Chemotherapy, Radiotherapy, Surgery	Yes	Working full time	Liverpool	Married
Stephanie	40	White	Sep-12	Chemotherapy, Radiotherapy, Surgery	Yes	Working full time	England	Divorced/live with partner
Helen	48	White	Aug-12	Chemotherapy & Surgery	Yes	Working part time	Nottinghamshire	Married
Kathryn	54	White	Nov-12	Chemotherapy, Radiotherapy, Surgery	Yes	Working part time	Yorkshire	Married
Iris	57	White	Aug-12	Chemotherapy & Radiotherapy	Yes	Working full time	Scotland	Divorced
Eila	57	White	Jul-12	Chemotherapy & Surgery	Yes	Working full time	England	Married
Lauren	68	White	Nov-12	Chemotherapy, Surgery & Tablets	Yes	Retired	Doncaster	Married
Julia	44	White	Sep-12	Chemotherapy & Radiotherapy	Yes	Working full time	Wales	Divorced
Cecile	59	White	Dec-12	Chemotherapy	Yes	Working full time	Chester	Married

Juliette	35	White	Nov-12	Chemotherapy & Surgery	Yes	Student	Leicester	Partner/ co-habiting
Dawn	44	White	Aug-12	Chemotherapy & Radiotherapy	Yes	Other	On the Wirral	Married
Debra	55	White	Aug-12	Chemotherapy, Radiotherapy, Surgery, Other	Yes	Self-employed full time	England	Married
Sienna	34	White	Dec-12	Chemotherapy, Radiotherapy, Surgery, Other	Yes	Working full time	Birmingham	Married
Mercedes	44	White	Aug-12	Chemotherapy, Radiotherapy, Surgery	Yes	Working part time	Essex	Married
Chenade	60	White	Nov-12	Chemotherapy, Radiotherapy, Surgery	Yes	Returning to work	Halifax	Married
Poppy	47	White	Jan-13	Chemotherapy	Yes	Working full time	England	Married
Whitney	59	White	Aug-12	Chemotherapy, Radiotherapy, Surgery	Yes	Working part time	Halifax	Partner

Table 4. Participants' demographic details

4.5.3 Ethical approval

As the study was classed as service evaluation, approval from NHS Research Ethics (IRAS) was not required (see appendix 6). Approval from the University of the West of England Research Ethics Committee was obtained (appendix 7). The research was conducted in accordance with British Psychological Society (BPS) guidelines (British Psychological Society, 2009).

The interview required active involvement from the participant, which may have produced an aspect of self-reflection which could stimulate thoughts and feelings in the participants which they may not have experienced before. This may have had a positive therapeutic effect but it could also have led the interviewee to recall distressing experiences, bringing negative emotions to light (Harber & Pennebaker, 1992; Pennebaker, 1989). The information sheet given to participants therefore contained contact details for support services should the participants wish to seek support.

4.5.4 Data collection

Following advice from staff at Breast Cancer Care and PPI, participants were given the option to have either a face-to-face or telephone interview (see appendix 4 for a copy of the interview schedule). All participants chose a telephone interview which followed a semi-structured format. The interview schedule was developed by the researcher and reviewed by three members of the research team and the patient-user representative. It was important to gain an insight into pre-disposing factors which included questions around demographics, hair loss status and what treatment participants had undergone. The semi-structured interview schedule also included questions relating to participants' experiences of the HeadStrong service and other support they had accessed or wished they had received.

4.5.5 Data analysis

The interviews were transcribed verbatim by an external, qualified audio typist and subjected to inductive Thematic Analysis (TA) - a method of systematically identifying, organising and offering insight into patterns of meaning across a data set

(Braun & Clarke, 2006). Braun and Clarke's (2006) thematic analysis is a widely used "method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p79). Advantages of thematic analysis include it being theoretically flexible, meaning that it can be used within a variety of frameworks, including the pragmatic approach and exploratory nature of this research. In terms of level of analysis too, there is flexibility with both descriptive and more interpretative levels being acceptable (Braun & Clarke, 2006). Themes can be generated inductively (i.e. data driven) or deductively (i.e. theory driven); an inductive approach was employed for the qualitative HeadStrong evaluation because this was exploratory in nature rather than being theoretically driven. While thematic analysis remains grounded in individual experiences, it is able to summarise features of a dataset and highlight the similarities and differences within individual accounts (Boyatzis, 1998; Braun & Clarke, 2006).

The software NVivo (http://www.qsrinternational.com/products_nvivo.aspx) was used to analyse the data, alongside analysing the interview transcripts by hand. Following recommended stages of thematic analysis (Braun & Clarke, 2006), analysis started with becoming familiar with the interview data (phase 1) by reading and re-reading each transcript whilst noting down initial ideas. The second phase involved coding interesting aspects, all the codes were gathered and organised into potential themes (stage 3). The themes were then reviewed and refined ensuring that the sub-themes were relevant to each main theme and a thematic 'map' was produced (stage 4). The themes were then named ensuring that they captured the true meaning of the themes (stage 5). Details of the analytic process can be found in appendices 8, 9 and 10.

Demonstrating quality in qualitative research is essential (Mays & Pope, 2000; Meyrick, 2006). It is important for the researcher to immerse themselves in the data both during data collection and analysis, demonstrating in-depth engagement (Yardley, 2000). Rigour and transparency are essential (Davies & Dodd, 2002; Morse, 2015; Yardley, 2000; Moravcsik, 2014), requiring the findings, particularly the codes and themes, to be verified by an impartial researcher and provided in a clear account that demonstrates how the themes were generated from the data. In this

study, a reviewer was asked to check five transcripts along with the codes and themes that had been produced. No disagreements came to light. Furthermore, the lead researcher kept a reflective diary throughout the interview process, to record thoughts and feelings before and after each interview. Reflective diaries help to make the process of data analysis as visible and transparent as possible (MacNaughton, 2001; Morse, 2015). An account of the researcher's reflection can be found in section 7.5.

4.6 Results

Thematic analysis of the 25 semi-structured interviews identified three main themes: facing the challenges of hair loss, receiving support for treatment-related hair loss and meeting unmet needs. Underpinning these three main themes were nine sub-themes. These are presented in Figure 9. The themes were chosen, in accordance with the guidelines for thematic analysis, on the basis of their prevalence and the emphasis placed on them by the participants. The themes are described below. Pseudonyms are used throughout; some of the participants chose their own, whereas others were happy to be given one

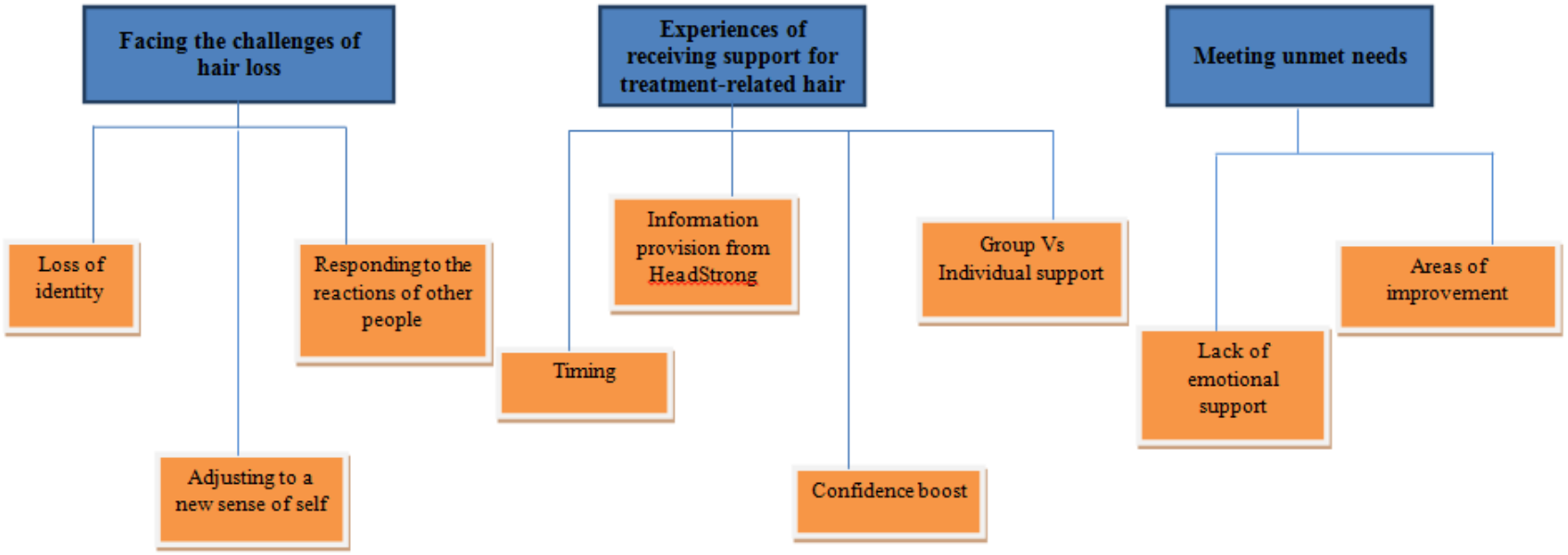


Figure 9. Thematic map of interview themes and sub-themes for the qualitative HeadStrong service evaluation

4.6.1 Theme 1: Facing the challenges of hair loss

During the interviews many participants referred to their breast cancer as a 'journey'. All the women had experienced treatment-related hair loss which they described as being extremely distressing. Hair loss-related distress typically began from the moment the possibility of chemotherapy was first discussed with them. The challenges in relation to hair loss, started when they anticipated hair loss, through to hair re-growth and beyond.

Cecile, Eila and Whitney spoke about their hair loss being the most distressing thing about being diagnosed with breast cancer. The fact that Cecile's first priority was that if she died, she wanted to ensure she has a wig on, shows the importance women placed on their hair and the extent of the impact which losing it could have. Cecile acknowledged that to have that thought seemed 'really mad' which could suggest that she was surprised at the extent the impact of losing her hair had on her:

> *"I said to her [the breast care nurse]... what worries me the most is if I die I want to make sure I've got a wig on…she said, you're not going to die. And I said, no but I need to tell my husband if I die he needs to put my wig on - I don't want to be in a coffin with no hair!...And it did seem a really mad thought to have, but it came into my head"(Cecile)*

Eila demonstrated that the distress she felt as a result of losing her hair was not due to her being vain but because hair loss has such a large impact on an individual. Hair loss brought with it a number of challenges, including its impact on participants' lives, confidence, relationships and others' reactions.

> *"I lost all my vanity through cancer, you know. I'm not vain in any way, shape or ... that doesn't mean to say I don't want to look good but I'm not vain anymore" (Eila)*

Whitney spoke about the importance of her hair to her and the impact which losing it has had on her, including the extreme distress she has felt. For Whitney, losing her hair was worse than cancer itself:

> *"Hair loss was worse than the cancer. Mind you..if I'd been diagnosed with terminal I don't think losing your hair would ... wouldn't be anywhere as bad"(Whitney)*

Whitney was very proud of her hair, it was very important to her. She had invested a lot of money and time, ensuring that her hair looked the best that it could. Now that Whitney's hair had started to re-grow different to how it was before, it was a continuing source of distress for Whitney:

> *"I've prided myself in my hair,... I don't ever wash my own hair unless we're on holiday, I go to the hairdressers once a week. It's always looked immaculate and... well, it's just the worse thing ever…it's not just losing your hair, I mean, it's coming back quite thick now but it's coming back grey and I look at myself and I don't even recognise ... I don't even look like I used to look like…everybody says you will eventually get back to it - it's not them going through it and I could still cry now…if I'd have had a pound for every blinking tear I've cried when my hair started falling out"* (Whitney)

Once participants started to lose their hair, they found it extremely distressing and mourned its loss. For some, the distress they felt continued throughout the course of their hair loss and extended to concerns over whether it would grow back the way it was before:

> *"You're actually mourning a loss that you think means something to you and I'm thinking am I going to get my hair back the way I want it?"* (Cecile)

Participants described how their hair loss was all consuming and feeling like they were alone, with hair loss constantly in their thoughts.

> *"It's like being in this little world of your own where all you're thinking about is hair"* (Emily)

Emma demonstrates how distressing losing her hair was and, as a result, she isolated herself so that she did not have to see anyone. Hair loss was a process, it did not happen straight away. Emma, like many participants, took steps to minimise the impact of the loss, including cutting her hair shorter before it started to fall out. Once participants' hair started to fall out, it was often a very quick process, which was incredibly distressing for participants:

> *"I couldn't face anybody…I literally did fall apart the day after the haircut and then 10 days later ... it started literally within a couple of days… I was in the bath and I was washing it and what was left was just coming out in absolutely massive handfuls. It was really, really upsetting"* (Emma)

Cecile demonstrates how shocking and upsetting it was for her to see her altered appearance:

> *"Wearing the scarf is like a statement - you are a cancer patient... you look in the mirror - I don't do it now but when it first happened…I felt I was like that painting the scream - my mouth just opens just aghast and I would weep buckets of tears. Terrible. And I'm just like that painting the scream and then I think why am I looking at it, cover it up, cover it up"* (Cecile)

Whitney discussed the impact hair loss had on her self-esteem. The experience was so profound for her, that she described it as the worst thing that could have happened to her since she had always placed a great deal of importance on her appearance. To help her to try to cope, she goes to the hairdressers regularly, to try to maintain some 'normality':

> *" I'm trying to be realistic about how I feel and I know I should be glad I'm still here and I am glad I'm here but.. I'm very proud of the way I look and how I dress. I'm a very vain person and…I've found it very hard - I'm sort of getting used to it now. Believe it or not, for my own self-esteem, I still go once a week to the hairdressers, put my wig on and she tickles it up a bit and I've just kept that going. I don't know ... it's a really emotional, difficult thing for me to have lost. I've not bothered about my boob because she's done an absolutely fantastic job on that, my fingernails I can cope with - I can cope with that…Worst thing that probably could've happened to me other than losing my life"* (Whitney)

The prospect of hair loss was significant for many of the participants and they wanted to prepare for it the best they could. Sienna describes below that, as she had been told in advance that she would lose her hair through chemotherapy, she felt that this enabled her to prepare and she was glad that she had prior warning. Also, there is an element of downward social comparison, for example, Sienna compared herself to other women who have lost their hair and she felt that they had been affected more by their hair loss than she had:

> *"I think because I was mentally prepared that it was going to happen ... I have seen some women ... I have known some women where it does affect them worse. I think, actually, I got off quite lightly because I was expecting it*" (Sienna)

Women spoke about how shaving their hair off before it fell out was a way of gaining a sense of control over the situation. Many of them had asked someone close to them to shave their hair off when they felt the time was right, however, it was difficult situation for the family especially the person who was asked to shave the participant's head. However, as Emma illustrates, although there are some things that participants felt they could re-gain control of, controlling how they would react once they lost their hair was not one of those things:

> *"It's nice to think that there's something that you have got control over because…once you get the diagnosis you just feel like you've no control over anything so little things like buying scarves, like organising your wig, you know, being able to get your hair cut at the right time, are just little things that you've got some control over. But what, unfortunately, you don't have any control over is the way you react when your hair goes because, obviously, nobody can prepare you for that. They can tell you it's going to happen but nobody can tell you how you are going to feel about it personally"(Emma)*

Mercedes talked about feeling like she resembled a baby chick once her husband had shaved her head but she felt that shaving her head not only helped herself but also her family reach a level of acceptance even though she did not want to do it:

> *"I did get my husband to shave my head. Not baldy, baldy shave, but where I had lots of little bits of hair... I did look like a chick - you know when they're first born they've got little bits sticking up so I did ask him and he really, really didn't want to do it... but I suppose…I think that helped then. I think it helped the family as well".* (Mercedes)

For many participants, humour was a coping strategy which they used:

> *"I said my hair isn't who I am and I realised that very quickly…in terms of how I felt, yeah it was a shock to see myself with no hair and my husband ... has been fantastic throughout but then he has made a joke about it all along and he ... the series Kung Fu on the television, and there's a bald Buddhist Monk called Grasshopper, so he started calling me Grasshopper! So, you've got to have humour in these things... I think it's how other people treat you and my husband hasn't baulked at the fact I've no hair. He says it'll grow back" (Eila)*

Some of the challenges for participants were practical challenges, including deciding whether to dye their hair. Also, there is an element of comparisons here as participants' re-grown hair was often different to how their hair was prior to losing it:

> *"Now I'm thinking Oh bloody hell, do I dye my hair?! Even though it's only sort of ... oh I don't know, not even half an inch thick, probably a quarter ... I don't know it's just dead, dead short but I can see it's coming back sort of grey and dark where my hair over the years got lighter and lighter... So my next worry is how quick it's going to grow and how quickly can I colour it! All these things to contend with!"* (Cecile)

Some participants' hair did not grow back as quickly as they were advised it would, or had hoped for. Managing personal expectations around the rate at which their hair would re-grow was a further source of distress for participants. Claire and Stephanie spoke about their disappointment and frustration at how slow their hair was re-growing and the fact that no one had told them how long it would take:

> *"No it was ... about 16 months since I've lost my hair and most people it's 3-6 months - might not have much but they've a full head of hair and I still don't have a full head of hair"* (Claire)

> *" It's beginning to recover ... nobody told me how long it would take and it's been six or seven weeks and it's still really bald and nobody talks to you about that - nobody says it's going to take a long time, or be patient"* (Stephanie)

Also, whilst some participants found hair loss a real problem, some managed it more easily. Being told in advance that they would lose their hair was a factor which helped participants to cope.

> *"And, to be fair I didn't have ... I've been very fortunate, I haven't had a really big issue with it, to be honest. I felt that, from the beginning really, I was told quite clearly that I would lose my hair"* (Sophie)

> *"I think because I was mentally prepared that it was going to happen ... I have seen some women ... I have known some women where it does affect them worse. I think, actually, I got off quite lightly because I was expecting it"* (Sienna)

However, for some participants hair loss was not as distressing as they anticipated. For example, Debra prefers her wig, to her own hair as it is easier to manage:

> *"It's a bit strange really, because I didn't actually like my hair! So, in some respects I wasn't traumatised by it, although when it did start coming out in big clumps, it was sort of more the physical aspects of that that was…sort of a bit freaky…you're washing your hair and it's all coming out, but ... you know, in that respect I wasn't too bothered and I've got ... a lovely wig which is so much nicer than my original hair! it's just frizz and, you know, so ... it's ... a lot of people envied me because it was curly... but it's just very hard to manage…I used to spend ages blow-drying and suddenly I could just stick this perfect head of hair on my head so I've actually ... I have enjoyed having the wig!"* (Debra)

4.6.1.1 Loss of identity

Some participants felt that losing their hair impacted on their sense of self and their identity which was very challenging. Many participants greatly valued their hair, as evidenced below by Cecile who saw losing their hair as losing a part of her identity:

> *"This woman came in with a scarf on and I turned to my husband and I went, I could no more come to the hospital wearing one of them scarves than fly to the moon. He goes, yeah, but you're not that sort of person, you're not even dressed like them are you? I've sort of got my clothes on, got my wig on, got my make-up on. I'm just thinking it's like a statement - I'm thinking does my hair look ... I've put on a wig now and I'm thinking is my hair looking alright! Do you know what I mean because I just ... your hair is your identity ... it's what makes you. So I mean, some people aren't hair people, are they?"* (Cecile)

Mercedes dyed her hair before having her mastectomy to ensure that it would be looking its best and uses the term 'how pathetic' when speaking about her decision to prevent her roots being visible when going into hospital for surgery. This demonstrates how important Mercedes' hair was to her and how it formed an integral part of her identity, so hair loss changed her sense of self:

> *"I am someone that always colours my hair and always has styles - and at the time, when I was diagnosed, it was very blonde and I went ... before I went in for the mastectomy, I went and had it dyed brown so that it wouldn't have roots while I was in hospital, that's how pathetic"* (Mercedes)

Hair loss was not just confined to one's head. Participants also lost their eyebrows and eyelashes, which some felt altered their appearance and their sense of self, more than the loss of hair on their head. This changed participants' self-image. Emma spoke about the distress of losing the hair from the top of her head and, when she thought it could not get much worse, she then had to adjust to losing her facial hair too:

> *"You think that's sort of, the rock bottom but then your eyelashes and your eyebrows go and you realise that actually yes it still can get worse in terms of your appearance, yeah"* (Emma)

In Debra's case it was these changes to her appearance that made her see herself as someone with cancer:

> *"The loss of the eyebrows that's, I think ... even though I'm sort of mousey blonde, they weren't very dark anyway, but it's obvious that they're not there, if you see what I mean, and the eyelashes as well. I think, in some respects that's been harder because they do make you look different, the loss of the eyebrows. You know, you can put a wig on your head…I think perhaps... I've missed those more than my hair I think really... once the eyebrows have gone you think yes I do look like I've got cancer*" (Debra)

Even when participants used false eyelashes to camouflage their hair loss, this still affected their appearance.

> *"Because, even when you put false eyelashes on it just gives a whole different appearance to your eyes"* (Julia)

When describing how she felt about her hair loss, Cecile compared herself to Jews in concentration camps who's heads were shaved to remove their identity. Cecile spoke powerfully about feeling humiliated as a result of losing her hair and felt that part of her identity had been taken away from her:

> *"I tell you what my first emotion or my first thought was ... the people, the Jews when they were taken in the concentration camp all had their heads shaved and that wasn't for hygiene purposes, that was for humiliation, so I actually felt humiliated"* (Cecile)

Several participants spoke about losing their pubic hair and how this made them feel like a child rather than a woman. Kathryn spoke about feeling defeminised both as a result of losing half her breast and her hair. Although Kathryn's hair may re-grow she is aware that she will need hormonal treatment in the future and that the bodily changes they may cause are yet another threat to her femininity.

> *"As a woman ... because you don't feel like a woman ... when you've only got, you know like I've got one and a half breasts now and a bald head and ... the alopecia, of course, isn't just on your head, you know, it's your pubic areas ...even when you look down there, you don't look like a woman anymore, you look like a child. And it all feeds back into you that you are a woman and, you know, you're still a woman even though you've got this disease and you've had these treatments that sort of defeminise you a little bit"* (Kathryn)

Polly and Sienna also spoke about the importance to them of feeling feminine, and Sienna also described her body not feeling like it was her own by referring to it as 'an alien'. This again demonstrates the role of hair in an individual's identity.

> *"Well obviously I wanted to look feminine, I didn't want to look ... I'm a positive person, I didn't want to feel kind of not feminine"(Polly)*

> *" I did feel a little bit like an alien for a time ... sounds a bit odd saying it out loud but it's because you're completely hairless and, you know, your body hair doesn't grown and ... yeah. I mean, I used to joke it was great, I haven't got to shave my legs ... no, so it was a sort of bittersweet thing really"* (Sienna).

The impact of identity keeps shifting; the future is a constant worry for participants, for instance at the beginning, the future possibility of hair loss, then later on the possibility of further changes:

> *And then of course you've got the endocrine treatments to come, your tamoxifen and things so, again, sort of defeminising you"* (Kathryn)

The majority of participants spoke about the impact that hair loss had on their appearance and how they had tried to manage this, often by trying to keep their appearance as 'normal' as possible:

> *"That wasn't what I wanted, I wanted to ... I needed things to be as normal as possible and that included my appearance"* (Eila)

> *"Like I'm wearing a skinhead now, you know! Not the most attractive look but ...!"* (Helen)

Participants were surprised by the impact that hair loss had on their identity. Some participants were not expecting their hair loss to have as much of an impact as it did, some spoke about the impact it had on their confidence and appearance, particularly around socialising.

> *"No, confidence in my appearance. I can still deal with day to day situations and things like that but ... that's not a problem, it's confidence in my appearance"* (Polly)

> *"I did think that it was going to be a problem but I had no idea just how much of an impact it was going to have. I certainly…never realised that it would actually have a knock-on effect into, sort of, all areas, my confidence in all areas"* (Emma)

Sienna describes how she had been brought up to be a very confident person and enjoyed singing in pubs and bars but because of her hair loss she felt unable to continue to perform in public:

> *"I'm one of the most confident people I know. I've got three brothers and I was brought up to be very confident and I'm a singer in a band, and I do that as a sort of ... in pubs and bars and things, and it took away my confidence to do that for a while"* (Sienna)

The following quote suggested that Whitney could be depressed. In response, the researcher asked Whitney if she had spoken to someone about her feelings and she replied that she had spoken with her doctor. The researcher recommended some charities that Whitney could contact if she would like further support and someone to speak to.

> *"I've lost a lot of my bounce. I feel ... I feel dead inside, I'm not interested in things and I've talked to the hairdresser and she thinks that maybe when my hair comes back ……..I'll probably be more myself again…. I've not stopped going out, I don't go as many places"* (Whitney)

4.6.1.2 Responding to the reactions of other people

The participants spoke about both the reactions of other people to their hair loss (such as staring, asking questions) and engaging in certain behaviours because of

this. Some positive aspects included feeling like they were being treated nicer than they normally would. For example, Poppy described the 'head scarf effect', which was evident when she spoke about her daughter's orthodontist being uncharacteristically nice to both of them. However, Poppy cannot be sure it was due to her headscarf but this is an example of how she was interpreting the reactions of the others around her:

> *"My daughter's got braces and she goes to this orthodontist and he's ...really quite ...well, if you carry on doing this I'm not going to do this again ... so I went oh well you never know, maybe he might be a bit nicer to you this time ... and we went in and he was nice as pie ....he was just really, really nice and we just came out and laughed our heads off because it was just like ... oh so there you go, the headscarf effect, it does ... and his whole attitude totally changed in a positive way"* (Poppy)

Some people's reactions were perceived as caring, as Poppy demonstrates below:

> *"I forget that I've got a headscarf on and I'll come out of a shop and I'm thinking ... they were nice ... and I'm thinking .. oh, that's why!"* (Poppy)

However, there were some negative reactions from other people. Penny and Stephanie all spoke about some of the reactions they had received from members of the public. Penny explained that she had expected children may ask questions about her hair loss, but was surprised by the reactions of adults. Stephanie spoke about the change in people's behaviour once they found out that she had cancer, which made her reluctant to go out in public, and fearful of being judged:

> *"I do find there are a lot of people who stare though. I was very surprised at how many adults. I was expecting a small child might go "mummy, mummy why hasn't that lady got any hair?", which if they'd asked me I'd have told them that "Well I've been poorly and the medicine I've had's made my hair fall out, but it will come back", which is what you do, but you can't do that with adults can you?"* (Penny)

> *"You know, "I like your hat, love" and we had a joke and then he went "You haven't got cancer have you?" and I went yeah and then of course he sat next to me "I'm so sorry" ... people stare at you everywhere you go, people stare*

> *at you and not in a cruel way in a "Oh has that poor girl got cancer?". And it's not ... it makes you feel uncomfortable out socially"* (Stephanie)

Emily embraced her hair loss and described it as a liberating experience, but felt that other people were shocked and reacted more negatively to it than she did:

> *"To be honest, I found it [hair loss] quite liberating!... I thought I'd be bothered about it but I really haven't and I find it's more confronting for other people, you know, because I'm bald most of the time - I only put a hat on if I'm cold…I've probably got about half an inch of hair now which, you know, opening the door to the postman or delivery man and you can see them taking a step backwards and getting quite ... So I've found other people have been more confronted by it than me".* (Emily)

Participants spoke about the impact which their hair loss had on family members and their reactions. Some participants reported negative reactions, not only from strangers but from family members. For example, Sabrina spoke about the insensitive comments and reaction she received from her husband:

> *"I was having conflict with my husband at the time, we've since divorced, and one of his very first comments about my hair loss was that I should wear a scarf in the kitchen because he didn't want my hair in his food. That was the most degrading comment anyone made"* (Sabrina)

A number of participants spoke about the stigma attached to both headscarves and very short hair, and how people assume that someone in a headscarf has cancer. As a result participants did not like to wear headscarves as they felt it was an external symbolism of their cancer and would make people aware that they had cancer, as Whitney and Sienna illustrate below:

> *"It's a stigma ... I'm not bothered about cancer but it's the look and your face looks fatter, you've no hair... I feel I've got this stigma about me that if I go out looking like this, my hair looks like it ... my face looks fatter so ... yeah. Well that's it she's ... you know? Or, the other side of the coin is nobody'd surely have their hair cut like that! And I have got a sense of humour, you know, but I find it difficult because of my vanity, I suppose*" (Whitney)

Sienna considered the experience of being in social situations with people that she knows well, compared to being with strangers where she feels less comfortable. Again, this demonstrates participants' feelings that short hair is an external symbol of their cancer.

> *"I went to a wedding when my hair was still very short and I do feel very self-conscious…I was fine at work and going around with a buzz cut … when it was already short - I'm fine with that because everyone knew me, but I think if I had to go on social situations I found it a bit more difficult.. I just feel very, very self-conscious because people who see you with short hair, I don't know, I think they tend to look at me and they go oh cancer patient, you know. And you don't want to feel like someone unique*" (Sienna)

Penny discussed how society has changed over recent years and as a result people have become more accepting and understanding compared to the 1980's.

> *"It's not something that personally bothers me - I just feel sorry for them... they obviously just don't comprehend coz you'd think in this day and age with people knowing a lot more about treatment that people would understand... I mean, when my mother was diagnosed with cancer in the 1980's you didn't discuss it. ..And if you did lose your hair ladies definitely wore a wig and wouldn't be seen out in a hat or a scarf. In fact they wouldn't leave the house for 6 months while they had no hair because it was considered a taboo thing*" (Penny)

Some participants spoke about engaging in behaviours such as wearing headgear to hide their hair loss, or not doing so if that drew more attention to them or upset other people, as shown in the quotes from Dawn below:

> *"My niece just said to me you look funny Auntie [xxx] and I thought oh right ... that's it, I need to do something now. It was ... of course ... and she didn't mean any harm by it but it upset my Mum because she was there at the time. It didn't upset me particularly, I just thought she didn't mean any harm by it"* (Dawn)

Helen spoke about wanting to try to keep her hair until after Christmas as that was her son's wish:

> *I sort of held onto my hair right until Christmas coz my youngest son said "Mum, I hope you get to keep your hair 'til Christmas" and how it hung onto my head for Christmas ... because on Boxing Day I washed it and it just matted on my head ... it was all dead* " (Helen)

Lauren described how she had scalp cooling whilst receiving her chemotherapy treatment in an attempt to prevent or reduce hair loss, because her grandchild did not like her wearing a wig – this is another example of the steps that participants had taken to protect the feelings of others:

> *"I'm glad that I did the scalp cooling, mainly because my youngest grandchild who's only four - she doesn't like wigs. She doesn't like me when I'm wearing the wig... I mean the others don't mind…the others have my wig on and all sorts but she's very much ... she'll say take wig off Nanna"* (Lauren)

For some participants, treatment-related hair loss had altered how they felt about themselves and as a result had impacted on their relationships with others including their partners, in particular their intimacy. Participants spoke about the negative impact hair loss had on their intimate relationships with their partners; in particular they felt it took away any aspect of spontaneity as they always wanted to make sure they had hidden their baldness and felt confident in how they looked.

> *"And you feel ugly and it affects your relationship. Because you don't have much confidence in yourself and your partner. He thinks I'm beautiful and adores me and told me all the right things - he's been amazing - but it doesn't matter because it's how YOU feel about yourself"* (Stephanie)

> *"Well me and my partner have only been together for three years so we're really quite new and still very loving and, you know, and we haven't sort of settled down into that mundane thing. We're very full-on sexually and stuff like that. We like to bath together and things like that and it's really, sort of ... it's ... um ... have to have something on my head to go in the bath and it just ... everything feels sort of awkward and has to be planned, nothing's spontaneous anymore"* (Katie)

4.6.1.3 Adjusting to a new sense of self

Participants spoke about adjusting to their hair loss and getting used to seeing themselves differently. Several participants spoke about not recognising themselves anymore as a result of their hair loss:

> *"You look in the mirror and you're not there anymore… like it's just a complete, sort of, stranger and you don't like, you know, what you're seeing looking back at you". (Emma)*

Helen spoke about losing her hair as being a time of anxiety and describes a process of adjusting to a new appearance and new identity:

> *"When I went from having long hair to …having it cut short that was really upsetting, you know, because, I've never had short hair and never thought I liked short hair, or wanted it... so that was awful. And then after that it's just a slow transition and I think, you know, one day you've got hair that's quite thick, the next day you've got hair that's a little less thick and then you're sorting of looking at it, seeing what you can do and you just learn to see yourself differently"* (Helen)

Over time participants started to adjust to a new self, as Debra, Helen and Chenade highlight below:

> *"I was saying I didn't like my hair, initially, when you see yourself in the mirror sometimes it was a shock and it did take a little bit of time to get used to it, just the first couple of minutes you're thinking oh no, I look terrible but once you'd got used to it ... but it did give you a real idea of what it could look like"* (Debra)

> *"But, you know, it's getting used to yourself looking different. And the difference of having no hair under a scarf or a fringe under a scarf makes you look less 'cancer victim'"* (Helen)

> *"At the beginning I never ... I wouldn't stand in the window, you know, without a head covering on. Now I'm more prone to bobbing outside to the car for things without anything on. I am aware of ... sometimes' of people's ... you know, sort of a double-take look but I'm more confident in myself now*" (Chenade)

Once participants' hair started to grow back, this presented another set of issues for their identity. Even though they were grateful that they now had some hair, there were still a number of challenges that they had to comprehend. Whitney, Claire and Stephanie spoke about adjusting to their new appearance. In particular, Whitney spoke about the excitement of adjusting to her new self:

> *"When it first started growing and my partner ... I mean, I've stopped wearing little hats in bed and everything now ... it is quite exciting watching your hair come back. It's not the same but it is quite exciting"* (Whitney)

Kathryn demonstrates that it is not only the women themselves that had to adjust to a new self but also family member. She spoke about how her daughters reacted when she wore a wig, and how upsetting it was for her to hear their comments that she 'was not mum' anymore. As a result, she had not worn the wig since.

> *"I didn't like the wig, I found it uncomfortable to wear and when I put it on at home ... I've got two daughters and the expression on their face, it was quite ... quite devastating. They looked at me and they said you're not Mum with that wig on. And I'm afraid the wig has been destined to a lonely life in a cupboard"* (Kathryn)

4.6.2 Theme 2: Experiences of receiving support for treatment-related hair loss

Participants spoke about receiving their cancer diagnosis in terms of shock, suddenly having numerous medical appointments to attend and the different strategies they had used to cope with their hair loss. These included attending support services such as HeadStrong, where they received advice and information which gave them a sense that they were better placed to cope by trying to re-gain control of the situation. Participants also reflected on their experiences of using the NHS wig service and also attending a Look Good Feel Better session.

Participants heard about HeadStrong through a number of avenues including from various health professionals, cancer support groups and through friends who had attended HeadStrong:

> *"I think I had…like a number of leaflets from a breast care nurse and it was among…you know, the leaflet about it [HeadStrong] was among there"* (Katie)

There were a variety of reasons why participants attended a HeadStrong session, the main reason being for help with the practical and emotional sides of hair loss. Most participants wanted advice around how to take care of their scalp and around the different head camouflage available:

> "*I went along because I know they do give you a free headscarf, so I thought oh well that's a bonus and I thought it might be quite interesting. I think, um, some of the techniques to tie the scarf ... I mean it was quite detailed and it was quite hard to remember that, but they do give you some information and, yeah, I just found it quite nice really. It was before, you know, I got into all the treatment properly so it was just a way of me preparing myself really"* (Sienna)

One of the main advantages of HeadStrong was that it enables participants to visualise what they would look like without their hair, and for those who had

attended before they had lost their hair, this helped them to come to terms with the prospect of losing it:

> *"I think one of the things that was very useful was that they put, you know, like a little stocking on your head, so it actually showed you what you'd look like with no hair ... you know, gave you a bit of an idea… once they'd done that I felt a bit, sort of, happier about the whole thing. And, obviously, they had things to, you know ... they showed you the scarves and I bought some little hats that I actually preferred to the scarves, so they introduced me to the products that were available*" (Debra)

> "*The two ladies that did it were lovely, you know, funny and ... I mean, I still had my hair when I went but they kind of put this stocking thing on my head and I thought it was the first time I'd get an idea what I would look like without it [hair] and I ... you know, we had a good laugh about it so it was ... you know, it was light hearted, that's what I'm trying to say really*" (Katie)

Some participants particularly liked that the HeadStrong volunteers were able to tailor the tone of the session to their needs, for example, some felt that the session was light hearted which is what they wanted:

> "*I'm fairly irreverent about the whole thing and they [HeadStrong volunteers] were happy to banter with me and some of the scarves they put on looked absolutely ridiculous and my daughter was there and she was, you know, she was like "no, no, take it off" and we were all falling about laughing so it was a really funny, bantering-type session…I think that the staff there gauged how I cope with stuff and worked…with that so ... I found that really good because some of the other services I felt you have to be a victim almost*" (Emily)

In particular, HeadStrong provided a welcomed break from medical appointments. Participants spoke very highly of the service and particularly liked that it was informal and feminine:

> *"The thing that was really nice… was that it was something that was light-hearted ... it was probably about six weeks after my diagnosis ... I was really, really freaked out by it and, you know, I was having all these medical appointments, kind of, really out of the blue ... this horrible diagnosis ... and I'm quite young, so it nice to have something that was just a bit girlie and, sort of, light-hearted"* (Juliette)

> *"Out of all the services, HeadStrong is head and shoulders above the rest"* (Helen)

HeadStrong showed participants that there were alternative camouflage options available to wigs. During the sessions, participants had been able to try on a variety of headscarves and hats and were shown different ways in which they could be styled. Eila talks about how HeadStrong showed her that she could still look good without having to wear a wig, and both the quotes below suggest that participants still placed importance on how they looked and how this could boost their sense of wellbeing.

> *"And I think at that time, that's what I really needed. It was better than any counselling session I could have asked for"* (Julia)

> *"I found going to buy a wig totally ... the most distressing, uncomfortable experience and I actually have never ever, EVER, worn my wig. But, I went to Headstrong and they showed me that, in actual fact, I could still look good without wearing a wig"* (Eila)

HeadStrong enabled women to talk about their hair loss without feeling a sense of guilt. Many participants had felt they should be grateful that they were receiving chemotherapy and worried that they would feel guilty and considered vain if they told health professionals or family and friends about their distress over losing their hair. In contrast, HeadStrong enabled them to voice their emotions, without feeling guilty.

> *"It was like giving you permission to talk about something which other people could have seen as a little bit of self- obsession and it was lovely to have that permission to sort of self-indulge and that they were quite happy for you to self-indulge and ... I mean, they empathised and sympathised, but it was like permission to grieve a little bit, as well, even though it hadn't actually happened"* (Kathryn)

A number of participants indicated how they enjoyed being able to talk to someone who understood what they were going through and how they were feeling. HeadStrong gave them this opportunity and a chance to talk freely about their concerns about hair loss.

> "*My own friends are wonderful but sometimes, you know, you don't want to sort of like moan on all the time about what's this and that's wrong with you and what's bugging you this time - you try to keep it sort of off the subject when you're with your friends, so ... it was nice to have someone who understood really*" (Katie)

> "*I just didn't realise what a devastation cancer is on an individual and on a family. But ... and it's why people like Headstrong are so needed. Because sometimes you actually need someone who isn't a member of the family that you can grieve with and who aren't going to judge and perhaps roll their eyes or think God is she self-obsessed with this illness. But they're quite happy to let you rant on about it or ... and without judging you"* (Kathryn)

Participants spoke about the benefits that learning from the volunteers at HeadStrong had on enabling them to cope with their hair loss, and the range of worries and concerns they had. For example, in the quote below, Sophie describes learning more about the possible consequences of losing all her hair.

> *"Generally being able to talk to other people (the HeadStrong volunteers) who had gone through the same so they know how you're feeling and how you're dealing with thing"* (Nicola)

> *"Which, in fact, nobody HAD told me and I was sort of thinking, oh gosh, am I starting with a cold, but she (HeadStrong volunteer) was explaining to me that that had happened to her, that her nose was just running all the time, simply because you lose hair in the nostrils as well!"* (Sophie)

4.6.2.1 Timing

Many participants worked either full-time or part-time whilst receiving treatment, which left them very little time for anything else, including accessing and attending support services. Also, as demonstrated by Juliette below, participants felt that there was limited time available for support in the NHS:

> *"I think it's difficult when you're getting your own treatment because you do tend to get a bit busy as well ... like you're going to appointments yourself all the time"* (Sienna)

> *"I'm always just a little bit aware that, you know, you get an appointment and I don't like to feel like I'm wasting their time and I'll write down questions but then, you know, won't remember everything I want to ask them or ...I'll ask a question but then not go into it in as much detail as I'd like because... I always feel rushed with the NHS and maybe that's partly me rushing myself"* (Juliette)

Participants spoke about the timing of when they chose to attend a HeadStrong session. Some went prior to losing their hair as this helped them to prepare, whereas others waited until they had started to lose it.

> *"I think I'd started to lose little bits…I think the appointment was something like 3 weeks I think maybe ... 2, maybe 3 weeks into the chemotherapy session and they knew it was going to happen pretty soon so the appointment came before that so I was prepared beforehand"* (Polly)

> *"I'm not sure some women might like to go once they've lost their hair, because the headscarves fit differently when you haven't got any hair, so they did advise me of that, they did say "oh you know it'll be a bit different when you haven't got any hair" but ... I think for me personally it did work to go then, yeah"* (Sienna)

However, with hindsight, others would have preferred to use HeadStrong once they had lost their hair and were able to see and use headscarves on their bald (or balding) head rather than on a full head of hair. Overall, 20 participants attended HeadStrong prior to hair loss, whereas five waited until they experienced hair loss before they attended HeadStrong:

> *"I think I would've probably been better, or I would have benefitted from waiting... when you've got a head full of hair nothing looks the same. Until you're faced with the reality of it, you know ... I don't know whether I should have just waited ... or had a second session maybe, do you know what I mean?"* (Eila).

4.6.2.2 Information provision from HeadStrong

Participants described HeadStrong as a great source of advice and information regarding coping with hair loss, including scalp care and where to purchase hair products. This helped them to manage the stress of the situation, by increasing feelings of control.

> *"HeadStrong was the most informative in terms of support services"* (Sienna)

> *"I would definitely recommend them just for the general advice I got and ... just talking about it really, especially as I'd not lost my hair at that point, it*

did reassure me a bit that it wasn't as scary as ... because it's just the fear of the unknown really" (Debra)

"I thought it's a good chance to buy some nice scarves and things but, I mean, they went on to give advice on different ways to tie them, they went on to give advice ... they gave advice on head care…they give tips (Kathryn)

4.6.2.3 Confidence boost

Anticipating hair loss was a daunting prospect and it was a time of great uncertainty. Participants were unsure about how they should take care of their scalps and use the various products (wigs, headscarves etc.) that could disguise their hair loss. HeadStrong was found to help participants with these questions and as a result increased their confidence around social interactions and meeting other people.

"As a woman with a full head of hair you suddenly think oh I don't know whether I'm supposed to put certain creams on or do certain things and actually I don't know how to tie a headscarf and ... so things like that, so I thought it was easier to do it before rather than after so that was it. Just a preparation to give myself a bit more confidence I suppose" (Poppy)

"I think it gave me a bit more confidence, you know, that when I started to lose my hair I would have something for it, you know, I wouldn't frighten the postman, you know, that sort of thing" (Chenade)

4.6.2.4 Group v individual support

A number of participants mentioned that they had known very little about HeadStrong or what to expect from their session, prior to attending. Participants had different views about the way in which it was delivered. Some were glad that it was provided on a one-to-one basis since this allowed them to feel more relaxed and to ask their individual questions.

"When I got there I was half expecting it to be a group session but I was really pleased then when it was just like me because there were questions that I wanted to ask and because it was focused on one person it wasn't a generalised chat" (Polly)

"I think it needs a one-to-one contact. I don't think I would have had the confidence to go into a room full of people and chat about losing my hair

> *before I'd lost my hair. After you've lost your hair it sort of becomes ... I don't know, I suppose it's like after you've had a child and maybe you're more self-conscious about your body but I think it would have been too personal to talk about before I'd been through it"* (Julia)

However, some were feeling alone with their hair loss and would have liked it to have been a group session so that they could have met others going through a similar experience, to reassure them that they are not alone.

> *"And all this one-to-one, well ... maybe they should start with, say even two or three people together where you actually felt that you were not alone in this hair loss thing"* (Cecile)

4.6.3 Theme 3: Meeting unmet needs

Although most participants talked positively about HeadStrong and the practical support it provided, a number of participants suggested ways in which the service could be developed in order to address their need for more emotional support. Cecile demonstrates that HeadStrong was not beneficial to her as she did not want to use head scarves:

> *"One of the things she [HeadStrong volunteer] said to me as I walked in, what's your expectations for today? I said how to cope with hair loss. And she was oh yeah, we've got loads of things here and then just pulled out big baskets of scarves, and I'm thinking, I don't even like scarves. I hate scarves. That's what was going through my head - why's she showing me scarves, I don't like scarves" (Cecile)*

4.6.3.1 Lack of emotional support

Many participants spoke about experiencing a number of emotions through their cancer journey, which they felt unprepared for. Some felt that the emotional support that they received from their oncology service was limited and, as a result, they had actively sought emotional support elsewhere but found this extremely difficult to access and thought it should be offered routinely.

> *"No-one see's to your needs"* (Poppy)

Stephanie and Cecile both felt that the emotional support they received was insufficient and they wished they had been offered more support, including the opportunity to speak to a counsellor. Cecile spoke about her distress at having to wait 16 weeks to speak to a counsellor, when she needed to speak to somebody immediately after receiving her diagnosis, so she could discuss her feelings about hair loss at that stage rather than feeling alone for several weeks:

> *"It's a whole new world when you've been diagnosed with cancer - it opens a whole new world and people say "Oh you'll be over it soon, it'll be over soon". It'll never be over, never. Not for anyone who's experienced cancer, it will be a part of their lives for the rest of their lives and, sort of, took me a long time to figure that out and it was an emotional time and counselling could've really helped there*"(Stephanie)

> *"Counselling straightaway. No use waiting 16 weeks when your hair's dropped out…you've gone through every emotion under the sun. From the word go, from the hospital, right, you've got a problem with your hair loss, we've got a counsellor, whether it be a breast care nurse, but somebody trained in that particular field that you can go and speak to who understands what you're trying to say and what you're going through"* (Cecile)

Participants spoke about feeling abandoned at times and wanting more contact with health professionals with expertise in psychosocial issues, yet appreciated that they are extremely busy with other patients, as Sienna highlights below:

> *"I know it's impossible there are so many patients and they've got new ones coming in, but I felt a little bit abandoned psychologically"* (Sienna)

Not all participants felt the same way, as some were able to manage the situation themselves. For example, Eila described how camouflage helped her to manage her hair loss and lessen its impact on her. This demonstrates that women's experiences and needs are varied, so there needs to be a range of options and means of support available in order to meet individual needs.

> *"I was more ... it very quickly became a non-issue to me and I just made sure that, as I say, I wore nice headwear so it wasn't ... I wasn't psychologically affected ... I didn't feel psychologically affected by it at all"* (Eila)

4.6.3.2 Areas for improvement

Participants still felt that the care provided by both the oncology service and HeadStrong could be improved, so that psychosocial support is provided throughout the hair loss journey, and highlighted some criticisms and limitations of HeadStrong. Cecile and Juliette both felt that the service could benefit from being run by professional employees rather than volunteers, since they did not know whether the information provided by the volunteers was correct or not:

> *"I just think it wants really, really revamping, and right the way through from when you know you're going to lose your hair, how you deal with losing your hair, then when you've lost your hair and your scalp is sore and you're not sure what to do with it, that you can go and ask this person on a professional level and know that the information they give you is correct"* (Cecile)

> *"I didn't think it was as good as I was hoping... I know it's volunteer run and I know that things that involve volunteers depend an awful lot on goodwill and you don't have as much control over what's going on as maybe you would with an employee"* (Juliette)

Some participants felt that HeadStrong was too prescribed and structured, and would have preferred it to be tailored more to the individual. Juliette describes below how she went to HeadStrong hoping to receive information about scalp care but she felt disappointed as she was given a leaflet rather than someone talking to her about her concerns and providing advice on products that she could use.

> *"I did find it helpful but I sort of felt they stuck a little bit to a kind of routine that they did... and when…I wanted to know was about care of my head once my hair was going…they just sort of gave me a leaflet about that, they did not really talk through that at all and they sort of said oh we can't recommend products and ... I thought well ... I don't need you to tell me to go and buy this product but it would be quite good to just have an idea"* (Juliette)

> *"But, I mean, they don't go ... it's like they're reading a script"* (Whitney)

> "*HeadStrong is a good service but it could be enriched by, you know, if we could donate so that, if a lady comes in ... you know, who can't afford to [buy a head camouflage], they could say, well look, these have been donated ..feel free to take it"* (Eila)

Some participants spoke about the difficulties of attending a HeadStrong session. For some it was difficult finding the time to attend an appointment at the hospital on top of all their existing medical appointments, reinforcing the importance of time as discussed earlier in the chapter. Others found it hard to travel to HeadStrong as they had to rely on someone else to take them. Some were unable to attend a session when they would have liked to, due to being ill and, as a result, had already lost their hair by the time they were able to attend HeadStrong.

> *"I was in the hospital at least once a day for a scan or an appointment of some sort or another, it was a very busy period and attending HeadStrong meant ... another visit to the hospital"* (Poppy)

> *"It's not really fair, to him, to have him take me, you know, to places like that [HeadStrong]"* (Whitney)

> *"I had to cancel two [HeadStrong] appointments because I was poorly……unfortunately, with not being able to get to them 'til after Christmas I had used my own scarves but they kept slipping off and ... because they weren't really the right thing"* (Dawn)

Participants also spoke about actively seeking out different sorts of support and taking up every opportunity available to them, further demonstrating participants want and need support. However, as Helen demonstrates below, time was an issue for many of the participants. Participants spoke about needing support which is easier to access, reinforcing the importance of timing as discussed above.

> *"Well I've got this to do, I've got that to do, I could really do without another hour or so down there and, as much as it would've been nice...I think if I'd have worked through it I would've tapped into it all (support services)"* (Helen)

An important issue for participants was where the HeadStrong session was held, with comments about the room needing to be bigger, and many preferring it to have taken place somewhere separate from the hospital or the Oncology department since this environment was a distressing reminder of their cancer diagnosis.

> *"I never thought, I never dreamt that I would be going down, turning down*

> *that department so I think to have to turn down that department again, I think ... yes, I suppose, that would have been the one thing I would have changed, was a different setting really"* (Chenade)

> "*I don't know where else I would suggest that they held these services, it was in the middle of a busy hospital, a private room, but I just sat while I was waiting for my appointment and I just sat there and I thought thank God I'm not coming to this to be treated because I would have run a mile. So I don't know whether there's a better environment ... that whether they should use something like ... something less threatening than the hospital environment, where you end up spending so much time anyway, I don't know whether a Health Centre room or whatever*" (Eila)

Participants spoke about using online forums and Facebook as a way of trying to re-gain control and seeking support and reassurance from other people, as it offered them the opportunity to speak to other's in a similar situation and offered peer support which they did not feel that HeadStrong offered:

> *"Oh look my hair's starting to come out, and then you'll get lots of comments back of kind of, 'oh but you know you look really beautiful' and,' it just shows how beautiful your face is'... so I think…the impression I get is that women who really feel ashamed of it and hide it, maybe don't deal with it quite as well as women who sort of grasp it and say, you know, this is me and ... to be able to share that with some people and to have some positive supportive comments"* (Juliette)

> *"It's [online support] good and bad in that you get lots of support but you also ... it can scare you a little as well just because, you know, people die on it. And people have worse experiences ... You can find yourself becoming too involved in the world of cancer if you're not careful"* (Stephanie)

Although some participants found online support helpful, others would prefer to speak to someone face to face who has been through a similar experience. Eila suggests that a 'buddy system' could be implemented, were women could speak to someone who is not a family member and who has been through a similar experience of hair loss:

> "*There should be a 'buddy system'... I know you can go on-line on these chatrooms and things but, quite frankly, the dead of night when people are on ... I don't want to be on ... you know, I want to speak to somebody like I'm speaking to you now.. you need somebody… who's actually been there, done that and got the t-shirt…you need somebody who knows what thoughts you have and what concerns…who's not going to sit there and cry*". (Eila)

4.7 Discussion

The aim of the study was to explore women's experiences of treatment-related hair loss and of the HeadStrong service. It was evident that many of the participants were experiencing appearance-related distress and hair loss had negatively impacted on their quality of life. Whilst HeadStrong often helped to an extent, the accounts from those women who felt it had not met all their needs suggested that greater access to alternative interventions offering individually tailored support is needed.

Three main themes were identified. The first '*Facing the challenges of hair loss'* focuses on the impact which hair loss had on an individual's sense of self, which often began before they had lost their hair since the anticipation could be a stressor in itself. Uncertainty continued as hair began to re-grow, supporting previous research whereby individuals have continued to perceive themselves as different, despite their outward appearance returning to 'normal' (Münstedt et al., 1997).

A range of individual differences were apparent. Some managed the impact of hair loss well, whereas others found it very distressing. Alopecia affected participants in a variety of ways, including their confidence and relationships with close partners and family members. Participants also viewed the general public as being more aware of their diagnosis because of their altered appearance. This supports previous research that has highlighted the negative impact of breast cancer and its treatment-related side effects (Sheppard, 2008; Shapiro et al., 2001). Participants not only lost their hair from the top of their head but also their eyelashes and eyebrows. Their accounts illustrated how hair loss not only affected their appearance but also their overall sense of self.

Hair loss had impacted on a variety of aspects of participants' lives including their identity, relationships and confidence – stopping some participants from engaging in activities that they had once enjoyed. This supports previous research whereby chemotherapy-induced hair loss has been found to cause anxiety, depression, negative body image, lowered self-esteem, and a reduced sense of well-being (Hesketh et al., 2004; Lemieux et al., 2008). Participants reported not wanting their partners to see their bald heads which, for some, impacted on their intimate

relationships as there was no longer an aspect of spontaneity. Münstedt et al (1997) previously reported that 13% of women with gynaecological malignancies believed they would be rejected by their partner once treatment-related hair loss occurred; therefore it is possible that women used head camouflage to conceal their hair loss from their partners out of fear of being rejected.

Once participants' hair had started to fall out they described how they mourned the loss of their hair, with some participants describing their distress and feelings of humiliation and comparing themselves with others who have had their heads shaved in traumatic circumstances.

The majority of participants spoke about how they had been informed by health professionals that they would lose their hair before starting chemotherapy. For many, this gave them time to mentally prepare and to attend a HeadStrong session so that they could learn different ways to tie headscarves and look after their scalp before they started to lose their hair. This supports Batchelor (2001) who argued that during the anticipation phase, there is a need to deal with the anxiety and uncertainty associated with hair loss, to provide accurate expectations about the physical changes that might take place, and to prepare patients for the psychological and social challenges they may experience.

The women in the current study discussed both the distress caused by other people's reactions to their hair loss and the lengths they went to in order to protect other people's feelings. These are consistent with previous research (Hilton et al., 2008). Even though they were given practical advice around scalp care and using wigs and headscarves, they were not prepared for other people's reactions to their altered appearance. As well as exposing them as a 'cancer patient' (see above), participants also felt that they were being stared at because their altered appearance went against social norms for what is considered to be an acceptable and expected way for women to look. Participants spoke about using scalp cooling to try to preserve their hair or covering their hair loss as they did not want their loved ones to see them with a bald head as this was a reminder of their cancer.

Many participants spoke about the impact hair loss had on their sense of self and identity. Traditionally, an individual's sense of self is seen as stable, however, over time it has now become to be seen as adaptable (Pilarska, 2016). An individual's sense of self is also linked to their sense of identity. Experiencing a traumatic event such as receiving a cancer diagnosis and experiencing treatment-related hair loss can affect the reaction that an individual receives from others which can have a negative impact on their identity. As a result an individual may view themselves as unattractive and may avoid socialising with other people for fear of rejection (Horowitz, 2015). This was supported by the current research whereby a number of participants spoke about avoiding social situations as a result of their hair loss, in fear that they would be judged.

The impact of hair loss on identity is an issue which has been acknowledged in the literature but little is known about the process for how this occurs. Embodying identity is defined as "the way in which a person changes how they view their self (mind, body, and spirit) in an effort to reconcile physical or body alterations" (Koszalinski & Williams, 2012, p. 116). It is argued that individuals undergo a process whereby they experience feelings of "it's not me" and gradually progress to recognising themselves with an altered appearance ("but, it's me"), before reaching the final stage of acceptance, where an individual incorporates their altered appearance into their sense of self ("it's me") (Koszalinski & Williams, 2012). This is the process participants described in the current study. Many women spoke about not recognising themselves when they first lost their hair and progressing through a process of gradual acceptance, whereby they started to incorporate the physical changes into their new sense of self. According to Koszalinski and Williams (2012) embodying identity proposes a framework to help ensure that individuals are supported through the process of coming to terms with their altered appearance, especially when their self-esteem is negatively affected and there are visible reminders of their cancer such as hair loss.

Women spoke about their hair loss signifying their loss of control, including control over whether or not to tell people about their diagnosis, which led to a transition from an initial private experience (shared with family and friends) to a publicly

visible indication of their cancer. This supports previous research that has highlighted how hair loss exposes an individual as a 'cancer patient' (Harcourt & Frith, 2008; Hilton et al., 2008). Once hair loss had begun, the majority of participants made the decision to shave their heads, to spare them from having to watch their hair fall out. Previous research by Hilton et al (2008) found that patients initially cut their hair shorter, followed by shaving their head, usually soon after their hair loss became noticeable. People's reasons for doing this ranged from practicalities such as to avoid having to clear up shed hair, physical discomfort caused by hair loss, aesthetic concerns, or wanting to take back some control (Hilton et al., 2008).

Previous research highlights that patients are eager for their hair to re-grow once they have finished treatment (Hesketh et al., 2004). Yet hair regrowth can bring even more challenges, as patients must decide when to stop using wigs, hats or headscarves. Some participants had unrealistic expectations regarding their hair regrowth and expected it to re-grow just as quickly as it fell out. Once hair starts to re-grow, if it is different to how it used to be, it can be very distressing for individuals especially if they are not prepared for this (Rumsey & Harcourt, 2005).

The theme '*Experiences of receiving support for treatment-related hair loss'* focuses on participants' experiences of the HeadStrong service. It was clearly a great source of advice, including information around scalp care and different types of headscarves and hats available to camouflage hair loss. Information about cancer treatment side effects has previously been shown to improve understanding, satisfaction, treatment compliance, emotional distress, anxiety and depression (Fallowfield, 1992; Whelan et al., 1998). Some participants in the current study were happy with the amount of information they received from HeadStrong, whereas others would have liked more. In a previous evaluation of a skin camouflage clinic, all participants highlighted their appreciation of having written information to take away from their appointment (McConochie & Pearson, 2006), however, information provision is a complex issue; individual preferences for information vary greatly and timing is an important issue, as individuals' information needs change over time. It was evident from the interviews that timing was an important issue. Specifically, finding the appropriate

time to attend HeadStrong, whether this was prior to hair loss or once it had started to fall out. This was an individual preference. Some participants found it difficult to find time to attend a HeadStrong session whilst also attending numerous hospital appointments, and juggling day-to-day responsibilities such as work and home life.

Psychosocial needs relate to a desire for help or support that underlies a person's emotional and psychological wellbeing (Watson et al., 2012; Swash, Hulbert-Williams & Bramwell, 2014). An unmet need is characterised by the gap between a patient's experience of a service and the actual service they required (Carr & Wolfe, 1976). The third theme '*Meeting unmet needs'* highlights that HeadStrong had not met all participants' needs and areas that could be improved were identified, including the possibility of providing both one-to-one and group sessions, offering more flexibility to meet individuals' specific needs. Some felt HeadStrong was not sufficiently tailored to the individual and should be delivered on a more professional level. However, individual needs are subjective and vary greatly, which can make it extremely difficult for service providers to ensure that their service is suitable for all. To further emphasise the importance of individual differences, Wiggins, Moore-Millar and Thomson (2014) highlighted the complex consequences around alopecia patients' use of camouflage, including modifying their behaviour in social situations to conceal their use of a wig, demonstrating that camouflage is a starting point but not a remedy for all the distress associated with hair loss.

There was a consensus from participants in the current study that very little emotional support is available specific to hair loss, which supports previous research related to hair loss and the impact of cancer more broadly (Armes et al., 2009; Shapiro, Wiseman & Liu, 2000). In a survey with 606 cancer patients, 58% of participants felt their emotional needs received less attention than physical issues (Macmillan Cancer Support, 2006). Support services which are currently available for patients affected by hair loss tend to focus around offering practical advice around scalp care and the use of hats and headscarves rather than emotional support. A few participants reported feeling let down by the lack of psychological support they received from their oncology service and felt that they would have benefited from being offered a counsellor to talk to. HeadStrong does not currently aim to

offer psychological support, but a recommendation would be to try to bridge the gap so that those who attend HeadStrong and discuss wanting psychological support, could then be signposted to the appropriate service. However the volunteers delivering HeadStrong would need to feel confident in doing so.

It became apparent through the interviews that a number of participants were unclear about what HeadStrong entailed prior to attending a session. Therefore, it is important that HeadStrong is publicised, including a description of the service.

A number of participants in the current study found it distressing to attend a HeadStrong session in the hospital setting which was so strongly associated with their cancer diagnosis and/or treatment. This supports ongoing literature about the link between environment, health and wellbeing (Weiss & Lonnquist, 2000). Edvardsson, Sandman and Rasmussen (2014) found that patients felt that being at the Oncology Centre meant being forced into a world of cancer, which included the loss of dignity and control. The present study also supports previous research highlighting patients' difficulties around travelling to appointments due to feeling unwell or because of a lack services closer to home (Shapiro et al, 2000). However, it is important to note that the systematic review (chapter 2) found that interventions delivered in hospitals/clinics were advantageous. Therefore, this further emphasises individual differences and preferences for where and how an intervention is delivered, highlighting the importance of flexible intervention delivery.

4.7.1 Methodological considerations

A strength of the current study is that recruitment was nationwide, allowing the inclusion of participants with experience of HeadStrong sessions from a variety of different geographical locations. However, a possible limitation is that the charity providing the service was key to the recruitment process, therefore leading to the possibility of sampling bias. Steps were taken to minimise this, including random selection of individuals who had attended a HeadStrong rather than purposeful sampling of individuals who had attended specific centres.

All the women invited to take part in the study were experts in their own experiences. Being a qualitative study with 25 White, English-speaking women who had undergone chemotherapy following a diagnosis of breast cancer, it would be wrong to assume that the themes identified above are necessarily applicable to breast cancer patients from other ethnic backgrounds, nor to men or women with other cancer diagnoses. People from other ethnic backgrounds might experience hair loss differently since hair conveys extensive symbolism across cultures (Etcoff, 1999). It is also important to highlight that the findings from this study cannot be generalised to all breast cancer patients who have attended a HeadStrong session.

4.7.2 Conclusion

This qualitative study suggests that the HeadStrong service can be an important and helpful intervention for breast cancer patients affected by hair loss, but it also indicates that it is not necessarily meeting all their needs. Some participants reported not finding hair loss as distressing as they had anticipated it would be, and managed the situation and their feelings well. As Tierney, Taylor and Closs (1992) suggest, it may be "unhelpful to assume that all patients will be concerned by the prospect or devastated by its occurrence" (p.79). However, many participants found treatment-related hair loss to be a very distressing experience. This variation again emphasises the importance of individual differences and how no two people are the same regarding their specific experiences and support needs (Independent Cancer Taskforce, 2015).

The wider appearance literature has demonstrated the importance of interventions to reduce avoidance and social anxiety by equipping individuals with effective social skills to manage everyday situations (Clarke, 1998; Thompson & Kent, 2001), rather than relying solely on camouflage-based approaches. Therefore, these interventions might usefully be offered to breast cancer patients whose appearance-related concerns around hair loss are having a detrimental effect on their daily lives.

Since support needs are likely to vary between individuals and over time, it is important that patients are equipped with a toolbox of strategies to help them to manage all aspects of hair loss, rather than relying on one strategy, i.e. camouflage.

Additional support and interventions that are readily and easily accessible are needed so that HeadStrong volunteers and health professionals alike can signpost patients to further sources of support as necessary.

As a mixed methods approach was taken, with the qualitative and quantitative (Chapter 5) HeadStrong studies conducted in parallel, a synthesis of the findings from both these studies can be found in section 5.4.2, together with recommendations for changes to practice which were presented to Breast Cancer Care on the basis of these findings.

4.7.3 Summary of the key points in this chapter:

- This is the first study of the national HeadStrong service which focuses on providing information and support around scalp care and the use of hats and headscarves to camouflage hair loss.
- The qualitative study aimed to answer the following research questions; what were service users' experiences of hair loss and of the HeadStrong service?
- Twenty five women participated in semi-structured interviews. Three main themes were identified: facing the challenges of hair loss, experiences of receiving support for treatment-related hair loss and meeting unmet needs.
- Hair loss brought with it a number of challenges, including an impact on women's lives, their identity, confidence and relationships, and having to deal with the reactions of other people.
- A key contribution from this study is that it is the first qualitative study of women's experiences of the national HeadStrong service. A key contribution to knowledge is that whilst the HeadStrong service offers practical support around camouflaging hair loss, it does not completely address women's distress or provide the emotional support that some need.

4.8 The next stage of the research

Although this qualitative study has given insight into women's experiences of HeadStrong, it is still unknown whether or not it offers measurable improvements to

their distress around hair loss. The following chapter therefore presents a quantitative study conducted with breast cancer patients who had made an appointment to attend a session. The focus was to assess whether HeadStrong reduces women's distress around hair loss, and improves their confidence in managing the consequences of hair loss, the reactions of others and the use of headwear, and whether any improvements are maintained in the longer term.

Chapter Five

A Quantitative Study Exploring the Impact of Breast Cancer Care's HeadStrong Service

5.1 Introduction

This study aimed to evaluate the HeadStrong service, specifically its impact on appearance-related distress, concern about hair loss, psychological well-being and confidence in managing the personal impact of the situation. The ARC (2009) framework helped to inform the development of the questionnaires; it was important to gain an insight into pre-disposing factors which included questions around demographics, hair loss status and what treatment participants had undergone. Also, it was important to gain an understanding of participants' thought processes, including the value they placed on their appearance, and in determining their adjustment to their altered appearance, whether it has affected their quality of life and whether they had experienced any appearance-related distress.

5.1.1 Research questions:-

1. Does attending a HeadStrong session improve participants' confidence in managing the consequences of hair loss, the reactions of others and use of headwear?
2. Are any improvements as a result of attending a HeadStrong session, maintained over time?
3. As a result of attending a HeadStrong session, are there any changes in the value placed on appearance, self-esteem, quality of life, fear of negative evaluation, appearance-related distress, anxiety and depression over time?

5.2 Method

5.2.1 Design

This was a multi centred study which took a quantitative approach using a pre-intervention questionnaire (see appendix 11) to evaluate the HeadStrong service, with a 2 week (see appendix 12) and 3 month follow-up to examine its short and longer-term impact. A 3-month follow-up (see appendix 13) was included on the basis that participants' hair might not have grown back fully in this time and they might still be facing the challenges of hair loss.

A randomised controlled trial (e.g. Bottomley, 1997) would have been an alternative design, with women allocated to either receive the HeadStrong service (intervention) or control group (an in-depth discussion of the suitability of RCTs has been presented in chapter 3). However, it was considered unethical to deny individuals access to the existing HeadStrong service by randomising them to the control group, at a time at which they could benefit from the intervention. Moreover, those who were distressed by their hair loss may have been unlikely to consent to join a study in which they only had a 50:50 chance of receiving an intervention that may benefit them, especially knowing that they could access the service directly if they chose not to agree to randomisation (Kaur et al., 2013). This highlights the need to conduct this study in a way that would enable a rigorous evaluation of the service, whilst accurately reflecting the circumstances in which the program would be delivered beyond the evaluation period. Therefore, a pre and follow-up evaluation was deemed the most appropriate way of conducting a reliable, ecologically valid assessment of the HeadStrong service, that would reflect most closely the way in which it is implemented in its everyday setting within the current provision of care for breast cancer patients.

5.2.2 Developing the questionnaires

The content of the questionnaires was informed by the ARC framework (see appendix 11, 12, 13 for the HeadStrong questionnaires). Relevant standardised measures were selected, with additional self-constructed items being included if suitable standardised measures were not available. Advice was sought from the

supervisory team, Breast Cancer Care's user representative group (Voices) and a user representative from ASWCN, during the development of the questionnaires to assess its suitability (further details regarding PPI involvement in this thesis can be found in Chapter 3).

The questionnaires were piloted on ten women of various ages (all over 18 years) who were not familiar with the research area, to see how long they took to complete. This indicated that each questionnaire booklet would take no longer than 30 minutes to complete, which the PPI representative agreed would be acceptable. The questionnaires were made available to participants as paper versions or online (using Qualtrics software), giving them a choice as to how they took part in the study. They were provided online in the hope that this would increase participation (Sax, Gilmartin & Bryant, 2003) and make the study more accessible for participants.

The questionnaires comprised of sections covering the components of the ARC framework (see figure 10).

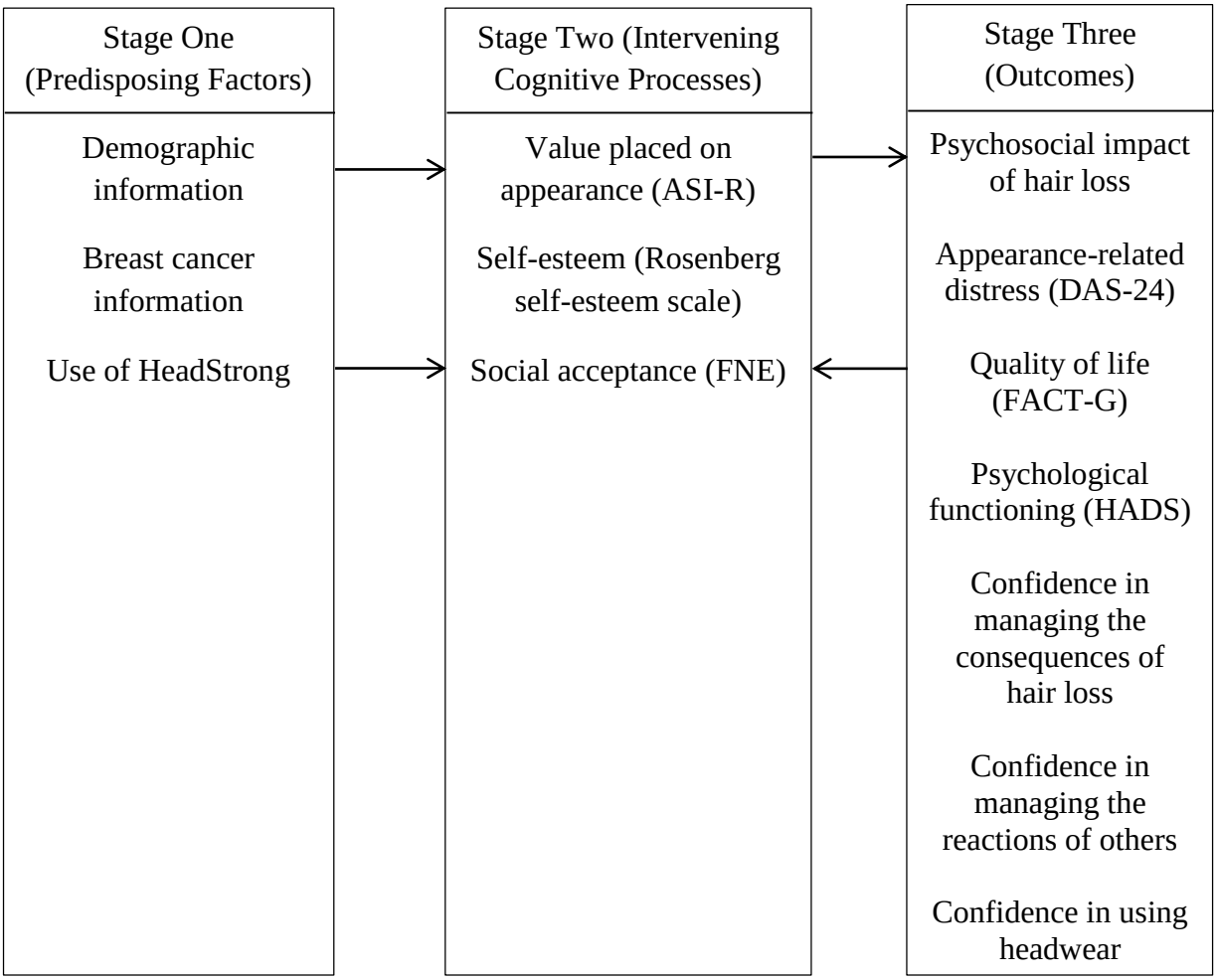


Figure 10. The guiding theoretical framework for the HeadStrong evaluation. Guided by the ARC (2009) framework, in Clarke, Thompson, Jenkinson, Rumsey and Newell. (2013). CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety due to Visible Difference. Figure 3.5, p. 35. (Reproduced with copyright permission from Wiley-Blackwell).

The rationale for the choice of measures is discussed below. Figure 11 summarises which measures were included at each data collection point.

Pre- HeadStrong questionnaire	2 week follow-up questionnaire	3 month follow-up questionnaire
Demographic information	Hair loss status	Hair loss status
Breast cancer information	Use of HeadStrong	Use of HeadStrong
Hair loss status	Psychosocial impact of hair loss	Psychosocial impact of hair loss
Use of HeadStrong	ASI-R	ASI-R
Psychosocial impact of hair loss	DAS-24	DAS-24
ASI-R	Self-esteem	Self-esteem
DAS-24	QOL	QOL
Self-esteem	FNE	FNE
QOL	HADS	HADS
FNE		
HADS		

Figure 11. The measures contained within the questionnaires at each data collection point.

5.2.2.1 Stage One: Predisposing Factors

5.2.2.1.1 Demographic details

Information including sex, age, ethnicity, educational background, employment status and residential area were obtained at baseline (Pre-HeadStrong questionnaire).

5.2.2.1.2 Breast cancer information

Details including type of cancer (this was to ensure that only breast cancer patients' data was included within the analysis, to prevent patients with a different type of

cancer mistakenly been given the questionnaire), time since diagnosis and treatment received, were obtained at baseline (Pre-HeadStrong questionnaire). Using a VAS scale, participants were asked about their hair loss status (i.e. whether the participant had already lost hair or was anticipating doing so) at baseline and at each follow-up data collection point. The scale ranged from 0-10 with 0 indicating no hair loss and 10 indicating complete hair loss.

5.2.2.1.3 Use of HeadStrong

Information was gathered regarding participants' use of the HeadStrong service, including number of sessions received, and how they knew about the service. Participants were also asked their reason(s) for attending HeadStrong, expectations of it and, at follow-up, the extent to which their expectations were or were not met, whether they would recommend it to others and whether they thought the information and techniques learnt at the session would help them in the future.

5.2.2.2 Stage Two: Intervening cognitive processes

5.2.2.2.1 Value placed on appearance

The Appearance Schemas Inventory-Revised (ASI-R) (Cash, 2003) measures the importance, meaning and impact of appearance on one's life. It consists of 20-items, based on a 5-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The 20-items are split into two scales; the self-evaluative salience scale is a 12-item measure of the degree to which one's appearance is considered important to self-worth, the motivational salience scale is an 8-item measure of the degree of motivation that a person has to maintain or improve his/her appearance. When scoring the ASI-R, a composite score is the mean of the 20 ASI-R items.

The internal consistency (as measured by Cronbach's alpha; Cronbach, 1951) for the self-evaluative salience is ($\alpha = 0.86$) and ($\alpha = 0.83$) for motivational salience. There are different aspects of value placed on appearance, with body investment being one of them. The ASI-R (Cash, 2003; Cash et al., 2004) has been widely used in studies of body image investment in breast cancer survivors (Chua, DeSantis, Teo &

Fingeret, 2015; Moreira, Silva & Canavarro, 2010). Importantly, high motivational salience has been found to be associated with better body image outcomes, whereas high self-evaluative salience has been found to be associated with negative outcomes in relation to appearance satisfaction following breast cancer treatment (Moreira et al, 2010).

Other validated measures of body image in breast cancer patients were considered but not used in this study. Specifically, the Body Image after Breast Cancer Questionnaire (BIBCQ; Baxter, 1998) and the Body Image Scale (BIS; Hopwood, Fletcher, Lee & Al Ghazal, 2001) are both widely used and highly reliable (Baxter et al,. 2006; Chen et al., 2010; Metcalfe, Esplen, Goel & Narod, 2004; Moreira et al., 2009; Zhang, Liu & Jin, 2011). However, they include questions about surgery which was not a focus of this study. Also, as the ASI-R was being used to measure the value placed on appearance and the DAS24 to measure appearance-related distress (outlined below), an additional body image measure was not deemed necessary. Furthermore, it was considered important for the questionnaire not to appear repetitive and to monitor the length of the questionnaire so as not to deter participants from completing it.

5.2.2.2.2 Self-esteem

The Rosenberg Self-Esteem Scale (Rosenberg, 1965), a 10-item measure of respondents' general feeling towards themselves, was included at each time point. Items are scored from 4 ('strongly agree') to 1 ('strongly disagree'), where higher scores denote higher levels of self-esteem. It is a reliable and valid measure of global self-worth (Rosenberg, 1965). It has received more psychometric analysis and empirical evidence than any other self-esteem measure and has been widely used in the breast cancer literature (e.g. den Heijer et al., 2011; Fernandez-Taylor & Bloom, 2011; Gómez-Campelo, Bragado-Álvarez & Hernández-Lloreda, 2014; Musanti, 2012; Park et al., 2015; Pauwels, De Bourdeaudhuij, Charlier, Lechner & Van Hoof, 2012).

Two alternatives to the Rosenberg Self-Esteem scale were considered: The Texas Social Behavioural Inventory (TSBI) (Helmreich, Strapp & Ervin, 1974) is a 32-item

measure which was developed to assess feelings of self-worth in terms of interpersonal interaction in the four domains of social confidence, dominance, social competence and relations to authority figures, however, the TSBI is not a global measure of self-esteem. The Feelings of Inadequacy Scale (FIS; Janis & Field, 1959) is a 23-item measure of self-esteem, which asks participants to indicate how bad they feel about themselves. Low scores indicate high feelings of inadequacy (low self-esteem) and high scores indicate high self-esteem.

The Rosenberg Self-Esteem scale was considered most appropriate for the current study as it is widely used in the breast cancer literature (Ates et al., 2016; Fernandez, Gregorio, Mas & Rodriquez, 2012; Kovačič & Kovačič, 2011; Musanti, 2012; Wang et al., 2014). It is a global measure of self-esteem, unlike the TSBI, and has 10-items compared to the FIS which has 23-items. So, in order to keep the questionnaire concise and ensure it was not too time consuming and burdensome for participants, the Rosenberg Self-Esteem scale was used.

5.2.2.2.3 Social acceptance

The brief version of the Fear of Negative Evaluation Scale (FNE, Leary, 1983) is a 12-item measure which examines the extent to which an individual is concerned about other people's opinions of them. Participants score each statement from 1 (not at all characteristic of me) to 5 (extremely characteristic of me). Scores range from 12-60 with high scores indicating a greater fear of negative evaluation. The FNE has a high level of internal consistency ($\alpha = 0.90$). The Social Avoidance and Distress Scale (SAD; Watson & Friend, 1969), a 28-item measure of social anxiety, was considered but the brief version of the FNE was chosen as it has 12-items as opposed to the SAD's 28-items.

5.2.2.3 Stage Three: Outcomes

5.2.2.3.1 Psychosocial impact of hair loss

Participants were asked about their confidence in managing the consequences of hair loss, confidence in managing the reactions of others and confidence in using the techniques learnt at HeadStrong. For each of these three questions, participants'

confidence was measured on a VAS scale from 0-10, with 0 relating to 'no confidence' and 10 meaning 'complete confidence'.

5.2.2.3.2 Appearance-related distress

The Derriford Appearance Scale (DAS24; Carr, Moss & Harris, 2005) is a 24-item measure used to assess appearance concern in clinical and research settings (Moss, 2005). Items relate to participants' behaviours and concerns surrounding an area of their body they are self-conscious about. Items are scored from 'not at all'/'never'/'almost never' (with a non-applicable option) to 'extremely'/'almost always'. High scores indicate high levels of distress. The DAS24 is psychometrically robust and has been found to discriminate well between clinical and non-clinical populations and within the general population between those concerned and those not concerned about their appearance (Carr et al, 2005).

The DAS24 has been widely used in appearance-related studies, including some breast cancer research (i.e. Nozawa et al., 2015; Moreira & Canavarro, 2012). Total scores range from 11-96 with lower scores representing lower levels of social anxiety and social avoidance. Internal consistency is high ($\alpha = 0.92$). The DAS24 has good construct validity, which has been found in both patients and members of the general population concerned and not concerned about their appearance and in correlations with a range of established scales.

5.2.2.3.3 Quality of life

The Functional Assessment of Cancer Therapy - General (Version 4; FACT-G; Cella et al, 1993) consists of 27 items, based on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much). There are 4 sub-scales: physical well-being (7 items), social/family well-being (7 items), emotional well-being (6 items) and functional well-being (7 items). Each sub-scale can be summed to give an overall quality of life score; the higher the score, the better the quality of life. Internal consistency of the sub-scales is as follows: physical well-being ($\alpha = 0.88$), social/family well-being ($\alpha = 0.87$), emotional well-being ($\alpha = 0.76$) and functional well-being ($\alpha = 0.90$).

The FACT-G and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30; Aaronson et al., 1993) and its breast cancer specific questionnaire (EORTC QLQ-BR23; Sprangers et al., 1996), are the most widely used instruments to measure quality of life in breast cancer patients (Montazeri, 2008). While the FACT-G and EORTC QLQ-30 include similar items, the FACT-G is shorter, especially if the EORTC QLQ BR23 is included (comprising of 53 items compared to 27 or 37 items with the FACT-G or FACT-B, respectively). The FACT-B includes an additional breast cancer subscale (10 items), which focuses on appearance. Since this was explored in detail in another section of the questionnaire (appearance concerns), in order to avoid repetition of similar items, the FACT-G was chosen as opposed to the FACT-B.

5.2.2.3.4 Psychological functioning

Psychological measures including the Hospital Anxiety and Depression Scale (HADS; (Zigmond & Snaith, 1983), Beck Depression Inventory (BDI; Beck, 1961) and the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) have been widely used and validated in cancer patients (Alexander, Palmer & Stone, 2010; Carver & Antoni, 2004; Land et al., 2006; Mitchell, Meader & Symonds, 2010; Montazeri, 2008). Other instruments such as the Profile of Mood States (POMS; McNair, Lorr & Droppleman, 1971) and the Mental Adjustment to Cancer scale (MAC; Watson et al, 1988) have been used to measure psychological functioning in cancer patients. These measures were considered for the present study, however, the HADS was felt to be most appropriate due to it being shorter (having 14-items as opposed to the other measures; BDI – 21 items, CES-D – 20 items, POMS short form – 37 items and MAC short form – 29 items). Also, the HADS covers both depression and anxiety, whereas the BDI and CES-D scales measure depression only.

The Hospital Anxiety and Depression Scale (Zigmond & Snaith 1983) has been widely used in psycho-oncology including breast cancer research (i.e. Alexander et al., 2010; Bidstrup et al., 2015; Saboonchi, Petersson, Wennman-Larsen, Alexanderson, Brännström & Vaez, 2014; Love, Kissane, Bloch & Clarke, 2002;

Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004; Rodgers, Martin, Morse, Kendell & Verrill, 2005; Sheppard, Harper, Davis, Hirpa & Makambi, 2014; Vahdaninia, Omidvari & Montazeri, 2010). Seven of the 14-items assess levels of depressive symptoms and seven measure anxiety, each are rated on a 4-point Likert-type scale ranging from 0 to 3. The items of the sub-scales can be summed to give an overall score (scores range from 0-21 for each sub-scale). Internal consistency of the sub-scales is: anxiety ($\alpha = 0.84$) and depression ($\alpha = 0.83$). Zigmond and Snaith (1983) have determined cut off values to indicate clinical levels of depression and anxiety; scores between 0-7 are regarded as being in the 'normal' range, 8 – 10 are considered to denote 'borderline' distress and scores of 11 or more are regarded as 'case' level, indicating severe levels of distress.

5.2.2.4 Open ended questions

At the end of each of the questionnaires, there was a box where participants could insert any comments if they wished.

5.2.3 Ethical and R&D approvals

Ethical approval was obtained from the Faculty of Health and Applied Sciences Research Ethics Committee at the University of the West of England (UWE), Bristol (see appendix 14). Also, Breast Cancer Care gave their permission and full support for their HeadStrong service to be evaluated.

R&D approval was sought from 6 HeadStrong centres; Liverpool, North Wales, St. John's (Scotland), Chester, London and Southend. These sites were selected on the basis of having the highest attendance rates (see appendix 15 for information regarding the number of patients seen at each centre per annum). Confirmation was obtained that NHS ethics approval was not needed (see appendix 6) since this was deemed service evaluation of current care, rather than introducing a new intervention, and no randomisation was involved (Health Research Authority, 2013).

Approval was granted from Research and Development (R&D) at the two HeadStrong centres in Chester and Southend. However, there were some barriers to

the set-up of the study and recruitment at some sites, where R&D departments thought that NHS ethics should have been obtained (despite having confirmation that the study was service evaluation), or insisted that the researcher should be an NHS staff member and that all questionnaires should be provided in Welsh (resources were not available for translation). Therefore, despite careful planning and discussions with Breast Cancer Care from the outset, the study could only take place at HeadStrong centres in Chester and Southend, both of which have above-average throughput of patients (as indicated by data provided by Breast Cancer Care, see appendix 14).

5.2.4 Eligibility criteria

5.2.4.1 Inclusion criteria

Women aged 18 and over, who had received a breast cancer diagnosis and were planning to attend a HeadStrong appointment in the next month.

5.2.4.2 Exclusion criteria

Women who were unable to read or speak fluent English were excluded from the study as resources were not available to translate the questionnaires, and the HeadStrong centres in this evaluation only deliver the service in English (it can be delivered in Welsh, if patients in Wales prefer). Moreover, the psychometric properties of the measures may be affected if translated into a different language as the meanings of items within the measures may change (Villagran & Lucke, 2005).

5.2.5 Sample size

A minimum sample size of 72 was needed, based on a priori power calculation using the primary outcome variable, the Derriford Appearance Scale (DAS-24). In order to allow for possible non-completion due to the unpredictable nature of breast cancer and side effects of treatment, which means participants may become increasingly unwell and unable to complete the questionnaires at all three time points, a sample of 84 was the target in order to allow for attrition. Recruitment took place over a 10

month period but unfortunately only 22 participants were recruited during this time, of which only 16 met the inclusion criteria as 6 had ovarian cancer.

5.2.6 Intervention delivery

The HeadStrong session was provided as usual. The way in which patients access the HeadStrong service varies from centre to centre. In Chester, patients either make an appointment in person or over the telephone. Letters confirming appointments are then posted out. The head of the HeadStrong centre in Chester agreed to post out study evaluation packs (containing an information sheet, consent form and baseline questionnaire) along with these letters. However, the Southend site does not send out appointment letters, so evaluation packs were handed out to patients when they attended their HeadStrong appointment.

Potential participants at each site were asked to read the information they had been given and to complete the baseline questionnaire if they wanted to take part. These were either returned to the researcher using a stamped addressed envelope provided with the letter, or taken to their appointment and given to HeadStrong staff who returned them to the researcher. It was important for the researcher to build strong links with the HeadStrong staff. This involved face-to-face or telephone meetings before recruitment for the study started and once recruitment started, the researcher rang each site every week to check on recruitment and address any queries that the staff may have.

5.2.7 Data collection

The questionnaire pack contained an information sheet (appendix 16), consent form (appendix 17), the pre-HeadStrong questionnaire and a pre-paid, stamped, address envelope for the participants to return the consent form and questionnaire. Participants were asked to provide either a postal or email address, so that the researcher could send them the subsequent follow-up questionnaires, either in the post or via email with a link to the online questionnaires.

5.3 Results

5.3.1 Data analysis

Data was analysed using the statistical program IBM SPSS. In order to conduct parametric tests, certain assumptions were tested by checking the distribution of variables. The Kolmogorov-Smirnov scores were examined for each of the measures to test for normality; they were all found to be normally distributed except for self-esteem at 3 month follow-up, the physical well-being (PWB) QOL subscale at 2 week follow-up, the functional well-being (FWB) subscale at baseline, the anxiety subscale at 3 month follow-up and the depression subscale at baseline, suggesting a violation of the assumption of normality. However, parametric tests are often robust and therefore unaffected by violations of assumptions (Norman, 2010).

The data was also checked for outliers, using histograms and boxplots. At baseline there was one outlier for QOL and two for FWB. At 2 week follow-up there were two outliers for PWB, four for EWB, one for FWB and three for depression. At 3 month follow-up there was one outlier for the ASI-R measure. However, given that the values are not too different from the remaining distribution; these cases were retained in the data set (Pallant, 2010). Therefore, parametric tests were justified.

Content analysis was used to analyse responses to the open ended questions. This is deemed appropriate within health research as it allows the researcher to examine the data in a systematic and objective way by identifying key concepts which can then be quantified and analysed using statistics (Hsieh & Shannon, 2005). A deductive approach was taken, so that the coding of the data was guided by the findings from the previous literature review, systematic review and qualitative HeadStrong evaluation.

5.3.2 Demographic information

Sixteen female breast cancer patients took part in the evaluation. This was the first time they had been to HeadStrong. Their ages ranged from 41-64 years (M = 52.93, SD = 7.29). Five (31.25%) had already experienced hair loss prior to attending HeadStrong, with four participants having started to lose their hair 14 days after

starting chemotherapy. See table 5 for further demographic and breast cancer information.

Table 5. Participants' demographic and breast cancer information.

	Participants (n = 16)
Age	
Mean (*SD*) (range) in years	52.93 (7.29) (41-64)
Ethnicity	n(%)
White	16 (100)
Employment status	n (%)
Working full-time	8 (50)
Working part-time	3 (18.75)
Retired	2 (12.5)
In education	1 (6.25)
Unemployed	2 (12.5)
Residence	n (%)
England	15 (93.75)
Wales	1 (6.25)
Cancer type	n (%)
Breast	16 (100)
Time since diagnosis	
Mean (range) in months	1.9 (1-5)
Treatment received (*note a*)	n (%)
Mastectomy	9 (56.25)
Lumpectomy	6 (37.5)
Chemotherapy	10 (62.5)
Radiotherapy	6 (37.5)
Herceptin	1 (6.25)
Tamoxifen	1(6.25)
Experience of hair loss (*note b*)	n(%)
Yes	5 (31.25)
No	11 (68.75)
Time to hair loss (*note c*)	
Mean (range) in days	14 (4-21)
Extent of hair loss at baseline (*note d*)	
Mean (range)	6.2 (3-9)

Notes: (a) Figures do not necessarily equal 100 as some participants received more than one type of treatment. (b) Experience of hair loss relates to whether participants had lost any of their hair. (c) Time to hair loss is how long after starting chemotherapy participants started to lose their hair. (d) Extent of hair loss relates to

the amount of hair loss participants had experienced at baseline, rated on a VAS scale from no hair loss to complete hair loss (0-10).

5.3.3 Follow-up recruitment data

Ten women completed the 2 week follow-up questionnaire (38% dropout). Seven of these participants had experienced hair loss at this time. Four attended HeadStrong at the Chester site, 5 in Southend and one did not state where they attended their session. Nine participants completed the 3 month follow-up questionnaire (44% dropout rate from baseline, 10% dropout rate from the 2 week follow up); all participants had experienced hair loss at this time point.

5.3.4 Accessing HeadStrong

Participants found out about the HeadStrong service through a number of avenues including their breast cancer nurse (44%), Macmillan (19%), the chemotherapy day unit (13%), chemotherapy nurse (6%), the internet (6%) or Breast Cancer Care website (6%). One participant did not answer this question.

Women gave a number of reasons for attending HeadStrong, with some indicating more than one reason. The most common reasons were to prepare for hair loss and to learn how to use scarves, see table 6 for details.

When asked about their expectations of HeadStrong, participants' hoped that the volunteers would be sympathetic, would be able to provide support, information and advice on where to buy headscarves, guidance on how to take care of their scalp, and that the session would boost their confidence. Participants' hoped that the volunteers had been through the same experience themselves. Two women reported that they did not have any expectations, as they did not know what HeadStrong was going to entail. At 2 week follow up, 6 participants indicated that their expectations were partially met; three indicated that they were completely met and one participant did not answer the question.

Table 6. Participants' reasons for attending HeadStrong

Reason	n (%)
For advice concerning scalp care	6 (37.50)
To find the best way to deal with the process	2 (12.5)
To help prepare for hair loss	7 (43.75)
To learn how to use scarves	7 (43.75)
Find out about where to purchase head scarves	1 (6.25)
To boost confidence	4 (25)
To meet someone in the same circumstances	2 (12.5)
Psychological support	2 (12.5)

Note. The figures do not equal 100% as some participants stated more than one reason.

5.3.5 Comparing completers with non-completers

The demographic and cancer variables were compared between the 9 participants who completed all three questionnaires (completers) and the 7 who only completed the baseline questionnaire (including the one participant who completed the baseline and 2 week follow-up questionnaire) (non-completers). The only significant difference was age (< .05), with the completers being younger than the non-completers (mean ages of 51 and 55, respectively).

A Mann-Whitney U test was carried out to compare scores on standardised measures from the completers and non-completers. A significant difference was found in functional well-being (FWB) scores of completers (*Md* = 18.00, n = 9) and non-completers (*Md* = 20.50, n = 7), *U* = 26.00, *z* = -2.62, *p* = .007. No statistically significant findings were found for any of the other standardised measures.

An independent-samples t-test was then conducted to compare FWB scores for completers and non-completers. There was a significant difference in scores for completers (*M*= 16.10, *SD*= 4.63) and non-completers (*M*= 20.67, *SD*= 1.21; *t* (14) = -2.34, *p* = .04, two-tailed). The magnitude of the difference in the means (mean difference = -4.57, 95% *Cl*: -8.76 to -.38) was large (eta squared = .17). No

significant findings were found for the other measures. These findings from the parametric test support those from the non-parametric tests, to show that no differences were found between completers and non-completers on any of the variables except the functional well-being subscale. However, caution is needed as parametric tests assume that the population from which the samples are taken are normally distributed and as discussed earlier in section 5.3.1, a number of variables including FWB violated this assumption of normality. Moreover, it is important to note that due to a small sample size, it is possible that a non-significant result may be found due to insufficient power.

See table 7 for the means and standard deviations (SDs) for each of the non-standardised (VAS) measures and table 8 for the standardised measures.

Table 7. Descriptive statistics for each of the VAS measures at each time point.

	Baseline Mean (*SD*)	**2 week follow up Mean (*SD*)**	**3 month follow-up Mean (*SD*)**
Confidence in managing the consequences of hair loss	4.25 (*2.52*)	7.80 (*1.32*)	7.00 (*1.73*)
Confidence in managing the reactions of others	3.88 (*2.53*)	6.70 (*2.41*)	5.44 (*3.00*)
Confidence in using head scarves and other head wear	3.87 (*3.10*)	7.70 (*1.77*)	7.67 (*2.00*)

Note. The above variables were measured on a Visual Analogue Scales (VAS) from 0 (zero confidence) to 10 (complete confidence).

Table 8. Descriptive statistics for the standardised measures at each time point.

Measure	Baseline Mean (*SD*)	2 week follow up Mean (*SD*)	3 month follow-up Mean (*SD*)
Composite Appearance Schemas Inventory- Revised (ASI-R)	3.15 (*.51*)	2.91 (*.39*)	3.19 (*.51*)
Self-evaluative salience (ASI-R)	2.81 *(.54*)	2.79 (*.51*)	2.96 (*.62*)
Motivational salience (ASI-R)	3.68 (*.48*)	3.65 (*.41*)	3.63 (*.47*)
Self-esteem	21.06 (*4.06*)	20.00 (*3.09*)	20.25 (*3.77*)
QOL (FACT G)	76.31 (*12.94*)	70.80 (*14.05*)	58.25 (*13.88*)
Physical wellbeing (PWB)	19.88 (*5.32*)	17.10 (*6.77*)	13.00 (*5.86*)
Social wellbeing (SWB)	23.63 (*3.48*)	20.50 (*3.72*)	18.63 (*3.34*)
Emotional wellbeing (EWB)	15.00 (*4.73*)	18.30 (*2.91*)	15.00 (*3.66*)
Functional wellbeing (FWB)	17.81 (*4.31*)	14.90 (*5.34*)	11.62 (*5.15*)
Fear of negative evaluation (FNE)	34.50 (*8.63*)	33.60 (*13.15*)	30.63 (*11.48*)
Anxiety (HADS)	8.13 (*3.88*)	6.70 (*6.09*)	7.50 (*4.72*)
Depression (HADS)	7.81 (*3.75*)	8.80 (*3.97*)	10.38 (*3.58*)
Derriford appearance scale (DAS-24)	31.69 (*10.41*)	37.10 (*11.21*)	41.78 (*11.12*)

Note. The composite ASI-R score is the mean of the 20 ASI-R items. Self-Evaluative Salience is the mean of 12 of the ASI-R items. Motivational Salience is the mean of 8 of the ASI-R items.

5.3.6 Inferential statistics

5.3.6.1 Pearson's correlations

The relationship between demographic and treatment variables (age and extent of hair loss) and standardised measures were investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity.

5.3.7 Research questions 1 and 2: does attending a HeadStrong session improve participants' confidence in managing the consequences of hair loss, the reactions of others and use of headwear? Are any improvements as a result of attending a HeadStrong session maintained over time?

The Friedman Test indicated a statistically significant difference in participants' self-reported confidence in managing the consequences of hair loss across the three time points; χ^2 (2) = 13.88, p = .001 < .05. There was an increase in median scores for confidence from pre-intervention (5.00) to 2 week follow-up (7.00) which remained stable at 3 month follow-up (7.00). In support of this a Wilcoxon Signed Rank Test revealed a statistically significant increase in confidence in managing the consequences of hair loss from pre-intervention to 2 week follow-up, z = -2.53, p = .011, and pre-intervention to 3 month follow-up, z = -2.57, p = .010.

A statistically significant difference in self-reported confidence in managing the reactions of others was found across the three time points; χ^2 (2) = 10.08, p = .006 < .05. Median scores increased from pre-intervention (5.00) to 2 week follow up (7.00) but then decreased at 3 month follow-up (5.00). Moreover, a Wilcoxon Signed Rank Test revealed a statistically significant increase in confidence from pre-intervention to 2 week follow up, z = -2.56, p = .011.

There was a statistically significant difference in reported confidence in using headwear to camouflage hair loss across the three time points; χ^2 (2) = 6.07, p = .048 < .05. Inspection of the median values showed an increase in confidence from pre-intervention (1.00) to 2 week follow up (9.00) which remained stable 3 months later (9.00). A Wilcoxon Signed Rank Test revealed a statistically significant increase in confidence in using headwear from pre-intervention to 2 week follow up, z = -2.32, p = .02 and from pre-intervention to 3 month follow-up, z = -2.36, p = .018.

All participants who completed the 2 week and 3 month follow-up questionnaires said that they would recommend HeadStrong to someone who is concerned about treatment-related hair loss, and felt confident that the techniques they learnt at HeadStrong would help them in the future.

5.3.8 Research question 3: as a result of attending a HeadStrong session, are there any changes in the value placed on appearance, self-esteem, quality of life fear of negative evaluation, appearance-related distress, anxiety and depression over time?

The Friedman Test indicated a statistically significant difference in ASI-R total scores, quality of life (QOL), social wellbeing (SWB), emotional wellbeing (EWB), fear of negative evaluation (FNE), depression and appearance-related distress (DAS-24) across the three time points, see table 9 for further details.

Table 9. Median and p-values for each standardised measure on the Friedman test

	Baseline	**2 week follow up**	**3 month follow-up**	***p* value**
ASI-R	63.00	59.00	64.00	.04*
QOL	74.00	76.50	59.00	.02*
SWB	22.50	20.50	19.00	.04*
EWB	14.00	18.50	13.50	.03*
FWB	17.00	16.00	11.00	.11
PWB	21.00	18.50	11.50	.13
FNE	40.00	32.50	30.50	.04*
Depression	8.00	9.00	10.00	.04*
Anxiety	8.50	7.00	5.00	.97
DAS-24	35.00	38.00	41.00	.03*
Self-esteem	20.00	20.00	20.50	.70

* $p < .05$

Moreover, a Wilcoxon Signed Rank Test revealed a statistically significant decrease in quality of life from 2 week to 3 month follow-up, $z = -2.52$, $p = .012$. A significant decrease in social well-being from pre-HeadStrong to 3 month follow-up, $z = -2.38$, $p = .018$ and a significant decrease in emotional well-being from 2 week to 3 month follow-up, $z = -2.37$, $p = .018$. There was a statistically significant decrease in fear

of negative evaluation from pre-intervention to 3 month follow-up, z = -2.31, p = .021.

A paired-samples t-test showed a statistically significant increase in appearance-related distress (DAS-24) (t (7) = -3.01, $p \leq .01$) and depression t (7) = -2.49, $p < .05$ between baseline and 3 month follow-up. A significant decrease was found in social wellbeing (SWB) (t (7) = 3.38, $p < .05$), physical wellbeing (PWB) (t (7) = 2.70, $p <$ .05) and fear of negative evaluation (FNE) t (7) = 4.00, p < .01 from baseline to follow-up, see table 10 for further details.

Table 10. Means and p-values for each standardised measure for the paired samples t-test

	Baseline Mean (*SD*)	**3 month follow-up Mean (*SD*)**	***p* value**
ASI-R	62.56 (*7.16*)	63.89 (*10.23*)	.61
QOL	71.63 (*15.46*)	58.25 (*13.88*)	.06
SWB	22.13 (*3.94*)	18.63 (*3.34*)	.01*
EWB	14.88 (*5.67*)	15.00 (*3.66*)	.93
FWB	15.25 (*4.77*)	11.62 (*5.15*)	.13
PWB	19.38 (*5.42*)	13.00 (*5.86*)	.03*
Self-esteem	19.75 (*2.71*)	20.25 (*3.77*)	.69
DAS-24	33.11 (*12.05*)	41.78 (*11.12*)	.01*
FNE	37.13 (*10.45*)	30.63 (*11.48*)	.01*
Depression	8.75 (*3.24*)	10.38 (*3.58*)	.04*
Anxiety	8.25 (*4.33*)	7.50 (*4.72*)	.40

*$p < .05$

Note. The figures in the above table are different to those in table 8, as only the data for the completers (i.e. those who completed both the baseline and follow-up questionnaires) are included in the analysis.

5.3.8.1 Partially overlapping samples

As the data set has a combination of independent and paired data (those 9 participants who completed all three questionnaires compared to the 7 participants who only completed the baseline and 2 week follow-up questionnaire), a standard approach would be to perform a paired samples t-test (as discussed above), which is acceptable if the number of discarded data was relatively 'small' and the samples were still relatively 'large'. However, this would result in half of the data being discarded and the power of the test being reduced. An alternative approach is to use the corrected Z-test, formulated by Looney and Jones (2003), which makes use of all the available data and accounts for the fact that there is a combination of paired and independent samples. The corrected Z-test combines the paired and independent Z-tests for comparing means together, this method has previously been found to provide adequate control of type 1 error and generally has equal power to that of the usual two-sample t-test (Looney & Jones, 2003), see appendix 18 for a copy of the test statistic.

When using the corrected Z-test at the 5% significance level there was a significant difference between the mean scores pre and 3 month follow-up on the DAS-24 [$Z = -7.24$, $p < .001$], physical wellbeing (PWB) [$Z = 3.12$, $p < .01$], social wellbeing (SWB) [$Z = 4.94$, $p < .001$], functional wellbeing (FWB) [$Z = 1.12$, $p \leq .001$], total quality of life (QOL) [$Z = 3.63$, $p < .001$] and depression [$Z = -2.32$, $p < .05$]. Therefore, there is statistically significant evidence that the mean scores on these measures are different between baseline and 3 month follow-up, see table 11 for further details.

Table 11. Comparison of the paired samples t-test and corrected Z p-values for each of the standardised measures.

	Paired samples t-test (discard unpaired) p- value	Corrected Z p-value
DAS-24	**0.012***	0.000***
Self-esteem	**0.692**	0.583
Total QOL	**0.056**	0.000***
PWB	**0.031***	0.002**
SWB	**0.012***	0.000***
EWB	**0.933**	1.000
FWB	**0.12**	0.001**
FNE	**0.005****	0.154
Anxiety	**0.402**	0.611
Depression	**0.042***	0.022*
ASI-R	**0.611**	0.838
		0.457
Self-evaluative	**0.222**	0.848
Motivational salience	**0.793**	

***p < .001; ** p < .01; < p < .05

As a non-parametric alternative to the corrected Z-test is currently unavailable, for triangulation purposes a Wilcoxon Signed Rank Test was conducted (see table 12). This revealed a statistically significant increase in appearance-related distress (DAS-24) ($z = -2.19$, $p < .05$, with a medium effect .45) and depression ($z = -1.98$, $p < .05$, with a medium effect .40) over time. Whereas, a significant decrease was found for quality of life (QOL) ($z = -2.90$, $p < .05$, with a large effect .59), social wellbeing (SWB) ($z = -2.38$, $p < .05$, with a medium effect .49) and fear of negative evaluation (FNE) ($z = -2.31$, $p < .05$, with a medium effect .47).

Table 12. Median and p-values for each standardised measure for the Wilcoxon Signed Rank Test

	Baseline	**3 month follow-up**	***p*-value**
ASI-R	63.00	64.00	.67
QOL	74.00	59.00	.03*
PWB	21.00	11.50	.06
SWB	22.50	19.00	.02*
EWB	14.00	13.50	.75
FWB	17.00	11.00	.12
FNE	40.00	30.50	.02*
Self-esteem	20.00	20.50	.60
DAS-24	35.00	41.00	.03*
Anxiety	8.50	5.00	.40
Depression	8.00	10.00	.05*

*p ≤ .05

5.3.9 Participants' experiences of hair loss and of the HeadStrong service

At the end of each of the three questionnaires, there was a box for participants' comments. At baseline, a number of participants commented on their feelings of apprehension and uncertainty towards their imminent hair loss:

> *"I am due to undergo chemotherapy very soon so……I am dreading it"* (Angela).

> *"At present I have not suffered any hair loss…..I think I know how I am going to handle it, but it may be very different when reality hits"* (Eva).

The majority of participants were feeling positive and took steps, including attending HeadStrong and cutting their hair, in order to re-gain a sense of control:

> *"I have booked HeadStrong and a wig fitting appointment for before my treatment/hair loss- taking control! I also intend to have my hair shaved before it all falls and have cut my hair considerably shorter since my diagnosis. Although I am feeling positive and strong and welcome treatment,*

> *I anticipate more negative emotions once treatment starts and the effects show"* (Freya).
>
> *"all my family and myself are positive about the forth coming treatment"* (Erica).
>
> *"4 days until 2nd cycle of treatment. Shaved hair off (not completely- number 1 razor) day of first treatment as couldn't bear the thought of hair falling out in clumps. As yet there are not patches although my nurse told me before my treatment that it would have completely gone by cycle 2 on AC chemo. I have always changed my hair style. I colour my hair frequently and was not as fazed by the 'skin head' as I thought I would be"* (Freya).

Participants spoke about the difficulties around staying positive when contending with cancer treatment and the side-effects of treatment:

> *"At the time I was diagnosed with breast cancer, I was being treated for a clinical depressive…this funnily enough made me quite accepting of the diagnosis. However, as I move through the different stages, surgery, treatment, treatment-side effects, it makes it harder to be positive"* (Ronnie).
>
> *"I feel very positive and strong. It will be interesting to see how my thoughts and feelings compare in 3 months, after another 3 cycles. Fingers crossed I'll feel the same :)"* (Jan).

Freya spoke about her main concern being how others would perceive her, particularly worrying that she will look 'ill' due to her hair loss:

> *"Throughout this experience I feel my main concern has been/is with the thoughts and perceptions of others rather than feeling bad about myself. My main insecurity is worrying that I look 'ill' not the hair loss. I have been lucky enough to keep my eyebrows and eyelashes- so far. This has helped with such insecurities"* (Freya).

5.4 Discussion

The findings from this study demonstrate the effect of the HeadStrong service on breast cancer patients' distress in relation to their hair loss. The majority of participants attended HeadStrong to learn more about how to use headscarves and to prepare for the process of hair loss. Previous research (i.e. Harcourt & Frith, 2008; Hilton et al., 2008; Rumsey & Harcourt, 2005) has highlighted that hair loss can render an individual visible as a 'cancer patient'. Some participants wanted to attend

HeadStrong to regain some control over this situation and hoped that feeling more confident about using headwear to disguise their hair loss would help them manage the reactions of other people and keep their cancer diagnosis more private.

Participants who completed all questionnaires were younger than those who did not. Previous research has highlighted that younger women with breast cancer report a lower quality of life than older women, as younger women are at a different stage in their life than older women and are thought to experience greater distress (Knobf, 2007). Side effects of breast cancer treatment tend to be more prominent in younger women including the onset of early menopause (Baucom, Porter, Kirby, Gremore & Keefe, 2006). It is, therefore, possible that the younger women may have completed all questionnaires as they felt more in need of support.

The findings show that HeadStrong significantly improved participants' confidence in managing their hair loss, the reactions of others to it and using the headwear to camouflage it. The benefits of the practical advice and information that they were given at HeadStrong was also evident in the qualitative study (chapter 4). Previous research has highlighted the benefits of information provision and advice (Fallowfield, 1992; McConochie & Pearson, 2006). The increase in confidence around managing hair loss and using headwear was maintained at 3 month follow-up, however confidence in managing the reactions of others dropped over this time. This may be because the HeadStrong session focused on making hair loss less obvious, rather than managing their feelings about how other people reacted to their altered appearance. Previous research has highlighted that, despite being told how to prepare for the changes to one's body as a consequence of chemotherapy, it is difficult to prepare for the reactions of other people (Hilton et al., 2008). The current study suggests HeadStrong may go some way to increase patients' confidence around hair loss and use of headwear but camouflage alone is not sufficient to manage all the challenges facing patients who have lost their hair. Patients may need access to more support in managing the emotions they are feeling and coping with the reactions of others in ways other than camouflage.

Quality of life scores were found to reduce from baseline to 2 week follow-up and to 3 month follow-up. Specifically a decrease in emotional well-being was found between 2 week and 3 month follow-up. However, it is not possible to determine whether this decrease in reported quality of life is due to hair loss alone, other side effects of cancer treatment or other things going on in participants' lives (Cancer Research UK, 2014). A number of factors can impact on an individual's quality of life, including age, treatment received, hair loss status and psychosocial factors including value placed on appearance, support received and health care experience, all of which are supported within the breast cancer literature (Helms et al, 2008; Knobf, 2007; Shapiro et al., 2001).

A decrease in fear of negative evaluation, whereby participants are less concerned with how they think others will judge them, was found from baseline to 3 month follow-up. This may be because patients' needs and priorities change as they progress through their cancer journey (Vogel, Bengel & Helmes, 2008), possibly becoming less concerned about what other people may think of them. Also, the increased confidence that participants reported at 3 month follow-up around managing their hair loss and using head wear may have positively influenced any fear of negative evaluation.

Appearance-related distress, depression and quality of life scores (including physical, social and functional well-being) were all poorer at 3 month follow-up compared to baseline. This may be due to participants having lost all their hair by 3 month follow-up and, along with the potential impact of other treatments (including weight gain and early onset menopause), may still be adjusting to an altered appearance, experiencing poor body image, loss of libido and an impact on intimate relationships (Fobair et al., 2006; Pauwels et al., 2012). This would suggest that despite HeadStrong going some way to help participants with some aspects of the side effects of their treatment, it did not buffer them against all aspects of appearance-related and other psychological distress, or help to maintain their quality of life.

Compared to other evaluations of camouflage-based interventions, these findings were similar to those of McGarvey et al (2010) who found that the education information provided alongside a computer imaging service was useful. Also, Nolte et al's (2006) Best Look Forward intervention found a small but significant change in body image and all participants said they would recommend the camouflage based videotape intervention to others experiencing hair loss, however, some participants did find some aspects of the intervention unhelpful which is similar to the findings from the HeadStrong service evaluation. Similar to the current findings, Taggart et al's (2009) Look Good Feel Better intervention was found to significantly improve self-image post intervention but these benefits were not maintained in the long term. Also, a significant reduction in self-consciousness was found. These findings suggest that camouflage based support services can go some way to support patients who are affected by treatment-related hair loss, however, additional interventions are required to meet individual support needs.

It is important to acknowledge that the ARC framework has not been tested in full in the current study due to the small sample size. The suitability of the ARC framework is considered in chapter 7. Also, if there had been a larger sample size, it would have been possible to compare normative data for each of the measures.

5.4.1 Limitations

This was a quantitative study with only 16 participants at baseline, 10 at 2 week follow up and 9 at 3 month follow-up, all of whom were English speaking. The findings cannot therefore be generalised to other patients who have attended the HeadStrong service. Even though there were open ended questions in each of the questionnaires, participants only included comments at the end of the baseline questionnaires, therefore it was not possible to make narrative comparisons across all three time points. Recruitment may have been low due to the nature of the evaluation; some patients may not have liked the idea of filling out numerous questionnaires and may have preferred to take part in an interview or focus group, where they may have felt they had more of a voice (Cornwall, 2008). Additionally, the timing may not have been appropriate as potential participants already had a lot to contend with including receiving treatment and attending hospital appointments.

As a result they may not have wanted, nor had the time, to take part in research. Similarly, some women wanted to take part but chose not to, or consented and subsequently dropped out, because the side effects of treatment meant they were too unwell. Additionally, although the researcher maintained regular contact with the managers of the HeadStrong centres in order to oversee the process by which service users were invited to take part, it was not possible to determine whether everyone who attended a HeadStrong session received a questionnaire. A suggestion for future research would be for the researcher to speak to potential participants in person; however this may not be practical if geographically diverse HeadStrong sites are involved. Staggering recruitment from different sites might be effective and more feasible.

Recruitment for the current study only took place at two HeadStrong sites, which may not be representative of other sites. However, HeadStrong is intended to be delivered in the same way in every centre since the volunteers all receive standardised training. Therefore, it is possible that similar findings would still be found if participants had been recruited from other HeadStrong sites.

As stated above, due to the small sample size it was not possible to test the predictive ability of the ARC framework in full, particularly the role of the predisposing and intervening variables as mediators or moderators of the outcomes. This makes it difficult to comment on the suitability of the ARC framework in this context. If the sample size had permitted, a hierarchical stepwise regression analysis would have been conducted to assess the predictive ability of the predisposing and cognitive processing variables on the outcome variables.

5.4.2 Synthesis of results

The findings from the qualitative and quantitative HeadStrong studies have found a number of similar findings; participants wanted to attend HeadStrong in order to regain some control over their hair loss, they found the information and practical advice they received to be particularly helpful, and they found it difficult to deal with the reactions of others to their hair loss. Yet, although they found HeadStrong beneficial to an extent (e.g. increasing their confidence around managing their hair

loss and using headwear), participants still reported a number of unmet needs including emotional support. Therefore, the findings from the qualitative and quantitative studies suggest that HeadStrong was potentially beneficial, but could not address all participants' needs alone.

5.4.3 Clinical implications of the qualitative and quantitative HeadStrong studies

The qualitative and quantitative HeadStrong studies support previous research demonstrating that hair loss is a very distressing side effect of treatment for many breast cancer patients. Whilst the findings cannot be generalised without caution, nevertheless they provide an insight into women's experiences of a particular camouflage-based intervention that aims to support women across the UK who are in this difficult situation. The following recommendations could improve the provision of care to support this patient group: firstly, it is important that patients have a clearer understanding of what a HeadStrong session will involve, so they can be better prepared for it. Whilst some participants were satisfied with the amount of practical advice and information they received from HeadStrong, others would have liked more, indicating that the level of information given may vary from one centre to another and that participants' information needs vary. Through the qualitative and quantitative studies, it became apparent that participants' expectations were beyond the remit of HeadStrong. For example, some participants thought that the service would be delivered in a group setting or that it would offer emotional support, thus demonstrating the importance of patients talking through their expectations with the HeadStrong volunteers at the start of the session. Ideally, the service would be tailored more to the individual, so that participants start the session by discussing with the volunteer what they hope to get out of it, in order that the volunteer can tailor the session to the individual. However, this would require volunteers feeling confident in doing this and may require additional training.

Secondly, the qualitative and quantitative HeadStrong studies highlighted that participants had been seeking emotional support, but this was not necessarily provided by the NHS. It is important that health professionals working with this patient group are aware of the potential emotional impact of receiving a cancer

diagnosis and experiencing treatment-related hair loss, and are confident in signposting patients towards emotional support, if needed. It is important that Oncology services ensure that people in their team (e.g. specialist nurses) are experienced and available to discuss hair loss with patients in order to assess the importance of hair to them, and their possible response to its loss. Such understanding is important for the provision of interventions that are meaningful to individual patients. It is acknowledged that many teams including specialist nurses do already go to great lengths to support patients well. A screening assessment could ensure patients are referred to appropriate sources of support such as other health professionals (including psychosocial specialists), support programs or self-help groups. For example, the Patient Concerns Inventory (PCI) (Rogers, El-Sheikha & Lowe, 2009) (www.patient-concerns-inventory.co.uk) may be useful to identify each patient's concerns (a discussion of the PCI can be found in section 7.4.1).

Further evaluation of HeadStrong is still warranted on a larger scale, as recruitment was a challenge for the current study. Some suggestions to aid future research include the researcher being on site to speak to potential participants as this has been found to benefit recruitment elsewhere (Jennings et al, 2014), and finding ways to establish the reasons why individuals do not want to participate. Evaluation of other, similar services (such as Head Start which is held at the Bristol Haematology and Oncology Centre (BHOC) and 'My New Hair' (http://www.mynewhair.org/for-hairdressers/) are needed. Both of these services focus on head wear to camouflage hair loss, similar to HeadStrong. The Head Start service is based solely at BHOC, whereas, the 'My New Hair' service is available through salons throughout the UK. 'My New Hair' is an organisation set up by Trevor Sorbie, a British celebrity hairdresser and offers a two stage, nurse and expert-led education program for hairdressers, in communication skills training and being able to style wigs. Also, Nicky Clarke, a celebrity hair dresser, also delivers training courses for hair stylists to learn how to cut wigs.

Despite the limitations outlined above, the findings from the current study might still help to inform future research and indicate a number of recommendations for the provision of care. It is important that health professionals are able to signpost

patients to available services such as HeadStrong, but are also aware that patients might have other needs that a service like this is unable to address. Additional, alternative interventions need to be freely available and easily accessible for patients; especially bearing in mind that time was a constraining factor for many of the participants in the qualitative study.

5.4.4 Disseminating the research findings

Once the researcher had completed both the qualitative and quantitative HeadStrong evaluation, she attended a meeting at Breast Cancer Care's Head Office, to present the study findings to the Director of Services and Engagement, along with BCC Heads at each of the NHS sites which host the HeadStrong Service. The researcher was also able to discuss the recommendations on how the service could be improved. As a result of the study findings, along with the feedback that Breast Cancer Care had received directly from their own ongoing feedback questionnaires, the HeadStrong service has been changed so that it is tailored more to individuals' needs. As a result, HeadStrong volunteers receive additional training so that, at the start of a session, they discuss with the patient what they hope to gain from HeadStrong, and then tailor the session to the individual's needs. Also, patients are provided with more information about the HeadStrong service prior to attending a session. A summary of the research findings were also shared with the HeadStrong volunteers, the participants from the qualitative and quantitative studies, BCC Cancer Voices and the member of ASWCN, who had been advisors for the study.

5.5 Conclusion

In conclusion, these qualitative and quantitative studies suggest that the HeadStrong service can be a helpful intervention for breast cancer patients affected by hair loss in terms of improving confidence in managing hair loss, particularly around using head camouflage. As highlighted previously (chapter 4) support needs vary between individuals and throughout their cancer journey; not all patients want the same support with hair loss. For some, their concerns centre around managing the reactions of others, whilst others focus on appearance concerns or practical issues such as having a cold scalp. Therefore, individuals warrant different support

depending on their specific concerns and efforts should be taken to ensure that each patient's individual needs are identified and addressed. It is imperative that patients are equipped with strategies to help them to manage all aspects of hair loss, rather than relying on one strategy, such as camouflage.

In summary, HeadStrong may be a valuable intervention for some patients but it will not necessarily provide all the support they require and it will not appeal to all patients. There is still potential to develop the range of interventions available for this patient group. The following chapter therefore considers the feasibility of an alternative intervention (expressive writing) to support breast cancer patients who are affected by treatment-related hair loss.

5.6 Summary of the key points in this chapter:

- The findings of this study provide an insight into women's experiences of one particular intervention.
- Benefits of HeadStrong included improvements in self-reports of confidence in managing hair loss, using headwear to camouflage hair loss and handling the reactions of others.
- Participants' reported quality of life, emotional well-being and fear of negative evaluation were found to reduce over time, but appearance-related distress and depression were all poorer at 3 month follow-up.
- The research has led to the development of a number of recommendations for the provision of care, including the HeadStrong session being tailored to individuals' needs.
- It is evident that HeadStrong maybe appropriate for some individuals, but additional interventions are required to address patients' unmet needs and to offer a broader, more holistic approach to supporting those who are affected by hair loss.

5.7 The next stage of the research

Although HeadStrong has been found to be beneficial for some people, a number of participants in the qualitative and quantitative HeadStrong studies highlighted a

number of unmet needs, mainly around emotional and psychological support. A sizeable body of research has demonstrated that expressive writing can offer benefits in physical health and psychological wellbeing (Pennebaker et al, 1997), which is important for this patient group given that breast cancer patients can experience an increase in appearance-related distress and decrease in QOL over time, as found in the quantitative HeadStrong service evaluation. To date, the potential benefits of an expressive writing intervention have not been explored with breast cancer patients who are affected by treatment-related hair loss. The following chapter therefore explores the feasibility and acceptability of an expressive writing intervention.

Chapter Six

Feasibility of an Expressive Writing Intervention to Support Breast Cancer Patients Affected by Treatment-Related Hair Loss

6.1 Introduction

The findings from the systematic review discussed in chapter 2 highlighted that there is relatively little evaluated, specialist support available to help breast cancer patients manage the challenges and emotional distress associated with hair loss. These findings, along with those from the HeadStrong service evaluation in chapters 4 and 5 which showed that despite the positive findings including helping them with the practical side of hair loss, women felt that not all their emotional and psychological needs were met, helped to inform the final study in this program of research: the feasibility of an expressive intervention to support breast cancer patients affected by treatment-related hair loss. Rather than conducting a full RCT of HeadStrong, after careful consideration, it was decided it would be more advantageous to conduct a scoping study of expressive writing interventions and to adapt an existing expressive writing intervention, to explore its acceptability and feasibility with a new patient group. As the participants in the HeadStrong evaluation highlighted a number of unmet needs, once these findings had been fed back to Breast Cancer Care, it was thought to be more advantageous to explore a different intervention with this patient group. Also, recent research has highlighted a need for interventions which utilise novel approaches such as writing activities, to address body image distress in breast cancer patients (Fingeret, Teo & Epner, 2014).

This chapter begins by providing an overview of what expressive writing is; the findings from a scoping study are then presented, followed by a justification of why an existing intervention was selected, by discussing the origin of this approach and outlining different theories which have been proposed to explain its benefits. Specifically, its use in previous research with breast cancer patients is then discussed before the feasibility study is presented. A noteworthy point is that the phrases ‘expressive writing’ and ‘emotional disclosure’ are used interchangeably as they are both used within the literature to denote essentially the same intervention.

6.2 Pennebaker and Beall's expressive writing paradigm

For a number of years research has investigated the health benefits of expressive writing using a paradigm developed by Pennebaker and Beall (1986), were participants are required to write about their deepest thoughts and emotions about a stressful or traumatic life experience, typically for 15 to 20 minutes on three or four consecutive days. Pennebaker (1993) argues that the process of making sense of an event, of gaining insight about a trauma, and of organising and interpreting an upsetting experience into one's self-schema is the mechanism by which expressive writing is helpful. This supports Piaget's cognitive development theory, where individuals can either assimilate the experience into their existing schema or accommodate their schema to the new experience (Poon & Danoff-Burg, 2011). Therefore, the benefits of emotional disclosure include the ability to disclose information which enables individuals to free their mind of unwanted thoughts, help them to make sense of upsetting events and teach them to regulate their emotions in a more beneficial manner.

Pennebaker's expressive writing paradigm is attractive to researchers, care providers and funders due to it being low-cost and requiring minimal time to implement (Lee & Cohn, 2010). Expressive writing can be carried out at any time and venue which suits the participant, making it potentially well suited for patients (Ashley, O'Connor & Jones, 2011). Since chronic illnesses including breast cancer are expensive to treat and manage, low-cost and easily administered interventions are particularly appealing to help control treatment costs while improving patients' quality of life (Broderick, Stone, Symth & Kaell, 2004). Self-administered interventions offer particular benefits, such as decreased need for direct health professional assistance and the potential for broad delivery (e.g. to target poorly served rural areas) (Smyth & L'Abaté, 2000).

6.3 Effectiveness of expressive writing studies

Despite emotional disclosure generally being considered beneficial, some researchers have begun to question its effectiveness due to the inability to replicate the effects. A number of meta-analyses have been conducted (Smyth, 1998; Frisina,

Borod & Lepore, 2004; Frattaroli, 2006; Harris, 2006; Mogk, Otte, Reinhold-Hurley & Kroner-Herwig, 2006; Zhou, Wu, An & Li, 2015). Overall, these meta-analyses showed expressive writing to work, with small significant effect sizes of .230 (Smyth, 1998) and .101 (Frisina et al., 2004). Zhou et al (2015) stated that a significant effect was found with expressive writing studies reducing somatic symptoms for breast cancer patients. Moreover, the results from a meta-analysis by Frattaroli (2006) confirm that experimental disclosure does have small but beneficial effects for participants with an overall *r-effect* of .075. This effect size is smaller than that found in the previous two meta-analyses, possibly because Frattaroli (2006) included a large number of unpublished studies. Frattaroli's (2006) meta-analysis highlighted that effect sizes tended to be larger when studies only included participants with physical health problems and/or a history of trauma or stressors, and were not college students. Furthermore, studies involved disclosure at home, with sessions of at least 15 minutes, and participants were instructed to discuss previously undisclosed topics and to write about recent events.

In contrast, Harris (2006) found expressive writing to be effective in healthy people but not in people who had received a medical diagnosis. Mogk et al (2006) found that expressive writing had either minor or no effects. It is important to acknowledge that the diversity of populations included and the heterogeneity of the meta-analyses may be accountable for the discrepancy in findings (Zhou et al, 2015). Recent research has argued that even small effects of expressive writing in subgroups of patients could still be clinically relevant (Zachariae & O'Toole, 2015).

6.4 Theories to explain why expressive writing is beneficial

A number of theories have been proposed as possible explanations for why expressive writing can be beneficial, the next section will provide an overview and critique of these theories.

6.4.1 Inhibition theory

Rather than inhibiting thought and feelings, it has been found that expression of thoughts and feelings about an upsetting event is beneficial, leading to a reduction in

stress and improvements in psychological and physical health (Frattaroli, 2006). Early emotional disclosure studies encouraged people to write about events which they had not previously discussed with anyone (Frattaroli, 2006). This suggests that those who naturally hold back and keep things to themselves would benefit the most from expressive writing. However, Francis and Pennebaker (1992) found that participants who were low in dispositional constraint benefited most from an experimental disclosure intervention, whereas those who were high in dispositional constraint benefited less. Moreover, the results from Frattaroli's (2006) meta-analysis provide very little support for inhibition theory, since there was some evidence that studies that instructed participants to discuss undisclosed trauma were only marginally better than studies that lacked this instruction.

In contrast there is evidence to suggest that writing about a stressful/traumatic event that one has previously discussed with others is as likely to produce beneficial health outcomes as writing about a stressful/traumatic event that has not been discussed previously (Greenberg & Stone, 1992). This may be because there is an important distinction between describing traumatic experiences and disclosing deep emotions and thoughts related to these experiences (Sloan & Marx, 2004). In summary, the inhibition theory has received mixed support as an underlying mechanism for the written disclosure paradigm.

6.4.2 Cognitive-processing

Another theory thought to explain the benefits of expressive writing is cognitive-processing theory. Pennebaker, Colder and Sharp (1990) asked participants who had reported benefiting from the expressive writing process why they thought they had benefited; most felt that writing allowed them to gain insight into what had happened to them. By using a computerised text-analysis program to examine the words used during the writing exercises, Pennebaker, Francis and Booth (2001) found that participants who had benefited most from emotional disclosure in previous studies demonstrated an increase in the use of causation words (such as because, effect, hence) and insight words (for example consider, know, think) during their writing

session. In contrast, those who did not benefit from disclosure did not increase their use of these types of words.

The cognitive-processing theory has proven difficult to evaluate empirically, as it is difficult to measure cognitive changes (Sloan & Marx, 2004). Also, research has provided very little support for this theory as cognitive-processing instructions were not significantly related to higher effect sizes (Frattaroli 2006). The evidence supporting the cognitive theory is correlational and it is possible that the changes observed in the language used to describe and discuss traumatic and stressful events may be associated with some other mechanism of change (Sloan & Marx, 2004).

6.4.3 Self-affirmation

Self-affirmation helps to explain why certain individuals are more negatively affected by certain situations than others. "A strong self is a self-affirmed self, a self that is able to deal with threatening events and information by drawing resources from itself" (Stapel & Van der Linde, 2011, p. 34). Individuals with greater self-resources (i.e. social status, personal characteristics) have been found to recover more quickly from negative events and experience greater well-being (Hobfall, 1989). There are two types of self-affirmation techniques; value affirmation and attribute affirmation. An example of value affirmation is where participants are asked to rank a number of values and personal characteristics (e.g. relations with friends, artistic skills) in order of personal importance. Participants are then asked to indicate their most important value and to write an essay describing why this value is important to them (Sherman et al, 2000). Whereas in attribute affirmation studies, participants are provided with positive feedback about their personality with an aim to increase the cognitive accessibility of positive self-definitions, an example of positive feedback is "although you may feel you have a number of personality weaknesses, your personality is fundamentally strong" and "You are very social" (Koole & van Knippenberg, 2007, p.673).

Value affirmation increases self-clarity by affirming an individual's core beliefs and through this process individuals are reminded of who they are, what they deem important and what they stand for, whereas attribute affirmation increases self-

esteem as an individual affirms positive self-descriptions, positive self-images are made salient, which is likely to temporarily increase one's feelings of self-worth (Stapel & Van der Linde, 2011). Creswell et al., (2007) found that self-affirmation mediated the relationship between emotional expression and benefit writing on early-stage breast cancer patients' physical symptoms at 3-month follow-up. Their study suggests that self-affirmation can help buffer the stress associated with writing about difficult cancer-related thoughts and feelings.

6.4.4 Self-regulation theory

Experimental disclosure allows individuals to observe themselves expressing and controlling their emotions, which is thought to give people a new or stronger sense of self-efficacy for emotional regulation (Lepore, Greenberg, Bruno & Smyth, 2002). A self-regulation writing exercise found that when students described problems they encountered in college and came up with ways to resolve them, this produced the same benefit as expressive writing (Cameron & Nicholls, 1998). King (2001) found that writing about one's 'best possible self' produced health benefits, including a reduction in visits to the doctor, similar to those found from writing expressively about a trauma. It is believed that people experience emotion as a result of the status of their goals, as a feedback system which tells them whether they are on the right track or are moving away from the path that will lead them to goal attainment. Therefore, emotional disclosure allows an individual to make sense of the event, explore sources of emotion, clarify goals and get the self-regulation feedback system back on track (King, 2002).

If self-regulation is the mechanism by which experimental disclosure works, writing about a positive event should produce the same benefits as writing about the negative. The self-regulation theory has received support; particularly for reducing symptoms of depression, however, to date there are few studies (Frattaroli, 2006).

6.4.5 Exposure theory

Exposure theory argues that the expression of thoughts and feelings about an upsetting event is similar to exposure therapy and learning theory (Sloan & Marx,

2004). Research has suggested that the written disclosure paradigm may allow an individual to be exposed to aversive stimuli that had been previously avoided, and that the repetition of confronting and describing their thoughts and feelings about their traumatic experience, should lead to these thoughts and feelings being eliminated (Lepore & Smyth, 2002; Sloan & Marx, 2004).

A number of studies have explored changes in intrusive thoughts and avoidance as outcome measures of the written disclosure paradigm, but findings have been mixed. Whilst some studies indicated reductions in intrusive thoughts (Klein & Boals, 2001; Schoutrop, Lange, Hanewald, Davidovich & Salomen, 2002) others found no effects (De Moor et al., 2002; Lepore, 1997; Stroebe, Strobe, Scut, Zech & van den Bout, 2002). A number of explanations may account for these mixed results; some studies have used small sample sizes (e.g. Gidron, Peri Connolly & Shaley, 1996; Walker, Nail & Croyle, 1999) which may not be surprising as the attrition rate for exposure therapy is relatively high at 80-90%; and some studies used only a single writing session (Lepore, 1997; Smyth, True & Souto, 2001), which may have not been long enough to clear negative emotional thoughts. Furthermore, studies have varied in their length of follow-up period which may account for the difference in efficacy. To date, the evidence provides inconsistent support for exposure theory.

Several theories have been discussed above, although there is some data to support them, there is contradictory evidence for each theory, suggesting that a single theory may not fully account for the effects of written emotional disclosure. Sloan and Marx (2004) suggest that it may be possible that one mechanism accounts for the initial changes in health and psychological status while another mechanism accounts for the maintenance of changes. However, regardless of the underlying mechanisms, evidence shows that expressive writing is malleable to differing situations and participants (Smyth & Pennebaker, 2008), making it a promising intervention for use with patient groups going through difficult and varied health-related experiences.

6.5 A scoping study of expressive writing studies

Scoping studies enable a researcher to "map the key concepts underpinning a research area and to highlight the main sources and types of evidence available"

(Mays, Roberts & Popay, 2001, p. 194). An advantage of a scoping study is the ability to explore the range and nature of studies in a research area and to identify any gaps in the literature. As there are no set procedures for scoping the literature, a scoping study using Arksey and O'Malley's (2005) framework which includes five stages was conducted to explore the available expressive writing studies. The scoping study started by identifying the research question, which was 'What is known from the existing literature about the availability and effectiveness of expressive writing studies?'.

To provide a comprehensive review of the available expressive writing studies, no date limits were set and in 2014 electronic searches were conducted on the following databases: Allied and Complimentary Medicine Database (AMED), Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index (BNI), Campbell Collaboration, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, PsychINFO, Science Direct. For each database specific MeSH terms were identified for the broad term; expressive writing/emotional disclosure. Inclusion criteria consisted of studies published in English, which focused on the health benefits of expressive writing, however, to maintain an inclusive approach, the studies included were not restricted to a clinical population. Hand searches were also conduced of key journals, in case any studies were missed from the database searches. The researcher also contacted experts in the field, to explore any unpublished expressive writing/emotional disclosure studies. Study data was then entered onto a 'data charting form' using Microsoft Excel, information included; the author(s), year of publication, intervention type, study population, methodology and results (see Appendix 19 for a list of the expressive writing studies identified). A noteworthy point is that a scoping study is not as rigorous as a systematic review, it provides a narrative account of the existing literature, it does not aim to assess the quality of evidence unlike a systematic review (Arksey & O' Malley, 2005). A narrative account of the findings from the scoping study is presented below, comparisons across the studies are provided and gaps in research are highlighted.

6.6 Expressive writing studies

Through the scoping study, twenty nine expressive writing studies were found. A critique of research on emotional disclosure studies is that they were conducted with healthy college/university students (Baum & Rude, 2013; Knowles, Wearing & Campos, 2011; Lepore, 1997; O'Connor & Ashley, 2008; O'Connor et al., 2010; Poon & Danoff-Burg, 2011; Sloan, Feinstein & Marx, 2009). Participants were required to go to a laboratory for three to five sessions of 15-20 minutes each, during which they were randomly assigned to either write expressively about a stressful/traumatic experience or write without emotion about a neutral topic (Frattaroli, 2006). Some of the benefits of emotional disclosure studies include improvements in immune function (Pennebaker, Kiecolt-Glaser & Glaser, 1988), reduction in health centre visits (Pennebaker et al., 1990), reduction in absenteeism rates from work (Francis & Pennebaker, 1992) and decrease in self-reported upper respiratory problems (Greenberg, Wortman & Stone, 1996). Moreover, although most people find experimental disclosure to be a positive experience, some individuals do report that they find the experience to be unenjoyable or unhelpful (Frattaroli, 2006).

Disclosure studies soon progressed from college/university samples to community members, including those with rheumatoid arthritis, asthma and migraine headaches. The first study of this kind was published by Kelley, Lumley and Leisen (1997) who explored the effects of experimental disclosure on arthritis-related problems in rheumatoid arthritis patients. Those who wrote expressively about traumas compared with non-writing controls reported less physical dysfunction in the weeks following writing. Research findings with medical patients include a reduction in cancer-related doctor visits for breast cancer patients assigned to an experimental disclosure group (Stanton et al, 2002). Emotional disclosure has more recently been used with individuals with psychiatric and psychological problems, the results from which are mixed; Russ (1992) found that disclosure improved psychological and physical health for college students who had a history of anxiety. Moreover, some studies have found null effects for disclosure, such as studies with former psychological

patients (Bird, 1992), participants with negative body image (Earnhardt, Martz, Ballard & Curtin, 2002) and those with suicidal tendencies (Kavoc & Range, 2002).

Imrie and Troop (2012) carried out a pilot study involving a self-compassion instruction in an expression task to identify the possible effect on psychological outcomes using participants from a day hospice. All participants in the experimental group reported an increase in self-soothing, at one week follow-up, whereby they were able to help themselves to reduce negative feelings and promote positive feelings, whereas those in the control group reported a decrease in self-soothing. However, there were a number of limitations of the study which include a small sample size, so there were not enough participants to carry out meaningful inferential statistical analysis. The study demonstrates that a simple modification to standard expressive writing instructions can improve self-soothing and self-esteem.

6.6.1 Expressive writing studies with breast cancer patients

A number of expressive writing studies have been conducted with breast cancer patients (Craft, Davis & Paulson, 2013; Gellaitry, Peters, Bloomfield & Home, 2010; Gripsrud, Brassil, Summers, Søiland, Kronowitz, & Lode, 2016; Laccetti, 2007; Low, Stanton & Danoff-Burg, 2006; Low, Stanton, Bower & Gyllenhammer, 2010; Stanton et al., 2000; Stanton et al., 2002; Przezdziecki, Alcorso & Sherman, 2016; Przezdziecki & Sherman, 2016). Merz, Fox and Malcarne (2014) conducted a systematic review of experimental trials of cancer patients who participated in an expressive writing intervention, nine of the thirteen studies included in the review were with breast cancer patients. Several main effects for expressive writing were found, including sleep, pain and general physical and psychological symptoms. Stanton et al. (2002) asked breast cancer patients to either write about their deepest thoughts and feelings regarding breast cancer (expressive writing group), positive thoughts and feelings regarding breast cancer care (benefit finding group) or a control group. It was found that both the emotional expression group and the benefit finding group made significantly fewer medical visits for cancer-related illness at a three month follow-up than the control group. Moreover, female participants commented that expressive writing was helpful to them personally. Przezdziecki and

Sherman (2016) found that a self-compassionate writing intervention led to reduced levels of negative affect and an increase in a self-compassion in breast cancer survivors with body image-related issues. Furthermore, Craft et al (2012) found that early breast cancer survivors who wrote about the trauma of their diagnosis or facts about their disease showed greater improvement in their quality of life than those who did not write or those who wrote about a self-selected traumatic event. However, the generalisability of the findings of this study are limited because it was conducted with a convenience sample.

Extensive research has demonstrated that social support is important for positive adjustment and decreased psychological distress, specifically, the perceived match/mismatch between wanted and perceived support is crucial with 'mismatch' being related to poorer psychosocial adjustment (Reynolds & Perrin, 2004). A study by Gellaitry et al (2010) found significant effects of an expressive writing intervention on perceptions of social support in a cohort of women who had recently completed treatment for early stage breast cancer. Women who wrote about their experiences of having breast cancer were more satisfied with the support that they were receiving from significant people in their lives compared to those in the control group. Recent research found that a self-compassion based writing activity was found to be acceptable by breast cancer survivors and health professionals (Przezdziecki et al, 2016).

Low et al (2010) explored the effects of a home-based expressive writing intervention among metastatic breast cancer patients. The findings are inconsistent with previous trials conducted with early stage breast cancer patients and no main effects were found. However, this is the first randomised control trial to examine the effects of expressive writing with metastatic breast cancer patients.

6.7 Health benefits of expressive writing

Expressive writing studies have found physical improvements in clinically relevant outcomes including reduction in blood pressure in those whose blood pressure is elevated (Beckwith McGuire, Greenberg & Gevirtz, 2005), improved immune function (Esterling, Antoni, Fletcher & Margulies, 1994; Pennebaker et al., 1988;

Petrie, Booth, Pennebaker & Davidson, 1995), faster wound healing following biopsy (Weinsman, Ebrecht, Scott, Walburn, & Dyson, 2008), improvements in patients with severe asthma or rheumatoid arthritis (Broderick et al, 2004) and reduced health problems (Greenberg & Stone, 1992; Pennebaker & Beall, 1986). Moreover, King and Miner (2000) highlight that writing about the benefits of a traumatic event was just as beneficial in reducing illness-related doctor's visits as the more traditional disclosure paradigm. With regards to the effects of expressive writing on psychological health, it has been found that some patient groups reported improvements in well-being (Broderick, Junghaenel & Schwartz, 2005), increased positive affect (Normal, Lumley, Dooley & Diamond, 2002), and reductions in depressive symptoms (Bodor, 2002).

It is believed that the traditional writing paradigm has become less effective, possibly because the idea of writing about stress and worries has become a common activity, particularly in western countries, alongside a cultural shift towards being more open and emotionally expressive (Smyth & Pennebaker, 2008). For example, social networking sites are now common and provide 'normal' opportunities for written forms of emotional disclosure.

6.8 Analysis of the use of language in expressive writing

The cognitive-processing theory has been outlined above in section 6.4.2. It has also been suggested that the use of cognitive mechanism words in describing an event may indicate a process of reappraisal, suggesting participants are changing from not processing to actively processing an event. Using a computerised text analysis program, Linguistic Inquiry and Word Count (LIWC) (Pennebaker et al., 2001), researchers have found that increasing use of cognitive mechanism words (e.g. causal words such as 'because' or 'cause' and insight words such as 'think' or 'consider') is linked to greater health improvements (Pennebaker & Francis, 1996; Pennebaker, Mayne & Francis, 1997). Increases in cognitive mechanism words have also been associated with improvements in posttraumatic psychological growth (Ullrich & Lutgendorf, 2002), improved immune function (Petrie et al., 1995), and

fewer negative changes brought about by being HIV + (Rivkin, Gustafson, Weingarten & Chin, 2006).

A study by Lee and Cohn (2010) used Pennebaker's LIWC program to gain an insight into the coping strategies of participants in their expressive writing intervention. It was found that participants who used proportionally more insight-related words in their writing samples scored lower than other participants on two of the three scales assessing emotion-focused coping. These findings provide tentative support that emotion-focused coping inhibits the use of insight when adults think about stressful experiences. Also, participants who used more essay words denoting negative emotion displayed a tendency to score lower on the problem-focused coping scale derived from COPE. This provides support that problem-focused coping inhibits the use of negative emotion words when thinking about stressful experiences. Moreover, Laccetti (2007) explored the relationship between patterns of word use in expressive writing and QOL scores at baseline and at three month follow-up in women with metastatic breast cancer. It was found that women who used more positive-affect words demonstrated higher scores on the emotional well-being subscale three months after the writing intervention compared to those who used more negative-affect words.

6.9 Factors used in expressive writing studies

This section discusses the factors that have been included in previous expressive writing studies.

6.9.1 Moderators and mediators

6.9.1.1 Alexithymia

Alexithymia is a personality construct which has been highlighted as potential moderator of the health benefits of expressive writing (Baikie, 2008). Although individuals with alexithymia are not characterised by an absence of emotional experience, they do find it difficult to identify and label their feelings (Taylor, Bagby & Parker, 1997) and express them verbally (Ashley et al., 2011). Engaging in

expressive writing requires an individual to be able to identify and express their feelings linguistically. The majority of studies have found that individuals lower in alexithymia derive greater benefits from expressive writing (Lumley, 2004). However, some studies have found that higher alexithymia scores are associated with better disclosure outcomes (Solano, Donati, Pecci, Persichetti & Colaci, 2003). Ashley et al (2011) found no main effects of a writing intervention on depressive or anxious symptoms but did find that alexithymia moderated the efficacy of expressive writing, as lower scores on alexithymia were associated with improved depressive and anxiety symptoms at follow-up in the positive and control writing conditions but not in a stress writing condition.

6.9.1.2 Individual differences

Individual differences among participants may account for some of the differences in the effect of emotional disclosure. Western culture typically discourages men from expressing emotion, therefore men may benefit more because this paradigm provides them with a context to express themselves that they normally would not have (Frattaroli, 2006). This can also be extended to ethnic groups who have a less expressive culture and to those who have an emotionally inhibited personality.

The effectiveness of expressive writing has been found to vary according to coping style. Cameron and Nicholls (1998) proposed that pessimists may use expressive writing as a means of ruminating on a problem and avoiding the pursuit of effective coping strategies, whilst optimists may use it as a means of gaining insight into a problem and developing effective coping strategies. A study of breast cancer patients supports the claim that individual differences influence the efficacy of expressive writing interventions. Stanton et al, (2002) assess the coping style of each participant using three subscales on the COPE measure and found that participants who displayed a non-avoidant coping style benefited more from the expressive writing intervention than did those who displayed an avoidant coping style. However, Miller and Cohen (2001) found that individuals with avoidant coping styles may benefit more than other participants from expressive writing.

In summary, research suggests that individuals who have difficulty feeling or expressing their emotions to others are more likely to benefit from writing, however to date there is no clear picture of whether personality or individual difference dimensions may moderate expressive writing (Smyth & Pennebaker, 2008).

6.9.2 Outcome variables

A number of studies (i.e. Pennebaker & Francis, 1996; Sloan & Marx, 2004) have relied on GP visits as the dependent variable, but many individuals do not visit a GP even when they are unwell. The exclusion of additional outcome measures limits researchers' ability to determine whether physical health complaints and visits to a GP may actually be an indication of depression or perhaps a history of trauma, therefore, it is imperative that studies employ psychometrically sound self-report measures of psychological functioning as well as a measure of physical functioning (Sloan & Marx, 2004).

6.9.3 Writing instructions

The instructions developed by Pennebaker and Beall (1986) allow participants to choose their writing topic, whereas some studies have directed the participant to write about particular issues. Smyth's (1998) meta-analysis of the available literature indicated that the instructions to write about current traumas resulted in a higher mean effect size for outcome than instructions to write about past traumas.

6.9.4 Number and duration of writing sessions

Typically, studies include three writing sessions (Batten, Follette, Hall & Palm, 2002; Esterling et al., 1994; Richards, Beal, Seagal & Pennebaker, 2000; Smyth, Stone, Hurewitz & Kaell, 1999), however some have used one (Greenberg et al., 1996; Lepore, 1997), four (Greenberg & Stone, 1992; Park & Blumberg, 2002; Pennebaker & Beal, 1986; Pennebaker et al., 1988), five (Schoutrop et al., 2002; Spera, Buhrfeind & Pennebaker, 1994) or seven sessions (Stroebe et al., 2002).

There has been recent debate over how long one should write in order to benefit from it. The majority of expressive writing studies ask participants to write for 15-20 minutes a day for 2 or 3 consecutive days, but this time period has been driven by convention rather than empirical evidence and few studies have sought to identify the minimum writing period required to benefit. Although the original session by Pennebaker and Beall (1986) used a 15-minute session, most studies have used 20-minute sessions and some have even used 30 (Greenberg et al, 1996) or 45-minute sessions (Schoutrop, Lange, Brosschot & Everaerd, 1997). A study by Burton and King (2008) instructed participants to write for two minutes each day for two days. Participants were found to gain health benefits from the two minutes of writing but this meant they were often cut off in the middle of thought. The first meta-analysis on expressive writing by Smyth (1998) found that duration was unrelated to writing benefits. Frattaroli's (2006) meta-analysis found that writing sessions longer than 15 minutes tended to show a larger effect than sessions less than 15 minutes. However, the meta-analysis employed studies which included physically and psychologically healthy participants. Consistent with both the cognitive and exposure theories of expressive writing, the number and duration of the writing sessions may be important, as only a few sessions that are short in duration may not be adequate for cognitive reframing and/or elimination of negative emotions.

6.9.5 Time between writing sessions

The spacing between writing sessions also seems to be flexible; research has found that 1 hour of intensive writing produced similar physical health benefits to the traditional 3-days, although students perceived the writing as less helpful in this shortened duration (Symth & Pennebaker, 2008). The meta-analysis by Smyth, Hockemeyer and Tulloch (2008) suggests that if the days where people engaged in expressive writing were spread out then the effects may be stronger, however research has failed to support this idea (Sheese, Brown & Graziano, 2004). A number of studies have conducted the writing sessions on consecutive days, although a few studies have spaced out the sessions over one (Esterling et al, 1994, de Moor, 2002), two (Schoutrop et al, 1997) or three weeks (Stanton et al, 2002). Smyth's (1998) meta-analysis indicated that studies that used a longer period of time between

sessions were associated with a higher effect size. However, this finding was based on a limited number of studies, making the interpretations of this data tentative. Therefore, there does not appear to be a clear indication that a longer time period between sessions is associated with greater benefits than writing sessions conducted on consecutive days.

6.9.6 Follow-up

Researchers have varied the time to follow-up such that they range from immediately following the last writing session to 6 months later. The variation of the follow-up period may explain some null findings (Batten et al., 2002; Stroebe et al, 2002) as it may be the case that any beneficial effect obtained through written disclosure may disperse after a few months (Sloan & Marx, 2004). A number of studies have included multiple follow-ups; however all of these studies have collapsed the multiple follow-up visits in order to compute a single follow-up visit score used in subsequent analyses (de Moor et al, 2002; Smyth, True & Souton, 2001; Walker et al., 1999). This approach does not allow for an examination of whether the beneficial effects of expressive writing are sustained. It is important to note that that some studies find increases in negative outcomes in the short term before the beneficial effects emerge in the medium to longer term.

This section has highlighted the different factors which previous expressive writing interventions have included. Expressive writing studies can vary with regards to their design, including the length of the writing sessions, the time between writing sessions. The following sections will discuss the feasibility and acceptability of an adapted expressive writing intervention for breast cancer patients affected by treatment-related hair loss.

6.10 Justification for the use of an expressive writing intervention to support breast cancer patients affected by treatment-related hair loss

As outlined above, a sizeable body of research has shown expressive writing can offer benefits in physical health and psychological wellbeing (Pennebaker et al, 1997), which is important for this patient group given that breast cancer patients can

experience an increase in appearance-related distress and decrease in QOL over time, as found in the quantitative HeadStrong service evaluation (chapter 5) and previous published literature (see chapter 1). Self-administered interventions offer a number of benefits not only to patients but to healthcare providers, as highlighted above. A study by Gripsrud et al (2016) highlighted the appropriateness of an expressive writing intervention for breast cancer patients, as it enables individuals to process their feelings and release cognitive and emotional worries. Whilst expressive writing interventions have been used effectively with breast cancer patients, including their ability to address body image issues in breast cancer survivors (Przezdziecki & Sherman, 2016), they have not been used with a specific focus on hair loss. Given the complexity of the personal impact of a cancer diagnosis and treatment, it is important to consider specific stressors (e.g. hair loss) and explore ways of helping patients (see chapters 1 and 4 for an in-depth discussion of the personal impact of a breast cancer diagnosis and the side effects of treatment).

The systematic review and HeadStrong service evaluation highlighted the importance of interventions being delivered soon after a cancer diagnosis and prior or soon after individuals have started to lose their hair. The systematic review also highlighted the importance of enabling participants to express their concerns (see section 2.4.10). A number of participants in the qualitative study (chapter 4) spoke about how time and travel were constraining factors on their attendance at support groups, and others stated that they preferred interventions that are one-to-one rather than with other people, which supports the same finding from the systematic review. Also, the quantitative HeadStrong study (chapter 5) highlighted the importance of re-gaining a sense of control. Whilst the HeadStrong service was found to go some way to increase patients' confidence around hair loss and the use of headwear, camouflage alone was found to be insufficient in helping patients to manage all the challenges they face. As previously highlighted in chapters 4 and 5, individuals want different support depending on the specific concerns they are facing at any particular point in time. It is imperative that patients are equipped with a range of strategies to help them to manage all aspects of hair loss, rather than relying solely on one strategy, i.e. camouflage. Therefore, Pennebaker's expressive writing intervention was deemed appropriate in response to what participants said they wanted in the

previous studies, in order to help support breast cancer patients with their thoughts and feelings in relation to treatment-related hair loss.

During the planning stages of the research, the researcher attended several meetings at the Bristol Haematology and Oncology Centre (BHOC). These included separate meetings with three of the Breast Consultants, the Head of the Clinical Trials Unit, a Clinical Psychologist and the Head of the Chemotherapy Unit. The researcher also presented the proposed study at a research forum at BHOC and gathered feedback from the health care professionals in attendance, all of which was invaluable in helping to guide the present study. Additionally, the researcher attended various international and national conferences throughout the program of research, providing the opportunity to discuss the plans for the expressive writing study with different audiences and to receive invaluable feedback (see appendix 20 for a comprehensive list of where the research has been discussed).

6.10.1 Justification for a feasibility study

As highlighted in section 3.1.1, the MRC framework guided this research. The framework highlights that once the need for an intervention has been established, it is important to design and evaluate the effectiveness and feasibility of an intervention prior to its wider implementation. The term 'feasible' has been used to describe whether an intervention is capable of being carried out (Hagen, Biondo, Brasher & Stiles, 2011). An important aim of a feasibility study is to determine important parameters for a larger main study and to test whether a larger study is likely to be successful in testing the intervention (Hagen et al., 2011; Arain, Campbell, Cooper & Lancaster, 2010). Therefore, it was important to conduct a feasibility study of an expressive writing intervention for breast cancer patients who are affected by treatment-related hair loss, to establish factors including whether patients were willing to be randomised, willingness of health professionals to recruit patients and to determine response rates (Arain et al., 2010).

6.11 Research questions:

This study set out to answer the following questions:

- Is an adapted expressive writing intervention feasible for breast cancer patients with treatment-related hair loss?
    - Is the timing of the intervention (i.e. for patients newly referred for chemotherapy) feasible?
    - What is the attrition rate?
    - Did patients take up the offer to take part in the study?
    - Did participants find the writing task useful?
- Are the measures which have been informed by previous literature and the ARC framework appropriate to detect changes and are they suitable for use in a larger RCT study?

6.12 Method

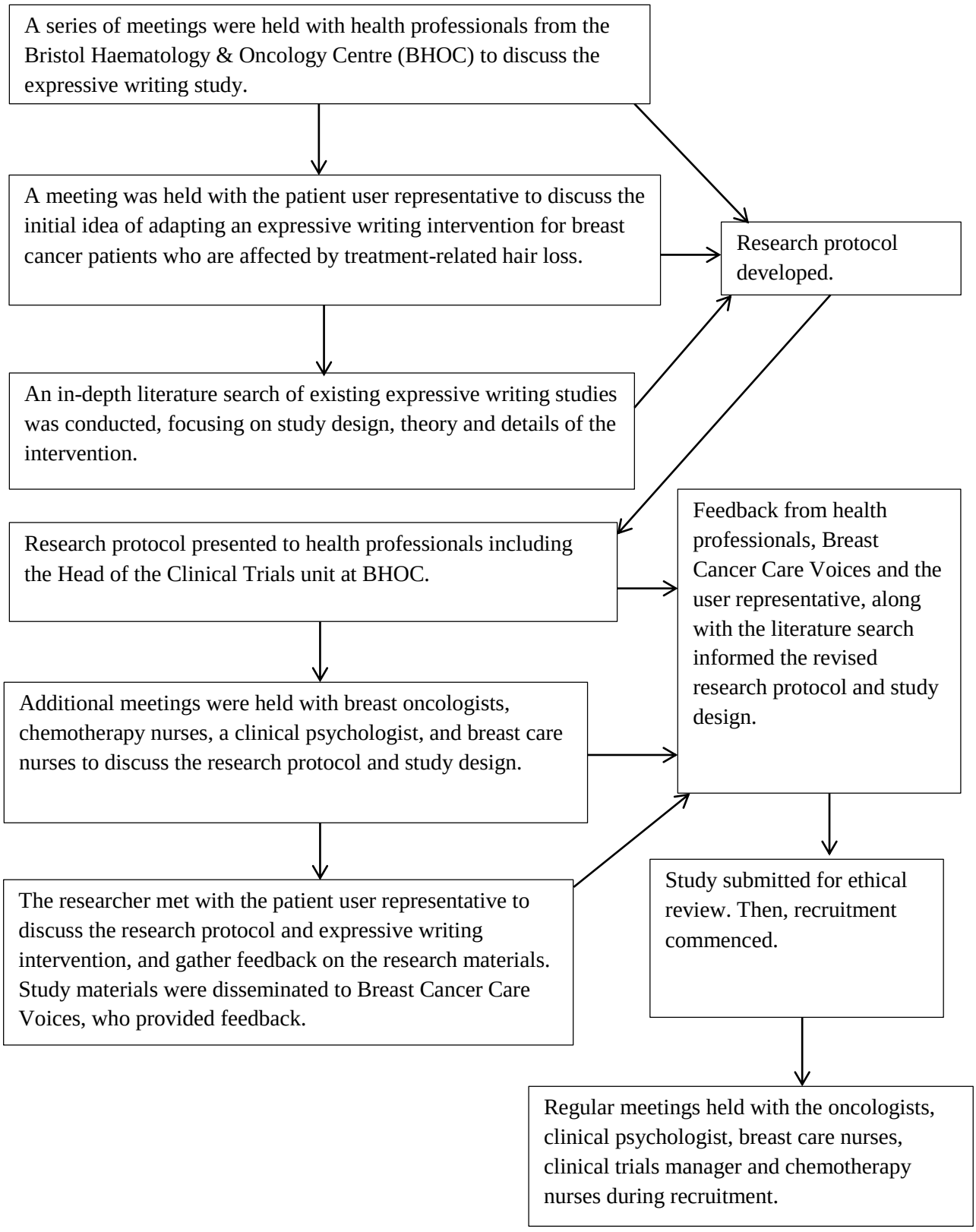


Figure 12. Flow chart highlighting the development of the expressive writing study

6.12.1 Design

This study was a two group comparison with participants randomly allocated to either an intervention or control condition. Measures were taken pre-intervention and again at 2 week, 1 month and 3 month follow-up. This 2 x 4 mixed design ranks highly in design hierarchy and permits unbiased comparisons for treatment effect and a direct assessment of short-term and long-term changes within the intervention group.

As discussed in section 3.6.2, it is acknowledged that RCTs are not without limitations, including the possibility that they can lead to self-selecting samples and underpowered studies (Campbell et al., 2007; McDonald et al, 2006; Page & Persch, 2013). Also, RCTs have been criticised for "being unable to uncover what is really happening underneath the surface of events and enable findings to be translated to 'real' practice" (Blackwood et al, 2010, p. 512) which reduces the generalisability of their findings. Despite these limitations, an RCT design was deemed appropriate for this study, primarily because they help protect against selection bias (Odgaard-Jensen et al., 2011). It is important to conduct studies that are appealing to the key audience if the research is to have impact – in this instance, policy makers and health professionals who might be in a position to implement any findings from a study of an expressive writing intervention. It is likely that these groups are more familiar with RCTs than with other designs, so might take more notice or put more significance on the findings from a study using this design.

Participants were block randomised to a writing condition using the Sealed Envelope tool (Sealed Envelope Ltd, 2015) which generated a randomisation list using block sizes of 2, 4, and 6; so that the researcher could not predict which group the participants would be randomised to. Random sampling is regarded as the gold standard in sampling methodology (Williamson, 2003). It was a single-blind trial, whereby the participants were blinded to which condition they were in. Block randomisation is commonly used in trials as it reduces bias and confounding since participants have equal probability of being assigned to either the intervention or control group, ensuring an equal number of participants are in each condition (Efird,

2011). The researchers were not blind to randomisation because participants had to be sent the specific writing instructions for their allocated condition.

6.12.2 Questionnaires

Similarly to the previous studies in this thesis, this study was informed by the ARC (2009) framework, demonstrating the importance of a theoretical framework of pre-disposing factors (demographic information, breast cancer information including hair loss status, information and support received) and moderating factors (importance placed on appearance, self-esteem and fear of negative evaluation, alexithymia) in determining psychosocial adjustment to treatment-related hair loss as indicated by relevant outcomes (appearance-related distress, QOL, psychological functioning).

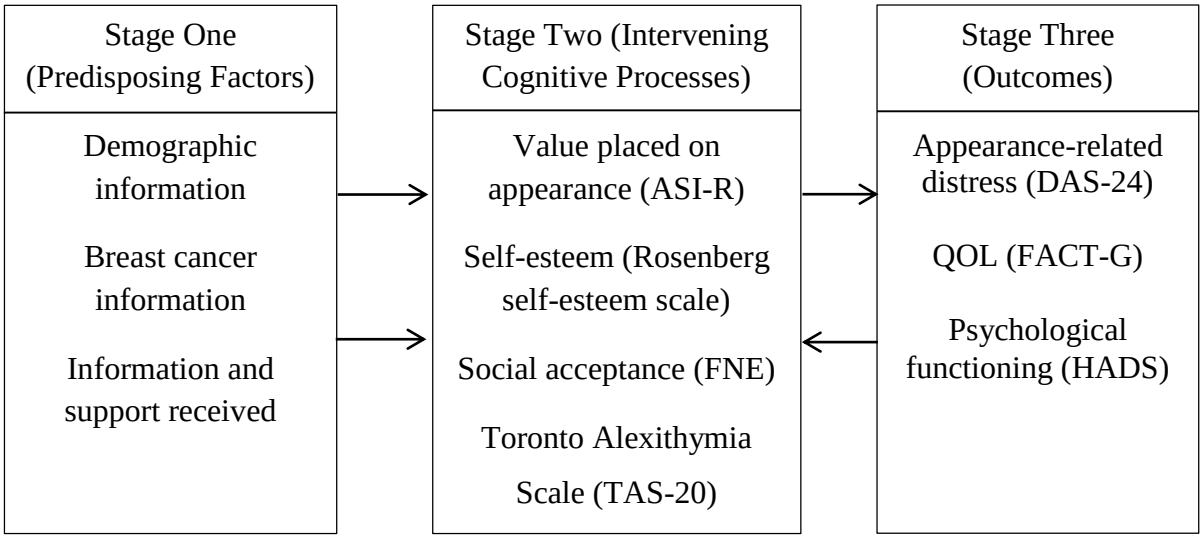


Figure 13. The guiding theoretical framework for the expressive writing study based on the ARC (2009) framework, in Clarke, Thompson, Jenkinson, Rumsey, and Newell. (2013). CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety due to Visible Difference. Figure 3.5, p. 35. (Reproduced with copyright permission from Wiley-Blackwell).

The findings of the previous studies in this thesis and the review of previous expressive writing studies, above, informed the choice of standardised measures, with additional self-constructed items being included if standardised measures were not available. The standardised measures used in the quantitative HeadStrong study

(chapter 5) were found to be acceptable which helped to inform the decision to use them for this study.

The questionnaires were piloted on 10 women who were over the age 18 and not familiar with the research area. Although it took this healthy group no longer than 30 minutes to complete the measures, it was expected that some breast cancer patients who have had at least one cycle of chemotherapy may take slightly longer to complete them if they are affected by chemotherapy-related cognitive impairments (Boykoff, Moieni & Subramanian, 2009; Collins, Mackenzie, Stewart, Bielajew & Verma, 2009; Myers, 2009; Wefel, Lenzi, Theriault, Davis & Meyers, 2004). The questionnaires were available online using Qualtrics, in the hope that it would increase participation, as they can be convenient and easy for respondents to complete (Brindle, Douglas, van Teijlingen & Hundley, 2005; Hunter, 2012; Jones, Murphy, Edwards & James, 2008; Katz, Fernandez, Chang, Benoit & Butler, 2008).

6.12.3 Demographic information

Details including sex, age, ethnicity, educational background, employment status were obtained at baseline (questionnaire 1).

6.12.4 Breast cancer information

Breast cancer information including type of cancer, time since diagnosis and types of surgical and adjuvant treatment(s) received were obtained at baseline (questionnaire 1).

Questions were included at each time point about participants' hair loss status (i.e. whether they had already lost their hair or were anticipating doing so); whether they were receiving any other practical or emotional support such as counselling, and whether they were keeping a diary. It was important to know if people were receiving support or keeping a diary as this may affect the efficacy of the expressive writing intervention (Smyth & Pennebaker, 2008).

6.12.5 Information and support

Participants were asked whether they were happy with the level of information and support that they had received from their GP, consultant, breast care nurse and other support organisations, since perceived satisfaction with support received has been found to impact on psychosocial outcomes (Reynolds & Perrin, 2004).

6.12.6 Standardised measures

The measures used for this study were those used in the quantitative HeadStrong study (see section 5.2 for a justification of their use), with the addition of the Toronto Alexithymia Scale (see below). The same measures were used as they were relevant to both studies, and this would allow direct comparisons of the evaluations of these two very different interventions, if the expressive writing intervention was deemed feasible and subsequently tested.

The measures included in this study were, therefore:-

- Appearance Schemas Inventory - Revised (ASI-R)
- Rosenberg Self-Esteem Scale (RSE)
- Derriford Appearance Scale (DAS24)
- Functional Assessment of Cancer Therapy - General (FACT-G)
- Brief Version of the Fear of Negative Evaluation Scale (FNE)
- Hospital Anxiety and Depression Scale (HADS)
- Toronto Alexithymia Scale (TAS-20)

Alexithymia

The Toronto Alexithymia Scale (TAS-20) (Bagby, Parker & Taylor, 1994; Bagby, Taylor & Parker, 1994) is a 20-item self-report scale. Each item is rated on a 5-point likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with scores ranging from 20 to 100. Higher scores indicate higher levels of alexithymia. TAS-20 assesses three dimensions of alexithymia; difficulty identifying feelings (DIF), difficulty describing feelings (DDF) and externally orientated thinking (EOT). The

three factor structure has been replicated in a number of studies both with clinical and non-clinical samples (i.e. Parker, Taylor & Bagby, 2003; Tsaousis et al., 2010). Good internal consistency and test-retest reliability have been reported in a range of samples (Erni, Lotscher & Modestin, 1997; Loas, Otmani, Verrier, Fremaux & Marchand, 1996; Pandey, Mandal, Taylor & Parker, 1996). It has been widely used within expressive writing studies (i.e. Ashley et al., 2011; Baikie, 2008; O'Connor & Ashley, 2008) and is a reliable and valid measure of the alexithymia construct (Taylor, Bagby & parker, 2003).

6.12.7 User involvement

As previously discussed in chapters 3, 4, 5 and mentioned above, user involvement was included throughout this program of research. In preparation for this study, both the patient representative and members of Breast Cancer Care's Voices reviewed the information sheet, consent form, questionnaires and debrief sheet to check for understanding, clarity and length of the questionnaires. Their feedback enabled the researcher to shorten the length of the questionnaire as it was felt that it was initially too long and to alter the information so that it was tailored to the lay person.

6.12.8 Feasibility data

In order to know whether it would be feasible to conduct a full RCT, study-specific questions included in the 3 follow-up questionnaires enquired as to where participants completed the writing task, their thoughts about it, the extent to which they found it useful and whether they had continued to write since completing the task (see section 6.11 for an outline of the specific questions). Moreover, any feasibility data such as the length of the writing exercise, the writing topic that the participants reported to the researcher regarding the intervention and questionnaires was noted. Feasibility data was also collected from breast consultants, breast care nurses and chemotherapy day unit nurses who helped with recruitment. This included records of the number of women invited to take part and informal feedback from these health professionals. Also, at the end of each questionnaire there was a space for participants to write any comments that they would like to add.

6.12.9 Recruitment

Recruitment took place at the chemotherapy day unit, breast clinics, new patient talks and through poster advertisement (see appendix 21) in waiting rooms at the Bristol Haematology & Oncology Centre (BHOC).

Meetings with several breast consultants prior to commencing the study confirmed that more than 300 early stage breast cancer patients who would meet the study inclusion criteria detailed below receive curative chemotherapy at BHOC each year (25 new patients per month). Recruitment was through a single NHS site as the researcher wanted to be available on site to speak to potential participants face-to-face about the study, which previous research has highlighted as being advantageous in recruitment (Jennings et al., 2014). Meetings were held with chemotherapy nurses, breast care nurses and consultants to build and maintain rapport and regular contact was maintained with them throughout the recruitment period, which is deemed essential when asking health care professionals to identify eligible research participants (McNees et al., 2005; Sears et al., 2003).

In order to increase recruitment, the study was also promoted through a number of alternative routes. Specifically, two support organisations (Breast Cancer Care (who advertised the study on their website and in their quarterly bulletin) and The Haven (who promoted the study at 3 of their counselling centres), the Call for Participants website (www.callforparticipants.com), Mumsnet, Twitter and media coverage following a press release (see appendix 22) and a radio interview (figure 14 includes full recruitment details).

Unfortunately, uptake to the intervention was slower than anticipated; therefore, in addition to the various recruitment strategies outlined above, recruitment was extended from the initially planned 6 months to 12 months. The recruitment challenges faced in this study are discussed fully in the discussion of this chapter (section 6.13) and chapter 7.

6.12.10 Participants

6.12.10.1 Inclusion criteria

Women over 18 years of age, who had received a diagnosis of breast cancer, had received at least one cycle of curative chemotherapy and as a result were experiencing hair loss (current and or/expected hair loss) were eligible to take part.

6.12.10.2 Exclusion criteria

Individuals who were unable to complete a written intervention and the questionnaires in English, or were unable to physically write by hand or word processor, for a 20-minute period were not eligible to take part. Women who were receiving palliative care or who were currently participating in another psychosocial intervention study were also excluded.

6.12.10.3 Sample size

Since this was a feasibility study, the intention was not to look for effectiveness of the intervention. However, it was still considered useful to explore the possible effectiveness of the intervention at this preliminary stage. A statistician at the University of the West of England (Dr Paul White) therefore helped to develop the sample size calculations. Based on a priori calculation using the Derriford Appearance Scale (DAS-24), a sample size of n = 50 per group would ensure at least 90% power for detecting a medium sized interaction effect and would have in excess of 90% power for a within group investigation of change using the paired samples t-test for detecting a clinically relevant medium sized effect (Cohen's d = 0.5) using contemporary levels of significance (alpha = .05) in a two-sided test.

6.12.11 Approvals

NHS ethics approval was obtained from the NRES Committee South West – Frenchay (see appendix 23). R&D approval was also obtained from University Hospitals Bristol and ethical approval from the Faculty of Health and Applied Sciences Research Ethics Committee at the University of the West of England

(UWE), Bristol (see appendix 24). Also, the study was adopted onto the NIHR Clinical Research Network (NIHR CRN) portfolio.

6.12.12 Data collection

Potential participants were identified by breast consultants, chemotherapy day unit nurses and breast cancer nurses from the Bristol Haematology & Oncology Centre (BHOC) who handed them a questionnaire pack that included an information sheet (see appendix 25) along with the study invitation letter (appendix 26) which was signed by the consultants, a consent form and the baseline questionnaire (questionnaire 1). Alternatively, health professionals identified and initially spoke to eligible patients about the study, before introducing them to the researcher who was available in clinic to discuss the study and answer any questions they may have. Potential participants who wished to take part were asked to complete and return the consent form (appendix 27) and baseline questionnaire using the prepaid envelope provided. The information sheet included the researcher's details as a point of contact for any queries. The questionnaires were also available online (using the secure online data collection site Qualtrics) if participants preferred to complete them in this way (see figure 14 for a flow chart of the data collection process).

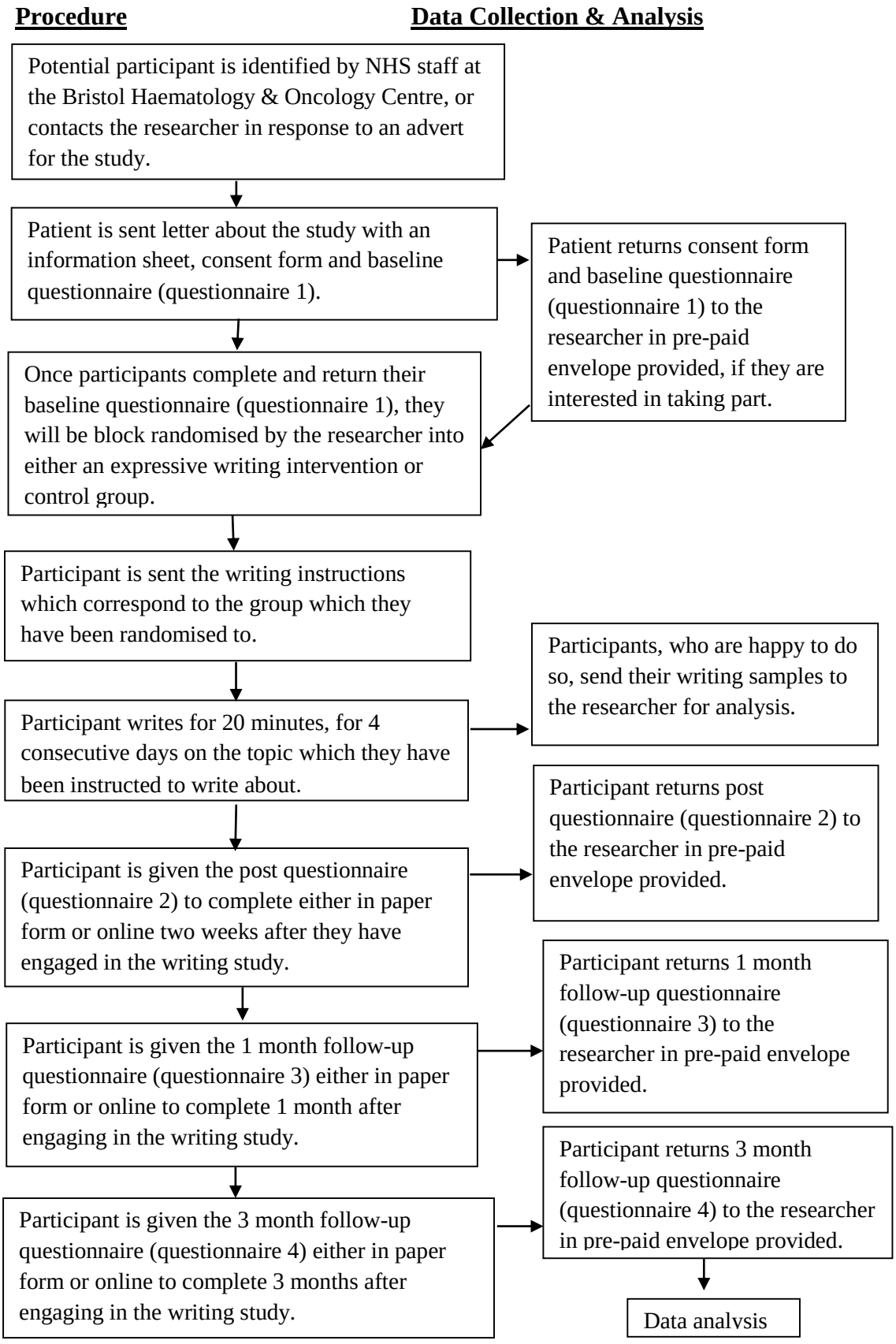


Figure 14. Flow chart of the data collection process for the expressive writing study

Women who consented to take part and completed the baseline questionnaire (appendix 28) were block randomised by the researcher using the Sealed Envelope (2015) tool, as discussed above in section 6.12.1, into one of two conditions; intervention or control group. Once participants completed and returned questionnaire 1 to the researcher they were sent the relevant writing instructions, either by post or email, depending on their preference indicated on the consent form.

Participants were encouraged to write in the week prior to their next cycle of chemotherapy, this was based on advice received from the health professionals at BHOC, including consultant oncologists who had extensive experience of working with breast cancer patients. The initial information sheet and consent form gave them the option of sharing their writing with the research team, in order for it to be read and analysed. Participants were invited to send what they had written to the researcher for two reasons; first, to check they had adhered to the writing instructions and second, to see what they had written about. Participants who gave consent for this posted their writing to the researcher using the prepaid envelope which was provided.

Participants were asked to indicate on the consent form whether they would prefer to receive the writing instructions and follow-up questionnaires (see appendix 29 for a copy of the 2 week follow-up expressive writing questionnaire, appendix 30 for the 1 month follow-up questionnaire and appendix 31 for the 3 month follow-up questionnaire) by post or email and were subsequently sent a pre-paid envelope or an email with a link to the online questionnaires, as appropriate.

6.12.13 The intervention

The intervention (expressive writing) group were instructed to write about their thoughts and feelings around hair loss for a period of 20 minutes for four consecutive days, since this has been the optimum timing favoured by many previous expressive writing studies. In line with the expressive writing intervention developed by Pennebaker, participants were instructed to let go, not to worry about grammar or sentence structure and to explore their deepest thoughts and emotions. Specifically, participants randomised to this group were asked to write about any

aspect of their experience of treatment-related hair loss which they found difficult to share with others, as previous discussed in section 6.4.1. Expression of thoughts and feelings about an upsetting event has been found to be beneficial including improvements in both psychological and physical health (Frattaroli, 2006). The present expressive writing intervention was adapted, so that participants were asked to write about their hair loss in relation to other parts of their lives, including how it related to their family life, relationships with their partner, children, parents and friends, daily activities, hobbies or work, and how they had tried to manage the situation and their feelings about it (see appendix 32). It was important to adapt the present expressive writing intervention as the focus of the study was to explore whether an expressive writing intervention is suitable for breast cancer patients who are affected by treatment-related hair loss, therefore, it was important that the writing topics were around hair loss. For each of the four days, participants were instructed to focus on a different aspect of hair loss:

- **Day one-** deepest thoughts and feelings about hair loss
- **Day two-** hair loss in relation to appearance
- **Day three-** hair loss in relation to life
- **Day four-** managing treatment-related hair loss.

A few expressive writing studies have used a no writing control group (i.e. Craft et al., 2013). However, to stay in line with Pennebaker's traditional expressive writing paradigm and other expressive writing studies with breast cancer patients, a writing control group was used. Careful consideration was given to deciding on a suitable control topic. Previous expressive writing studies with cancer patients have used what were deemed to be a variety of neutral control topics including what they had done the previous day (Mosher, Johnson, Dickler, Norton, Massie & DuHamel, 2013), facts about cancer and treatment (Low et al., 2006; Stanton et al., 2002) or daily activities (Zakowski, Ramati, Morton, Johnson & Flanigan, 2004). Additional control topics used by previous expressive writing studies with non-cancer populations include time management (Arigo & Smyth, 2012; Gortner, Rude & Pennebaker, 2006; O'Connor et al, 2010; O'Connor, Allen & Kaszniak, 2005; Sloan

et al, 2009), describing their home (Danoff-Burg, Mosher, Seawell & Agee, 2010) or describing landscapes pictures (Ashley et al., 2011). However, despite previous expressive writing studies with cancer patients often focusing on time management, discussions with the supervisory time including a clinical psychologist with extensive experience of working with breast cancer patients and advice from the patient representative for this program of study indicated that time management was not a 'neutral' topic for cancer patients who's time typically revolves around multiple clinic and treatment appointments. Therefore, a purely descriptive topic was deemed appropriate for the control group and they were instructed to write for 20 minutes a day for four consecutive days about a neutral topic without any emotional expression (See Appendix 33). Specifically, they were asked to describe a different topic each day:

- **Day one –** their home
- **Day two –** the neighbourhood/area they live in
- **Day three –** their town/city
- **Day four –**a place they have recently been to

Once participants had completed the study, they were sent a debrief sheet outlining the aims of the study and explaining the two different writing groups (see appendix 34 for a copy of the debrief sheet).

6.12.14 Analysis

As this was a feasibility study the data and analysis primarily included information about recruitment, response rates and qualitative feedback from patients and health professionals. Secondly, the numerical data collected through the baseline, 2 week follow-up, 1 month follow-up and 3 month follow-up questionnaires was analysed using the statistical program SPSS. The data from the open-ended questions was also examined.

6.13 Results

Recruitment and retention

As mentioned previously, the expressive writing study was promoted through a number of avenues; figure 14 includes the recruitment details. The majority of patients identified and assessed for eligibility were through the Bristol Haematology and Oncology Centre (BHOC) (N = 43). Call for Participants and Twitter were particularly advantageous in promoting the study, with 741 study page views on Call for Participants and 395 views on Twitter. Patients who heard about the study through an alternative avenue to BHOC informed the researcher of how they heard about it, allowing the researcher to collate this information. Ten participants consented to take part in the study, nine completed the baseline questionnaire. Of these nine participants, five completed the writing exercise and four completed the 2 week, 1 month and 3 month follow-up questionnaires.

6.13.1 Summary of the recruitment strategy

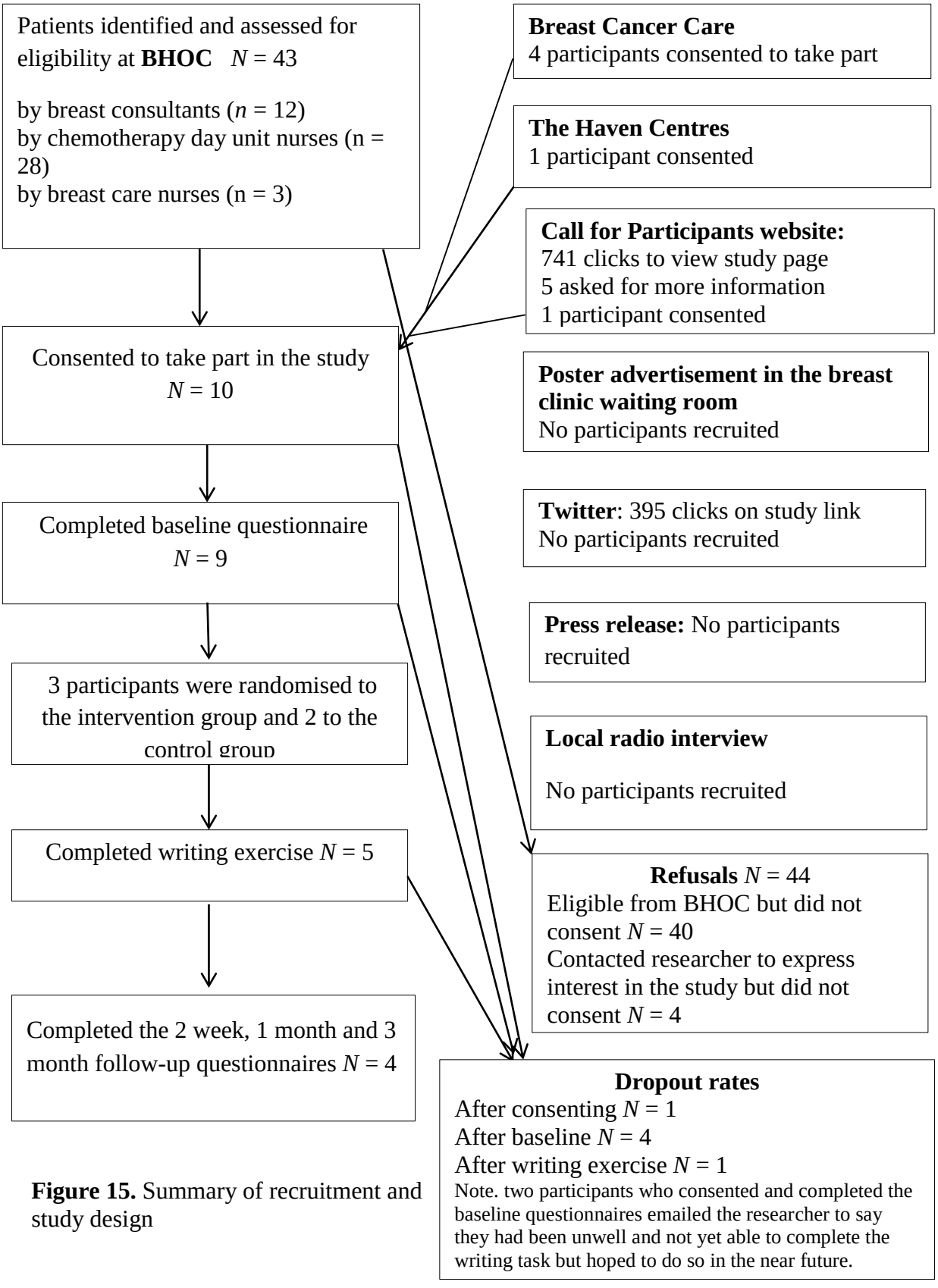


Figure 15. Summary of recruitment and study design

Note. It was not possible to assess the eligibility of the individuals who clicked on the study link on Twitter and Call for Participants if they did not contact the researcher for further information

6.13.2 Demographic information at baseline

Nine female breast cancer patients completed the baseline questionnaire. All were within the age range 34-55 years (M = 44.89, SD = 7.82). Eight (88.89%) had already experienced hair loss at baseline, with most participants starting to lose their hair 2 weeks after starting chemotherapy. Table 13 presents further demographic information. Four (44.44%) participants reported being very upset by their hair loss. Three (33.33%) were receiving support from their breast cancer nurse or the Penny Brohn Centre. Four participants reported keeping a diary, the reasons for which included:

- to monitor the side effects of chemotherapy
- to record the physical and emotional impact of each chemotherapy session so as to report the impact of treatment to oncologists
- a friend suggested it
- to enhance motivation and positive thinking

Table 13. Demographic Information

	Participants (n = 9)
Age	
Mean (*SD*) (range) in years	44.89(*7.82*) (34-55)
Ethnicity	n (%)
White	8 (88.89)
White-Caribbean	1(11.11)
Employment status	n (%)
Working full-time	3 (33.33)
Working part-time	1 (11.11)
Housewife	2 (22.22)
Self-employed	1 (11.11)
Unemployed	2 (22.22)
Cancer type	n (%)
Breast	9 (100)
#Time since diagnosis	
Mean (range) in months	30.02 (1.5 months-15 years 11 months)
Treatment received	n (%)
Chemotherapy	9 (100)
Surgery	7 (77.78)
Radiotherapy	3 (33.33)
Hormone therapy	1 (11.11)
***Experience of hair loss**	n (%)
Yes	8 (88.89)
No	1 (11.11)
$Time to hair loss	
Mean (range) in days	19 (5-49)
~Extent of hair loss	
Mean (range)	6.78 (0-10)

Notes: Figures do not always equal 100 as some participants received more than one type of treatment.

*Experience of hair loss relates to whether participants had lost any of their hair.

$Time to hair loss is how long after starting chemotherapy participants started to lose their hair.

~Extent of hair loss relates to the amount of hair loss participants had experienced, rated on a likert scale from 0 (no hair loss) to 10 (complete hair loss).

#The mean time since diagnosis has been increased as one participant received their breast cancer diagnosis 15 years and 11 months ago, compared with the majority of

participants receiving their diagnosis between 1.5 months and 4 months prior to completing the baseline questionnaire (*M*= 30.02).

6.13.3 Two week, 1 month and 3 month follow-up

Only four participants completed the 2 week, 1 month and 3 month follow-up questionnaires (55.6% dropout rate). Three had been randomised into the intervention and one into the control group. All four participants reported that they had completed their writing at home. Although they had all lost their hair, one was not upset by it, two were a little upset and one reported feeling very upset. Participants' satisfaction with the information and support they received from their GP, consultant, breast care nurse and support organisations varied, with satisfaction generally decreasing from 2 week follow-up to 3 month follow-up for the four participants who complete the 3 month follow-up questionnaire (see table 14).

One participant who was randomised into the expressive writing group had received support from a number of sources including financial support and nutritional advice from Macmillan, and had attended a living with cancer course. This participant also stated that she was receiving ongoing psychotherapy which she started before receiving her cancer diagnosis and found that it was helpful in providing emotional support not only with cancer but other aspects of her life. This has a number of implications which are discussed in detail in section 6.14.2.

Unfortunately, the very small sample size was insufficient to conduct statistical analysis on the patient reported outcome measures. Small sample sizes are a limitation and acknowledged characteristic of feasibility studies, resulting in the inability to determine statistical significance of the effectiveness of an intervention (Cope, 2015).

Table 14. Participants' satisfaction with level of information and support received.

	2 week follow-up (*n* = 4)				**1 month follow-up (n = 4)**				**3 month follow-up (*n* = 4)**			
	Not at all	A little	A lot	Extremely	Not at all	A little	A lot	Extremely	Not at all	A little	A lot	Extremely
Are you happy with the level of information and support you have received from your GP?			2	2		1		3		2		2
Are you happy with the level of information and support you have received from your Consultant?		1	1	2		2		2	2			2
Are you happy with the level of information and support you have received from your Breast Care Nurse?	1	1		2	2			2	2			2
Are you happy with the level of information and support you have received from support organisations?		1	2	1	1		2	2	1		1	2

6.13.4 Acceptability data

6.13.4.1 Participants' experiences of the writing task

As can be seen in figure 14, five participants completed the writing task (four in the intervention group and one from the control group), of whom four completed the 2 week, 1 month and 3 month follow-up questionnaires (three from the intervention group and one from the control group). Of the three participants who had been randomised to the intervention group, one participant reported that she did not find the writing task useful, whilst one did.

At 2 week follow up, Sally described the writing task as being difficult because she did not know what to write about:

> "*Hard work, I didn't really feel I had that much to write about!" (Sally).*

At 1 month follow-up, she indicated that she did not feel particularly affected by losing her hair:

> *"I'm not that bothered about losing my hair, it will grow back*" (Sally)

At 3 month follow-up, Sally added:

> "*I found it quite hard work, and don't like to dwell on it*" (Sally)

In contrast, at two weeks follow-up, Audrey and Cally both found the writing task helpful as it provided an opportunity for them to reflect on their hair loss:

> "*It really made me stop and think and reflect on my feelings and thoughts about the hair loss specifically and I had not really done that up until that point and might not otherwise have done so either*" (Audrey)

> *"Makes you think deeply about hair loss instead of just accepting it"* (Cally)

At 1 month follow-up, Audrey found it helpful to explore her thoughts in relation to her hair loss which she thought she would not have done if it was not for the study:

> "*It was a way of exploring what I thought and felt about losing my hair and I don't think I would have done that if I'd not been writing about it*" (Audrey)

Writing also helped Cally to think about her diagnosis and treatment and to realise how well she had come to terms with what she had been through:

> *"Made me really think about what had happened - and I realised I was ok with it, which was less scary. It helped to process thoughts - and look back and realise how well I have come to terms with diagnosis"* (Cally)

At 3 month follow-up, Audrey and Cally both described how writing about their hair loss had helped them:

> "*Helped to explore deeper, inner feelings about hair loss and treatment and in fact the business of having cancer*" (Audrey)

> *"good way to express thoughts - and useful to look back on, to realise how I have adapted"* (Cally)

Also, Cally commented that she had enjoyed taking part in the research and had found it beneficial:

> *"I have found it really helpful taking part in this study - helped me recognise how I am feeling about e.g. hair loss"* (Cally)

At all three time points, Lucy who was randomised into the control group did not see the relevance of the control writing topic:

> "*I do not understand the relevance of writing about my surroundings*" (Lucy)

Unfortunately, one participant who completed the writing did not complete any of the follow up questionnaires, so their feedback on the intervention is not available.

Three participants had continued to write after completing the writing task by keeping a diary; one participant did not give a reason for why she had kept a diary, one woman did so because a friend recommended it, whilst the other participant reported keeping separate diaries for the physical and emotional impact of their treatment:

> "*I keep two diaries; one to track the chemo, what I ate, activity I've done, drugs taken, energy levels and the second diary is to report streams of*

> *consciousness in the mornings, about anything I'm thinking about or feeling at that point*" (Audrey).

The feedback from these women supports the acceptability of the intervention condition of the expressive writing study, although Smyth and Pennebaker (2008) express concern that keeping diaries may alter the effects of expressive writing interventions. However, as demonstrated above, some patients prefer to write about the wider challenges of cancer diagnosis and the impact of cancer treatment, rather than being restricted to write about a specific aspect. Feedback from the participant in the control condition indicates that this was not acceptable, suggesting a need for an alternative topic for the control group in any further study or the use of an alternative design without an active control condition. However, it must be remembered that only one woman completed and fed back on the control condition, a response rate which itself indicates the need for caution over the acceptability of this condition.

Three participants sent their writing to the researcher, two from the intervention group and one from the control group. Participants' writing was not analysed but it was checked to ensure that they had adhered to the writing instructions, which they had done. Interestingly, there was a substantial difference in the quantity of writing received from the two participants from the intervention group; one woman had written half an A4 side of paper each day, whereas the other participant had written 2 sides of A4 paper and documented the time that started and finished writing, demonstrating that she had written for precisely 20 minutes, as instructed. This is further evidence to suggest that expressive writing is not necessarily suitable for everyone, but for some women expressive writing could be a beneficial and enjoyable intervention.

6.13.4.2 Feedback from health professionals and patients

Feedback was received from both the nurses at the Chemotherapy Day Unit and the three consultants who helped to identify eligible patients. The nurses confirmed that 6 patients had declined to take part because they wanted to focus on their chemotherapy treatment without taking part in research at the same time and two

patients had difficulty writing. The consultants identified 5 patients who felt they did not have time to take part.

A noteworthy point is that as well as identifying patients for the current study, breast cancer nurses were also trying to identify patients to participate in a drugs trial, alongside trying to provide emotional support to breast cancer patients. Therefore, understandably, the time they could allocate to identifying eligible patients for the expressive writing study was limited and is likely to have contributed to the low uptake to the current study.

Timing was an important barrier to uptake. As noted in figure 14, two participants consented to participate and completed the baseline questionnaire but had been unwell due to the side effects of chemotherapy treatment yet still wanted to complete the writing task as soon as they felt well enough. Unfortunately these participants had still not felt well enough or did not have the chance to complete the writing task several weeks later. One patient who the researcher spoke to at a new patient session was interested in taking part but felt they would not have time to participate due to the concurrent demands of being a carer and having to rely on public transport to regularly attend hospital appointments.

6.14 Discussion

Based on the feasibility data received, it is concluded that the expressive writing intervention and evaluation is not feasible for breast cancer patients newly referred for chemotherapy in its current form. This could be due to aspects of the intervention and/or aspects of the study design.

Owing to the small sample size, it was not possible to comment on the suitability of the measures. However, participants did not report any problems with any of them and there was no missing data in the questionnaires that were returned, suggesting this small group of participants found the measures to be acceptable.

As described above, despite using a number of approaches to recruitment based on a review of the challenges of recruitment previously reported in the psycho-oncology and RCT literatures (see chapter 3), this was still a major challenge for this study.

Before designing the study in terms of deciding what to ask participants to write about, a thorough review of the expressive writing literature found that very few studies in this area provided a detailed description of their recruitment strategy. This is an additional reason why PPI was included to help ensure that the materials and design were acceptable to participants. This supports previous research highlighting a paucity of published literature in psycho-oncology regarding recruitment strategies, specifically in studies regarding sensitive or stigmatized issues (Jennings et al, 2014). It has been proposed that many researchers consider recruitment to be an implementation problem that may not warrant analysis and discussion in their research (McNees et al, 2005). However, better reporting of recruitment information is critical because it remains unclear whether interventions are viable if it is not possible to easily recruit patients for evaluation studies (Boonzaier et al, 2010; Cope, 2015).

Only one expressive writing study with early stage breast cancer patients (Stanton et al, 2002) reported that participants declined or terminated participation without giving a reason and, when a reason was given, these included being too busy to commit to the study. The current study also found that women dropped out or refused to consent due to being unwell or too busy with their cancer treatment. However, two expressive writing studies with metastatic breast cancer patients have reported recruitment difficulties; Laccetti (2007) reported reducing their study's power as a result of recruiting 68 participants as opposed to their original target of 100 women and Low et al (2010) reported that patients dropped out due to being too ill. However, once again a lack of information regarding the recruitment strategy was provided.

A low uptake to home-based expressive writing interventions has been reported in three studies; two with arthritis patients (Broderick et al, 2004; Wetherell et al., 2005) and one with early stage breast cancer patients (Gellaitry et al., 2010). These studies reinforce the need to consider the possible burden of research on patients who are managing serious and/or chronic health conditions and to consider each study and patient group on an individual basis.

The few authors who have provided recruitment details in their study write-ups include Baum and Rude (2013) who reported high attrition, which they attributed to the study being online. The authors believed that lack of face-to-face personal interaction with the researcher might have reduced participants' commitment to completing the study. However, in an attempt to avoid this from happening in the present study, the researcher attended the BHOC on a daily basis to speak to eligible participants and maintained regular contact with those who had consented in order to check their progress with the study. Jennings et al (2014) suggest that allowing extra time to provide information and build rapport with potential participants, medical staff briefly mentioning the study to patients prior to being approached by the researcher, and approaching potential participants in the privacy of a clinic room all increase willingness to take part. All these recommendations were followed in the current study, as highlighted above. Sending participants an introductory letter under the letterhead of the physician shows their support of the research and can promote recruitment (Sears et al., 2003). A letter was therefore printed on the hospital's headed paper, naming the hospital consultants who supported the study and the charity that funded it. This letter was included in the questionnaire pack, with the hope that this would add to the credibility of the study and make it more inviting to potential participants.

Once it became apparent that recruitment was much slower than anticipated, the literature was searched for guidance on additional ways to improve recruitment. A number of studies have found that a financial incentive can help to improve recruitment (Free et al., 2010; McDaid et al., 2006). It was therefore decided to offer participants a £20 Marks and Spencer voucher as a gesture of gratitude for completing the study. An amendment to the study's ethics application was submitted to the University of the West of England (UWE) and approved, so that new participants and women who had already consented to take part before this amendment were all sent a voucher. However, introducing an incentive did not appear to make any difference to recruitment.

6.14.1 Limitations

In addition to the limitations resulting from the low levels of recruitment discussed above, it is possible that the study attracted a self-selecting sample, whereby those that might most need and want support did not participate as they did not want to risk being randomised to the control group. Furthermore, individuals may not feel they have the emotional or cognitive capacity to take on more commitments, such as research, whilst going through treatment. An additional limitation is that the researcher was not blinded to which condition the participants were randomised to, which could have led to experimenter bias, where the researcher's expectations of how a participant would perform based on the condition they were randomised to may have affected the study.

6.14.2 Implications

As discussed at the start of this chapter, the current intervention and study design was informed by previous expressive writing studies, including the few that have been conducted with early stage breast cancer patients. Without conducting further research it is impossible to draw specific conclusions, but it appears that the timing of the current intervention was not appropriate since most patients had recently received a breast cancer diagnosis and were starting cancer treatment. Future research may benefit from conducting a longitudinal exploratory study to follow individuals from their initial diagnosis up to two years post primary treatment, to provide an insight into how breast cancer patients adjust to their hair loss in the longer term including hair re-growth. This would enable researchers to gain an understanding of when would be an appropriate time to implement interventions to support breast cancer patients. The enthusiasm of one woman to take part several years after treatment adds to the suggestion that it may be more appropriate to offer the intervention to women who have completed their treatment but are still struggling with hair loss issues. Also, the study appealed to one patient who had tried several sources of support and may have taken part in the present study as she felt in need of the support. However, if a full trial was to be conducted, including patients who were receiving additional sources of support, this could lead to a contamination

effect, as it would be difficult to know whether it was the expressive writing intervention or other interventions that was effective. In order to know whether a full expressive writing study is effective, patients would have to be excluded if they were receiving support elsewhere.

Furthermore, the expressive writing intervention was not attractive to everyone. Previous research has found that individuals have different preferences for interventions, sources of support and involvement in research (for example, see Frith, Harcourt & Fussell, 2007 who found that some breast cancer patients were very keen to take part in a photo elicitation study of their experiences of chemotherapy, whilst several others did not find this appealing). It is imperative that a variety of interventions are available in order to accommodate individual preferences for support. Therefore, future research in this area may benefit from including a needs assessment to identify patients who are distressed by their hair loss and in need of support. It is important to not only know what patients' needs are but also to know how they can be supported and how to refer patients for support.

In hindsight, rather than employing an RCT design, it may have been more beneficial to conduct a single arm exploratory study, whereby all participants receive the expressive writing intervention. This may have encouraged more patients to participate, on the assumption they chose not to take part as they did not want to be randomised to the control condition, also this would mean that a smaller sample size would be required. If this design was considered feasible and in line with the MRC framework, a definitive trial (but not using an RCT design) could then be conducted and the long term implementation explored.

6.15 Summary of the key points from this chapter:

- This is the first study to adapt Pennebaker and Beall's expressive writing intervention for breast cancer patients who are affected by treatment-related hair loss.
- The aim of the study was to explore the feasibility of an RCT to evaluate an expressive writing intervention for breast cancer patients with treatment-

related hair loss and to investigate whether the timing of the intervention and the recruitment strategy is appropriate.

- Participants were either randomised to an intervention group, where they write about their thoughts in relation to their hair loss or a control group where they took part in a descriptive writing task.
- Nine female breast cancer patients completed the baseline questionnaire. Four participants completed all follow-up questionnaires, three of which had been randomised into the intervention group and one into the control group.
- Reasons for declining to participate included; wanting to focus on their treatment, two patients reported having difficulty writing, not having time to take part.
- The expressive writing intervention and evaluation is not feasible for patients newly referred for chemotherapy in its current form. This could be due to aspects of the intervention and/or aspects of the study design.

6.16 Next stage of the research

The following chapter presents the main findings from this program of research and highlights their contribution to knowledge, including the contribution it has made to current knowledge around the psychosocial impact of hair loss due to chemotherapy and the provision of supportive interventions for those affected.

Chapter Seven

Discussion

7.1 Introduction

This chapter discusses and synthesises the key findings from this program of research, including the contribution it has made to current knowledge around the psychosocial impact of hair loss due to chemotherapy and the provision of supportive interventions for those affected. The studies in this thesis are considered in the order in which they were conducted and presented earlier. This chapter discusses the research findings in relation to current NHS policies on the provision of cancer care and implications for future research and practice. Limitations of the research are then outlined ahead of a reflection on the methodologies employed, the use of PPI and the research process as a whole.

The purpose of this research was to explore psychosocial interventions to support breast cancer patients affected by treatment-related hair loss. The studies in this thesis have revealed a number of interesting findings relating to this issue.

7.2 Synthesis of the research findings and contribution to knowledge

Previous research has highlighted the need for rigorous evaluations of interventions to support patients affected by treatment-related hair loss (Lemieux et al., 2008). The systematic review discussed in chapter two was the first review of this sort to date to explore the effectiveness of psychosocial interventions for patients experiencing hair loss. The aims of the review were to identify existing research into current psychosocial interventions, to comment on the scientific quality of those studies and identify aspects of effective interventions in order to inform future intervention design and evaluation.

Of the 5,182 potentially relevant papers identified, only 8 articles met the inclusion criteria; 4 focused on behavioural techniques to camouflage hair loss, 3 provided psychological support and one was based on hypnosis. The interventions were delivered face-to-face in an individual or group setting, or online. The review

concluded that the scientific quality of research in this area is mixed. Whilst some research was of reasonable quality, the overall quality of the design of the evaluations was poor since they were underpowered and were limited to short term follow-up, so it is unknown if any benefits were maintained in the longer term. Few interventions had been manualised, therefore making it difficult for other researchers/health professionals to replicate them. Only one study provided reasons for attrition, making it difficult for researchers/health professionals to identify for whom the interventions may or may not be suitable. All interventions were delivered in a hospital/clinic setting and only 3 studies included a control group. Lack of details regarding the training of researchers and health professionals delivering the interventions makes them difficult to replicate.

The effectiveness of the 8 different interventions was mixed; 6 showed improvements in either all or some of their outcome measures, yet 2 of these only found a very small improvement in body image (Nolte et al, 2006) or upset with hair loss (Salonen et al, 2011). The two qualitative studies (Amiel et al, 2009; Zaninni et al, 2012) reported women's experiences of beauty-based interventions and concluded that the majority of participants found them to be beneficial. Key aspects of the successful interventions included the immediacy of the intervention, the inclusion of information provision and an opportunity to express emotions and concerns. However, many currently available interventions were not included in the review as they did not meet the inclusion criteria.

The findings from the systematic review highlighted that few interventions for individuals affected by hair loss had been evaluated, this informed two further studies: an evaluation of Breast Cancer Care's HeadStrong service and a feasibility study of an expressive writing intervention. Chapters four and five presented the first evaluation of Breast Cancer Care's HeadStrong service. The HeadStrong service evaluation used a mixed methods approach, consisting of interviews with 25 women who were an average of 8 months post-diagnosis and a pre-post- and 3 month follow-up survey with 16 women who were an average of 1.9 months post-diagnosis at baseline. Nine women completed all follow-up data collection points.

The qualitative study revealed three main themes; challenges of hair loss, experiences of receiving support for treatment-related hair loss and meeting unmet needs. The challenges women faced as a consequence of hair loss began at diagnosis when they were advised that they would lose their hair as a side effect of chemotherapy, and continued until and after their hair had started to re-grow. Women in both the qualitative and quantitative studies indicated that their hair loss had impacted negatively on their lives, including the impact on their confidence, relationships with close family and friends and also the general public. Some women were able to manage the consequences of their hair loss relatively well whilst others could not. Timing was a significant factor in their use and the perceived usefulness of HeadStrong; some participants felt it was important to attend a session prior to losing their hair, but it was difficult for many to find the time to attend due to managing work commitments and hospital appointments. Preference for individual versus group sessions was mixed, reinforcing the different individual support needs and suggesting the need for a patient-focused individual needs assessment. Whilst HeadStrong enabled participants to re-gain a sense of control through the practical advice and information they received, which was evident from both the qualitative and quantitative HeadStong studies, it did not necessarily address their emotional support needs. Additional suggestions for improvement included tailoring the service to each individual's needs.

Some participants reported that wearing headscarves and/or having short hair signified a 'cancer look' that made other people aware of their diagnosis, and that using these to hide their hair loss did not therefore remedy all the distress they had been experiencing. In contrast, some women felt more confident in using headwear and managing the physical consequences of their hair loss, including the reaction of others after attending HeadStrong. However, the quantitative HeadStrong study highlighted that participants' confidence in managing the reactions of others was not maintained at follow-up. Quality of life and emotional well-being reduced significantly from post-HeadStrong to 3 month follow-up, whilst social well-being and fear of negative evaluation decreased significantly between the pre-HeadStrong and 3 month follow-up. These findings suggest that the HeadStrong service may not help to improve individuals' quality of life in the longer term. However, due to the

small sample size the findings cannot be generalised and should be interpreted with caution.

In view of the need to develop additional interventions to meet the needs of patients experiencing alopecia, the feasibility of an expressive writing intervention was explored with 9 breast cancer patients who had lost their hair, or were expecting to do so, due to curative chemotherapy treatment. This was the first study to explore the feasibility and acceptability of Pennebaker and Beall's expressive writing intervention with breast cancer patients who are affected by treatment-related hair loss. The main finding of this study was that the expressive writing intervention and/or the design of the evaluation, as used in this study, was not feasible for this patient group. Recruitment was very difficult and the response rate was low, whilst the attrition rate of those that consented to take part was high. This may be because patients had recently received their diagnosis and may not want to take part in research during this difficult and distressing time. Also, some people may not have found the intervention appealing or perhaps did not want to risk being randomised into the control group. Amongst those that did take part, feedback on the expressive writing was mixed, with some participants reporting that they found it useful and very interesting participating in the study, whilst others commented that they found the writing task difficult as they did not feel they had enough to write about. Also, one participant queried the relevance of the control group topic. This suggests that expressive writing may be appealing to some patients and it is possible that some may benefit from the intervention but, based on the small sample size of the current research, no definitive conclusions can be made and careful consideration would be necessary before conducting a further feasibility study of an adapted intervention or design, or a larger trial.

The findings from this program of research have provided an important insight into the psychosocial interventions available for individuals affected by hair loss, women's experiences of a particular type of intervention (HeadStrong) and of an expressive writing intervention. On the basis of this original research, the following recommendations are made if attempts are to be made to continually improve the provision of care to support this patient group:

- Women need to be provided with a tool box of strategies to help them manage their treatment-related hair loss.
- It is important that a needs assessment is conducted, so that patients are informed of the appropriate services available to them and what they incorporate.
- Available interventions need be tailored to individual's needs, including interventions which provide emotional support and do not solely focus on camouflaging hair loss.
- It is important that health professionals are able to signpost patients to available services like HeadStrong but are also aware that patients might have other issues or concerns that a service like HeadStrong is unable to address.

7.3 Implications of the current research

This section discusses the implications of these studies for future research and practice. Throughout the studies it was apparent there was a great diversity in the psychosocial impact and consequences of treatment-related hair loss for breast cancer patients. Some women seemed relatively unaffected by the experience, whereas others had been and continued to be very distressed and were enduring adverse consequences both during treatment and in the longer-term, once treatment had ended. This supports previous research (Batchelor, 2001; DoH, Macmillan Cancer Support & NHS improvement, 2013; Lemieux et al., 2008; Rosman, 2004). Specifically, the interviews in the qualitative part of the HeadStrong service evaluation (chapter 4) highlighted women's experiences of emotional, physical and social difficulties including appearance concerns, psychological distress and impacts on work, socialising and personal relationships around the time of diagnosis, during and after treatment had finished. Indeed, some were still distressed by their hair loss at the time of interview, demonstrating the need for psychological support throughout the cancer journey (Department of Health et al, 2013; NICE, 2014). The following sections offer recommendations for the provision of appropriate support for breast cancer patients affected by treatment-related hair loss in the future, and consider areas for further research.

7.3.1 Support for hair loss distress

NICE guidelines state the need for breast cancer patients to be offered access to specialist psychological support, yet highlight that the quality and provision of psychological support currently offered to breast cancer patients varies significantly (NICE, 2014). A recent report has highlighted that 30% of patients were bothered by hair loss one year after diagnosis and, interestingly, this rate improved at two and three years but returned to 29% at 5 years (DoH, 2012). This corresponds with findings from the qualitative HeadStrong service evaluation, whereby some women were still affected by their hair loss several months after finishing treatment. It has been reported that 49% of breast cancer patients reported having difficulty with their appearance/body image (DoH, 2012), which is reinforced by the current research. Women's concerns were diverse and not only confined to their hair loss.

Cancer patients often report greater satisfaction with their healthcare professional and the extent to which their needs are met when they have discussed the emotional impact of cancer with them, despite having no recollection of a direct conversation regarding their emotional needs (Bonito, Horowitz, McCorkle & Chagpar, 2013). Health professionals are pivotal in providing information and signposting people towards emotional support if required. Health professionals may not appreciate the importance of addressing appearance concerns with patients or perhaps are unsure of how to broach the topic with patients (Cadogan, 2012). Research has demonstrated the benefits of communication skills training includes improving skills and confidence in recognising patient concerns and can improve health professionals' attitudes towards psychosocial care (Razavi et al., 2003). However, many healthcare professionals, including breast care nurses, are often over stretched and under resourced to be able to determine the level of information and support individuals want and are unable to signpost them to the relevant resources (Macmillan, 2014). It has been suggested that patients may be more likely to discuss psychological health with patients if they know psychological support is available (Cadogan, 2012). Therefore, it is imperative that interventions are available which patients can self-refer to. However, in order to do this, a variety of interventions need to be available

to meet individual needs, and patients need to know what types of interventions exist, and how to access them.

7.3.1.1 Information provision

Macmillan (2014) highlighted the variation in the level of information and support that cancer patients in the UK receive, with a third of outpatients reporting they had not received sufficient emotional support. In addition, the latest national Cancer Patient Experience Survey (CPES) (Quality Health, 2014) reported that 17% of patients did not receive information about support or self-help groups when they had wanted or needed it. This supports the findings from the qualitative HeadStrong study where some women were happy with the information and support they received, whilst others wanted more specific information and support.

Many oncology departments now include an area, often run by Macmillan, where information leaflets are available and a number of breast cancer charities include information on their websites. Also, both in the literature and in the HeadStrong qualitative study, patients report discussion forums as being an important source of information. However, some patients are cautious of relying on discussion forums for information as they do not know how credible it is. This demonstrates that although lots of information is available, perhaps patients do not know how to access it or perhaps they find the amount of information available overwhelming or do not know which sources of information are credible and which are not, especially if they read conflicting information. Therefore, it is imperative that information is accessible and streamlined for patients, to ensure they do not receive conflicting information (Carpenter, Geryk, Chen, Nagler, Dieckmann & Han, 2015). It is acknowledged that this is a difficult task as individual information needs vary greatly. Further suggestions on how to improve information provision are discussed in section 7.4.2.

7.3.2 Meeting unmet needs

The need for pathways and services that address individuals' needs efficiently and effectively has been documented (DoH et al, 2013; Macmillan, 2014). Both the current research and previous studies (e.g. Armes et al, 2009) have suggested that

many cancer survivors have unmet needs, including those struggling with the consequences of treatment (Santin, Mills, Treanor & Donnelly, 2012), and the one-size-fits-all follow-up approach adopted by the NHS has been criticised in terms of failing to meet individuals' specific needs (Macmillan, 2014). This thesis further supports the need for a patient-centred service which is directed by individual needs, as evidenced by the systematic review and HeadStrong service evaluation. The National Cancer Survivorship Initiative (NCSI), launched in 2007, aims to develop services to support and enable cancer survivors to live as healthy and as good a quality of life as possible. The initiative promotes a holistic needs assessment so that each individual receives the support they require, for example by being referred to appropriate support programs or self-help groups and organisations, leading to improved quality of life for the patient in a cost effective way (DoH et al, 2013).

The NCSI identified five areas in need of improvement in the care and support for people living with and beyond cancer, including focusing on health and well-being after cancer treatment, support for self-management and tailored support at follow-up (DoH et al, 2013). It has been highlighted that psychological and emotional support are an essential part of patient care (NICE, 2004; NICE, 2012), which was evident in the present research particularly during the qualitative HeadStrong service evaluation where a number of patients spoke about the importance of psychological support during their cancer journey and the difficulties they faced in accessing it. NICE (2012) highlights that patients wish to be treated as individuals, so it is imperative that services are tailored to each individual's needs. The researcher met with Breast Cancer Care's Heads of Services to discuss the findings from the HeadStrong service evaluation. Based on these findings, along with the feedback from their own audit forms given to individuals who have attended a HeadStrong session, Breast Cancer Care now intend to tailor their service more to individuals' needs, so that at the start of a HeadStrong session the volunteer delivering the service will take time to ask the patient what they hope to gain from the session and what they would like help with.

One-to-one peer support programs have shown to be effective amongst cancer patients (Meyer, Coroiu & Korner, 2015). The majority of participants in the

HeadStrong evaluation preferred the session to be provided on a one-to-one basis as they did not think they would feel confident asking questions in a group session. However, some participants would have preferred the session to be group based in order to provide peer support. This further emphasises individual preferences for patient-centred support and the need to provide easy access to a variety of interventions and support services. Self-management is becoming a key aspect of tailored care to meet individual needs (DoH et al, 2013), and the internet has been highlighted as an effective mode of delivery to support self-management (Murray, 2012).

7.4 Provision of care and future research

This program of research has highlighted that there is still room for improvement in the provision of support for this patient group. This section highlights areas for future care provision and research.

7.4.1 Identifying future research priorities for breast cancer patients

To facilitate the development of a research agenda to support breast cancer patients affected by treatment-related hair loss, one suggestion for future research is to conduct a Delphi survey of breast cancer patients' research priorities for support. A Delphi survey is a consensus technique widely used in health research (Downing et al., 2015; Fearon et al, 2011; Rayner, Price, Hotopf & Higginson, 2011), they are particularly useful when there is insufficient information available (Hasson, Keeney & McKenna, 2000). A Dephi is a multi stage process, consisting of rounds, to combine participants' opinions into a group consensus on a research question, the responses from each round are then summarised and fed back to participants (McKenna, 1994). A Delphi survey would provide an insight into women's priorities for research into psychosocial support.

7.4.2 Utilising a screening tool to identify patients' distress related to hair loss

As discussed above, the impact of treatment-related hair loss varies greatly from one patient to another and it is extremely difficult for health professionals to assess individuals' needs due to the time restrictions of out-patient consultations. Also, patients can find it difficult to raise concerns related to their appearance, and health professionals often underestimate the consequences of hair loss and do not know how best to broach appearance concerns with their patients (Clarke & Cooper 2001; Randall & Ream 2005). Over the last decade, health policies have focused on detecting and meeting the psychosocial needs of cancer patients, including screening for emotional distress at key points along the patient pathway (Salmon et al., 2015). The main aim of these health policies are to reduce stress amongst cancer patients and to ensure they receive the psychological help they need (Holland et al., 2013). Evidence suggests that screening can improve clinicians' and patients' communication regarding psychological needs (Ristevski et al., 2013).

Research has highlighted the benefits of a Patient Concerns Inventory (PCI) (Rogers, El-Sheikha & Lowe, 2009) (www.patient-concerns-inventory.co.uk) which is completed prior to out-patient consultations and allows patients to indicate their needs and concerns, which can help to promote discussions during out-patient consultations, resulting in health professionals being able to signpost patients to the support they need. The PCI was originally developed for use in head and neck cancer clinics, however, recent research with breast cancer patients has shown that it helped them to identify issues including body image, psychological and social functioning for discussion with health professionals (Kanatas et al., 2014). Similarly, Question Prompt Lists (QPLs) aim to promote patient participation during consultations and help them acquire information suited to their needs (Dimoska et al., 2012). QPL interventions in oncology settings have been found to increase patient participation and improve psychological outcomes including anxiety (Brandes, Linn, Butow & van Weert, 2015). Macmillan Cancer Support is currently undertaking a pilot study of the role of support workers in a number of NHS sites across the country. Early findings indicate that these staff can undertake holistic needs assessments and

provide the coordination of care that patients state they need (Independent Cancer Taskforce, 2015).

These interventions might all offer great benefit to breast cancer patients, if rolling them out for routine use in breast clinics enables the identification of those who are negatively affected by treatment-related hair loss, and helps them to receive the support they want, however, before they are offered as part of routine care, more research including pilot testing is required to ensure that the screening tools can offer benefit to patients.

7.4.3 Stepped care models

Service provision in the UK generally includes specialist NHS services and support offered by charities (Hansen & Clarke, 2009). Healthcare services in the UK are developed in accordance with the Department of Health and the National Institute for Health and Clinical Excellence (NICE) (Cadogan, 2012). Stepped care models are used within the NHS to help organise the provision of services and to help healthcare professionals to select the most effective interventions. Patients are offered the least intensive intervention first and can then step up or down the pathway depending on their needs (NICE, 2011). Stepped care models are particularly appealing as they are cost effective; people receive the least intensive interventions for their need (NICE, 2011). NICE guidelines have led to the development of a stepped care model known as Improving Access to Psychological Therapies (IAPT), whereby primary care mental health workers deliver psychological interventions.

There are currently very few services within the UK which offer specialised support to those with appearance concerns. ‘Outlook’ is an NHS outpatient specialist service for people with appearance concerns, which uses Social Interaction Skills Training (SIST), to help patients manage the challenges of social situations (Robinson, Rumsey & Partridge, 1996) and Cognitive Behavioural Therapy (CBT) (Cadogan, 2012). To the best of the researcher’s knowledge, ‘Outlook’ is the only NHS outpatient service in the UK specific to patients’ appearance-related concerns. Research and support around appearance concerns, such as that provided through

Outlook, which is not cancer specific may be beneficial to those affected by hair loss.

Moving forward in supporting breast cancer patients affected by treatment-related hair loss, it could be useful to consider the suitability of the Centre for Appearance Research (CAR) framework of appearance-related interventions (Rumsey & Harcourt, 2012) to inform both research and provision of care. In line with current stepped care frameworks (NICE guidelines, 2007, 2009) the CAR framework of interventions includes different levels of therapeutic intervention, depending on individual needs (Jenkinson, 2012). The CAR framework follows the philosophies of similar stepped care models, so that all patients are offered support at levels 1 and 2 and, if required following an assessment with a trained health professional, may be offered more intense therapeutic approaches such as those at level 4 and 5, thus aiming to provide cost effective care like other stepped models.

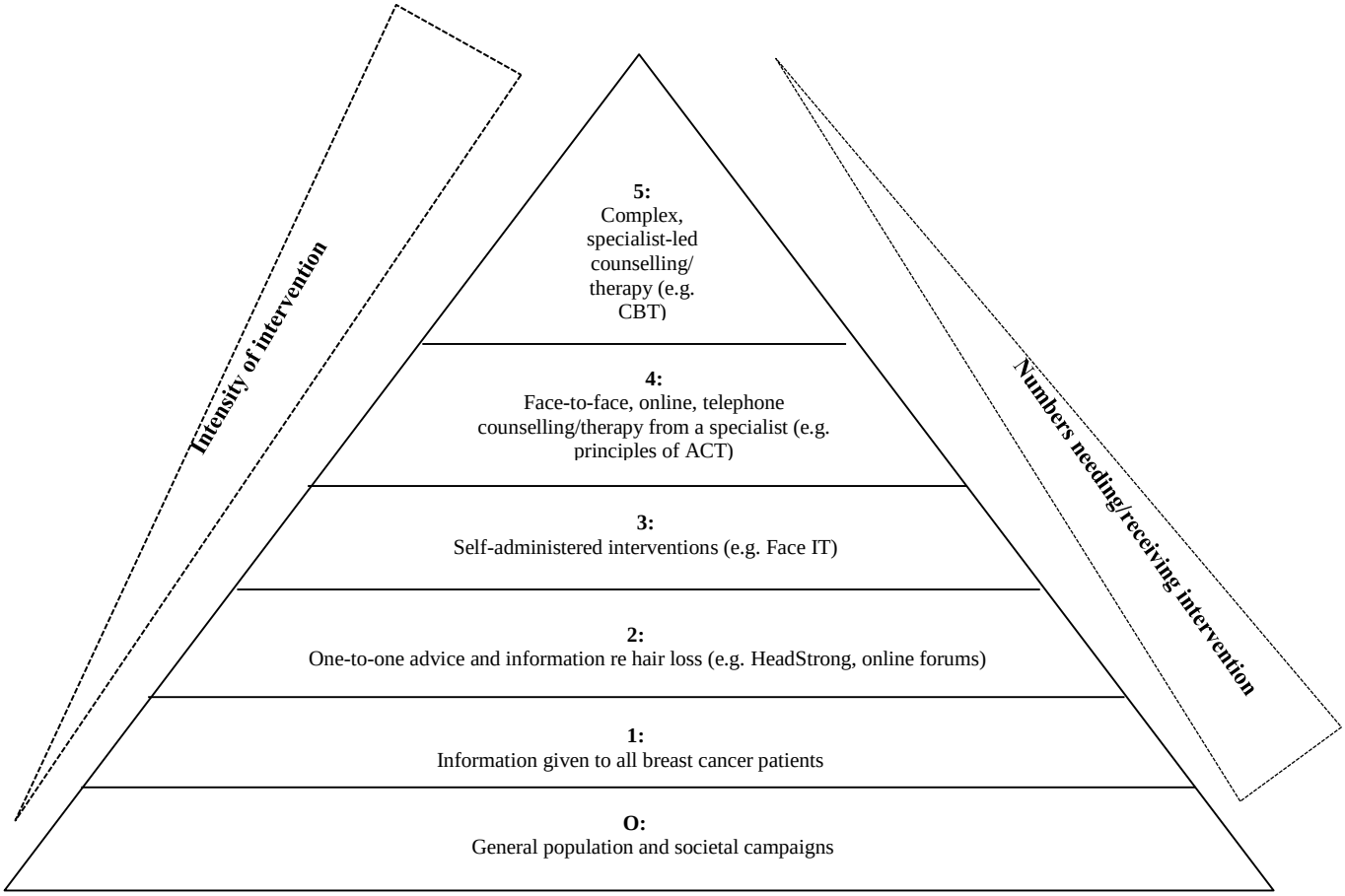


Figure 16. The CAR framework of interventions for people with visible differences (Rumsey & Harcourt, 2012). (First produced by Professor Nichola Rumsey and Professor Diana Harcourt (2012), p. 684, Figure 50.1. Reproduced with copyright permission from Oxford University Press).

The CAR framework is a tiered model of interventions. It is important to determine what level of intervention a patient might benefit from, by using a needs assessment or screening tool, as discussed above. At the societal level (level 0 on the framework), public attitudes towards hair loss and breast cancer treatment could be explored, with a view to challenging societal messages, including appearance-related beliefs. However, it is extremely difficult to bring about societal change. Managing other people's reactions can be particularly difficult for many cancer patients affected by hair loss, as found in both the current and previous research (e.g. Hilton et al., 2008), so interventions that promote understanding and acceptance of diversity in appearance, for example, through the media including poster campaigns, could be beneficial for those whose appearance is different. For example, Breast Cancer Care's recent body image campaign (BCC, 2014,

www.breastcancercare.org.uk/body) includes a film of individuals talking about their experiences of body image after breast cancer. Also, a number of school based interventions promote positive attitudes and behaviours in secondary education towards body image. An advantage of these interventions is that children might then educate their parents and family members too. However, even if population and societal campaigns were to bring about change in some people's attitudes, they would be unlikely to remedy all the concerns that breast cancer patients affected by hair loss have. Additional interventions to offer support at an individual level, as evidenced in the framework, are still needed.

For those in need of low level psychological support, written information in the form of leaflets and information booklets can offer accessible advice (Jenkinson, 2012). Level 1 of the framework would involve all breast cancer patients who are likely to be affected by hair loss receiving information in different formats (e.g. written, online). Notably, in many cases this is already happening thanks to charities and organisations such as Macmillan and Breast Cancer Care who have a wealth of information booklets including some specific to hair loss and body changes after treatment. However, some patients do not receive information and are unaware of the resources freely available to them (Independent Cancer Taskforce, 2015). Providing each patient with the information that meets their individual needs is a major challenge. One way of moving forward may be to introduce an online hub, whereby one website is promoted by breast cancer charities and health professionals and from where patients can be directed to resources and interventions based on their needs. This could make information much more accessible for some breast cancer patients; however, it is important to acknowledge that online materials are not accessible or popular with everyone and a number of participants in the present research preferred paper copies of questionnaires rather than online materials. Also, breast cancer generally affects older individuals; in the UK between 2010 and 2012, 24% of breast cancer cases were diagnosed in those over the age of 75 (Cancer Research UK, 2015). It is possible that this age group may be less confident in using computers, therefore information provision cannot solely be online, even though web-based interventions are being used successfully by older people (Yardley & Nyman, 2007).

One way of fostering peer support (level 2 of the framework) is through discussion forums which some charities already run (e.g. Breast Cancer Care), whereby patients can talk to peers online. However, patients may read about other patients' distressing experiences which may have a negative effect on their own wellbeing. A number of participants in the HeadStrong qualitative study spoke about engaging in online discussion forums - some found them to be an easily accessible form of peer support, whereas others found them unhelpful.

However, the level of information patients seek varies greatly and some will require a higher level of intervention. Patients could attend a HeadStrong session or a similar service, for example Look Good Feel Better, which offers advice including scalp care, the use of hats and headscarves to camouflage hair loss and make up to disguise facial hair loss. As highlighted in the systematic review and HeadStrong service evaluation, camouflage-based support services may be exactly what some women want and need, but they may not necessarily meet all patients' needs. Therefore, patients warranting further support may benefit from a level 3 intervention. This could include the expressive writing intervention explored in chapter 6, although it is not clear from the current research whether this is effective or acceptable for this patient group.

As highlighted above, cancer patients report a number of unmet needs during and after they have finished active treatment. As a consequence of receiving a cancer diagnosis and treatment, individuals may lack confidence and feel vulnerable, which is a potential barrier to accessing support (Foster et al., 2015). Many cancer survivors believe eHealth interventions could be a valuable addition to follow-up care (Lubberding et al., 2015). Future research could explore the development and effectiveness of online interventions to specifically support patients troubled by the appearance-related impact of their treatment. Online interventions are readily available at any time, overcoming some of the problems patients have reported around difficulty in accessing support and attending face-to-face interventions (a problem that was reported in the HeadStrong evaluation in this thesis). Clinicians have advocated the use of remote online interventions as a way to increase access to

interventions for patients unable to attend interventions in a hospital setting (Bessell, Clarke, Harcourt, Moss & Rumsey, 2010). Also, recent research has highlighted the utility of online interventions in aiding patients to self-manage (Murray, 2012). For example, Face IT is an online CBT-based intervention specifically to support people with appearance-related concerns associated with an altered or unusual appearance. It has been found to increase positive adjustment, whilst reducing anxiety, depression and appearance concerns in adults with a range of disfigurements (Bessell, Brough, Clarke, Harcourt, Moss & Rumsey, 2012). Importantly, findings from Face IT compare favourably with a similar intervention delivered face-to-face by highly trained health professionals (Bessell, 2009).

Face IT could be beneficial for breast cancer patients who are affected by treatment-related hair loss as it targets the underlying concepts of body image and appearance concerns. Moreover, although the systematic review in chapter 2 highlighted that currently evaluated interventions for hair loss are delivered either in a hospital or clinic setting, the findings from the HeadStrong study found that patients would prefer interventions to be delivered away from the environment they associate with their cancer treatment. This further supports the need for varied and flexible interventions to meet patient's individual needs. An online intervention would make psychosocial support easily accessible for patients, enabling them to use it at a time and location convenient for them, meaning they would not have to travel for the intervention (see the HeadStrong evaluation in chapter 4). However, engagement in internet-based interventions can be low (Gorlick, Bantum & Owen, 2014). It would be imperative to engage users in future research, to understand their experiences and needs throughout the development of an intervention of this sort, highlighting the importance of including PPI.

Levels 4 and 5 of the CAR framework are the most intense and include interventions aimed at the most distressed patients with complex support needs, who would benefit from more expert input and specialist therapy such as that available through a qualified, experienced psychologist or counsellor. Interventions provided at these levels include Cognitive Behavioural Therapy (CBT) and third wave approaches

such as Acceptance and Commitment Therapy (ACT) (an in-depth discussion of these interventions can be found below in section 7.4.3). Level 4 interventions may include brief remote one-to-one or telephone therapy, whereas the level 5 interventions are for those experiencing the highest levels of psychosocial distress and include a one-to-one intervention with a specialist health professional and would typically last longer than the level 4 interventions. As highlighted above, rather than seeking a one-size-fits-all approach it is imperative, even at this level, to assess individual needs since the psychosocial consequences of treatment-related hair loss are diverse and cannot be judged on severity of hair loss alone.

7.4.4 Exploring additional interventions

Within the UK, cancer policy (i.e. Department of Health, 2011) is supportive of the use of psychological interventions to improve the patient experience (Hulbert-Williams, Storey & Wilson, 2015). Literature on interventions developed for long-term conditions could help advance the support provided to cancer survivors (DoH et al, 2013). The suitability and efficacy of alternative interventions to support breast cancer patients affected by treatment-related hair loss could usefully be investigated, including Cognitive Behavioural Therapy (CBT), Mindfulness, and Acceptance and Commitment Therapy (ACT).

7.4.5 Cognitive behavioural therapy (CBT)

CBT offers a problem-focused approach whereby "dealing with distress, positioning it within a medical model and as something abnormal to be corrected or fixed, distress cognitions are identified and their impact minimised to improve behaviour and outcome" (Hulbert-Williams et al., 2015, p. 17). It is often used within the NHS to treat anxiety and depression (Jenkinson, 2012). CBT approaches to appearance concerns have received favourable support (Jarry & Ip, 2005). Specifically, CBT has been found to be effective in reducing depression and anxiety and improving quality of life in cancer patients, with large effect sizes > .9 (Osborn, Demoncada & Feuerstein, 2006). It has also been shown to help psycho-sexual adjustment (Siddons, Wootten & Costello, 2013; Watson et al., 2013). However, despite the

acceptability of CBT from clinicians and researchers, it is important to acknowledge that, to date; only a few studies provide good quality evidence to support its use with individuals with appearance concerns (Bessell & Moss, 2007; Jenkinson, 2012). Also, the longer-term benefits are unclear (Hayes et al., 2004) and CBT interventions currently lack a replicable underlying intervention framework (Hulbert-Williams et al., 2015). Therefore, a CBT based approach may be beneficial for breast cancer patients who are affected by treatment-related hair loss but before definitive recommendations can be made, more research is needed to demonstrate its effectiveness in supporting this particular patient group.

7.4.6 Mindfulness

Mindfulness is described as paying complete attention to the experiences occurring, in a non-judgemental way (Brown & Ryan, 2003). It is related to alexithymia, as they both describe how people handle and process their internal experience. Mindfulness requires an acceptance and awareness that adopts a willingness to face and accept thoughts and emotions (Brown, Ryan & Creswell, 2007). An individual has to assimilate the traumatic experience into their system or alter their schema so that the traumatic experience can be accommodated (Sloan & Marx, 2004). Poon and Danoff-Burg (2011) examined trait mindfulness as a moderator of the expressive writing paradigm, and found that a higher mindfulness score predicted greater improvements in physical and psychological symptoms, negative and positive effect, and sleep quality. Therefore it is suggested that individuals who are more mindful benefit more from disclosing their emotions and thoughts regarding stressful experiences than do those who are less mindful.

There is evidence for the adoption of third wave interventions within cancer care including mindfulness-based approaches (Hulbert-Williams et al., 2015). Mindfulness training involves encouraging individuals to enter a state of mind where they pay active, non-judgemental attention to both positive and negative experiences (Hayes & Smith, 2005). There is growing support for mindfulness interventions for cancer patients including benefits in reduced fatigue, and improved mood, quality of life, sleep and benefit-finding (Casellas-Grau, Font & Vives, 2014; Monti et al.,

2013; Ott, Norris & Bauer-Wu, 2006; Schroevers & Brandsma, 2010; Smith, Richardson, Hoffman & Pilkington, 2004; Lengacher et al., 2015). Mindfulness also plays a key role in other third-wave therapeutic approaches including ACT (Hulbert-Williams et al., 2015).

Ledesma and Kumano (2009) conducted a meta-analysis that found a mindfulness-based stress reduction (MBSR) program was effective in improving the well-being of breast cancer patients. Due to small sample sizes and as the meta-analysis relied to a large extent on data from observational studies, conclusions must be taken with caution. Furthermore, mindfulness has gained attention for its ability to improve acceptance of symptoms which are impossible or difficult to change (Fjorback, Arendt, Ørnbøl, Fink & Walach, 2011), suggesting its potential use to help patients affected by chemotherapy reach a level of acceptance of their hair loss.

7.4.7 Acceptance and commitment therapy (ACT)

To date, few interventions have explored the effectiveness of psychological interventions that promote acceptance of the distress which is evident in cancer populations (Feros, Lane, Ciarrochi & Blackledge, 2013). ACT is a theory driven behavioural approach (Arch & Mitchell, 2015) that "focuses on changing a patient's relationship with their thoughts, rather than changing the content of the thoughts" (Feros et al., 2013, p. 459). Patients learn to experience difficult thoughts and feelings without being controlled by them. It promotes forms of coping that predict positive psychosocial outcomes, which could include accepting cancer-related distress; reducing cancer-related avoidance and committing to behaviour change (Stanton, Ravenson & Tennen, 2007).

ACT aims to develop psychological flexibility to enable a person to act effectively with their distressing symptoms through the use of acceptance strategies, mindfulness techniques and a range of behavioural approaches to ultimately buffer against psychological distress (Feros et al., 2013). Research focused on interventions based on the use of ACT demonstrates positive findings (Köhle et al., 2015). Research with cancer patients (i.e. Feros et al., 2013; Karekla & Constantinou, 2010; Rost, Wilson, Buchanan, Hildebrandt & Mutch, 2012), has shown improved distress,

mood disturbance, anxiety, depression and quality of life (Arch & Mitchell, 2015; Feros et al., 2013).

Future research may benefit from exploring the use of mindfulness and ACT-based interventions specifically to support breast cancer patients affected by treatment-related hair loss, at levels 4 and 5 of the framework in figure 16. Following the MRC guidance, this included exploring their acceptability and feasibility, before piloting the interventions to exploring the recruitment procedure, before rolling out a large scale RCT of the interventions to explore if they could offer any benefit to patients.

7.5 Reflection

This section outlines my reflection on the ARC framework, my personal experience of the methods used and of conducting mixed methods research. A reflective diary was kept throughout, which proved useful at each stage of the research process. A summary of the key points from the reflective diary are included below.

I have always had a passion for appearance and body image research. I found the process of conducting the research to be extremely challenging at times but I have also found it enjoyable and I feel like it has been a steep learning curve. I had no experience of conducting a systematic review but fortunately I was able to attend the Health Psychology Doctorate lectures on systematic reviews. Once I knew what a systematic review involved, I enjoyed conducting the review; however, it was tedious at times; especially when checking thousands of study titles. After determining the final studies for my review, I found reading and quality checking the studies enjoyable.

I found the qualitative interviews daunting at first, particularly as I was concerned that I was inconveniencing the patients at a very difficult time; when they are undergoing treatment. As soon as the interviews commenced I relaxed and enjoyed listening to women's experiences. I was honoured when many of the women thanked me for listening to their experiences and said that talking about their experiences had really helped them. I was initially surprised to find that the women's experiences of treatment-related hair loss were so diverse and at times I was concerned when some

women disclosed difficult experiences, however, I had a very supportive supervision team which I was able to discuss these concerns with afterwards.

One of my greatest difficulties has been the NHS ethics process and navigating my way through this process. I spoke to several people from my research centre who had experience of the NHS process and sought their advice prior to applying for NHS ethics, but as the process changes frequently; they were not always able to provide any assistance with the process.

I felt that it was imperative that I invested a considerable amount of time and effort in meeting with various gate keepers and health professionals prior to commencing each study. In advance of recruiting for the HeadStrong study, I attended a meeting with senior staff members from Breast Cancer Care to ascertain information about the HeadStrong service and to arrange for me to attend a number of HeadStrong sessions; to gain an insight into the service and to meet the volunteers that deliver the service. I attended numerous meetings and research forums in order to meet with health professionals to inform them of my expressive writing study; to ask them for their advice at the planning stage of the research, and for their assistance with recruitment. I was quite apprehensive prior to my initial meeting with the health professionals as it was crucial that I made a good impression. However, I found that all meetings went exceptionally well, with all health professionals being very supportive of my research, and my confidence increased as I undertook more meetings.

The research process has increased my awareness of the practicalities and further reinforced the importance of conducting applied research. I feel that my confidence both as a human being and as a researcher, along with my research skills have grown considerably over the course of the research process and it has helped to highlight future areas for professional development.

7.5.1 Reflection on the ARC framework

This program of research was informed by the ARC framework (2009) which demonstrated the importance of a theoretical framework of pre-disposing factors and

moderating factors in determining psychosocial adjustment to treatment-related hair loss, further details can be found in section 1.14. This is the first time the ARC framework has been used with individuals with breast cancer. It was used as a starting point to explore psychosocial interventions to support breast cancer patients who are affected by treatment-related hair loss. Specifically, the ARC framework informed the development of the questionnaires used in the quantitative evaluation of HeadStrong and the expressive writing feasibility study. Utilisation of the ARC framework was advantageous in gaining an insight into the pre-disposing factors of adjustment to treatment-related hair loss and an understanding of participants' thought processes including the value they placed on their appearance and in determining their adjustment to their altered appearance. Unfortunately, it was not possible to test the ARC framework in full due to the small sample size in both studies, therefore, support for the framework is limited and no definitive conclusions about its suitability with this group can be made. If researchers were to consider using the ARC framework in the future, a key consideration would be; what are the key predisposing factors, intervening cognitive processes and outcomes in adjusting to an altered appearance. Although it is difficult to predict what the rate of uptake would be to a study, it is important to optimise recruitment and try to overcome any foreseeable barriers to recruitment, in order to be able to test the ARC framework to the full.

7.5.2 Reflection on the methods used

The widely used MRC (2008) framework also guided this program of applied research, which has taken a stepwise mixed methods approach. Following the MRC framework, firstly, a systematic review was conducted which allowed a rigorous consideration of the quality of evaluations of interventions for people affected by hair loss. Secondly, the exploratory nature of qualitative research enabled an in-depth understanding of women's experiences of treatment-related hair loss and of the HeadStrong service. All participants in the qualitative and quantitative HeadStrong study were recruited through the support charity Breast Cancer Care, suggesting they either wanted support or to share their experiences in order to be able to help others in the future. Interviews used in the qualitative HeadStrong study allowed women to

recall their experiences in detail and allowed me to gain an understanding of their experiences. Building a rapport is an essential part of the interview process and it was relatively easy to build a rapport with the participants; it was important for them to feel comfortable and able to talk openly and share their experiences without judgement.

As a consequence of having become familiar with the breast cancer literature and having observed a few HeadStrong sessions prior to conducting the interviews, it was anticipated that participants would have emotional stories to tell and it would be important to be mindful of being empathetic to their experiences. The majority of women's stories were extremely positive about the support they had received from health professionals, through HeadStrong and from their family and friends. Several women commented that they found the interview helpful and appreciated the opportunity to speak to someone outside of their immediate family or friends. Every woman who consented to participate in the qualitative HeadStrong study was interviewed. The low attrition rate may reflect a desire from participants to re-pay the HeadStrong volunteers and service providers for their help and support. A strength of both the qualitative and quantitative HeadStrong studies was the recruitment of individuals from several different HeadStrong centres.

The study helped to understand participants' experiences of the HeadStrong service, allowing an executive summary report to be compiled and given to Breast Cancer Care (see appendix 35). As discussed previously in chapter 5, the researcher attended a meeting with the Director of Services and Engagement, along with the Heads of Services at Breast Cancer Care, to present the findings from the study and to discuss the implications for practice, which the charity has now considered whilst reviewing its provision of the HeadStrong service. As a result of the study findings, Breast Cancer Care has altered the HeadStrong service, so that it is tailored to individuals' needs.

Recruitment was difficult for both the quantitative HeadStrong service evaluation and the expressive writing study. On reflection, the timing of the interventions and

studies needs careful consideration. Time since participants' diagnosis in the qualitative HeadStrong study was 8 months compared to 1.9 months in the quantitative study and 30.02 months in the expressive writing study (however there was a very wide range in this study: 1.5 months - 15 years 11 months). Patients newly referred for chemotherapy attend numerous hospital appointments and are also adjusting to their diagnosis, whereas those further along their cancer journey may have had time to make this adjustment and have more time to take part in research as the commitment to treatment and check-ups reduces. The side effects of treatment may play a role in patients' uptake of the invitation to participate in research. Research has highlighted that more than a quarter (28%) of patients report that their arms were swollen or tender to some extent, including difficulties with mobility and undertaking usual activities (DoH, 2012). These physical factors could influence recruitment into study such as the HeadStrong and expressive writing intervention, where participants were asked to complete questionnaires on a number of occasions soon after diagnosis or amidst treatment regimes. The question remains as to what extent women in these studies are representative of breast cancer patients affected by treatment-related hair loss. It is difficult to know whether the women who declined to participate would differ from those who took part. However, it has previously been noted that any research into a sensitive topic will have an inevitable bias, since individuals who are finding a situation stressful may be reluctant to participate (Kent, 2000).

The possible burden that the research may have on participants was the main reason why there was input from patients and support organisations in the planning stages of the studies (see chapter 3 for a full discussion of the use of PPI) and steps were taken to ensure that the research materials would not be overly burdensome. Also, it was important to make the materials accessible, in order to hopefully increase recruitment. However, research is needed to explore this further, particularly if looking to recruit patients at a later stage in their cancer journey who are experiencing the ongoing distress of hair loss.

As previously discussed in chapter 3, RCTs are considered to be the gold standard in health research, but they require larger sample sizes than were possible in the current

studies. Based on the literature discussed in chapter 3 a number of incentives, including financial, were provided to individuals in the hope that it would help recruitment; however, this was not the case. The importance of maintaining regular contact with participants has been highlighted in the literature (see chapter 3), therefore, for both the quantitative and expressive writing studies, the researcher regularly contacted both the participant and healthcare professionals who were helping to identify eligible participants. This was found to be beneficial, particularly for the expressive writing study, where having the researcher present in the oncology department served two purposes; firstly, it helped to remind healthcare professionals to identify eligible participants. A number of health care professionals commented that because they are understandably extremely busy it was good to see the researcher as a reminder to identify eligible patients. Secondly, it enabled eligible patients to ask the researcher any initial questions that they may have had. Also, for both the HeadStrong service evaluation and expressive writing study, building a rapport with the researcher may have made both the health professionals and patients feel more confident in asking questions regarding the studies. However, there are still barriers to recruitment and it is important to find ways of overcoming the challenge of recruiting breast cancer patients for psychosocial interventions. Future researchers run the risk of facing the same challenges and pitfalls which could potentially impede future research in this area (Cope, 2015).

It is important to acknowledge there are some methodological limitations to this program of research. Firstly, a problem with applied research of this nature, as discussed above, is the need for the researcher to build rapport with health professionals in order to obtain access to participants. Yet this could have impacted on recruitment if eligible patients were perhaps concerned that the researcher was not independent from their medical team. Whilst every effort was made to ensure confidentiality in each study, there is a possibility that women who were dissatisfied with any aspect of the care they have received might not participate for fear that what they say may be reported back to the health professionals or HeadStrong volunteers.

7.5.3 Reflection on the methodology

There are benefits of combining qualitative and quantitative research methods; some researchers have even argued that it results in superior research (Johnson & Onwuebbuzie, 2004; Yardley & Bishop, 2015). Mixed methodology was deemed most appropriate for addressing the different research questions within this thesis (Lee & Rowlands, 2015). A pragmatic approach was taken as the researcher believed that despite there being fundamental epistemological differences between quantitative and qualitative approaches, these methods are complementary (Bishop, 2015). Several benefits of using mixed methods included gathering different types of data that would be useful to various stakeholders including Breast Cancer Care, which was a key consideration related to the utility of the findings. Whilst it may have been easier to maintain the integrity of each method using a sequential design, a benefit of using a concurrent triangulation design for the HeadStrong study meant links were made between the qualitative and quantitative components.

There are limitations to both qualitative and quantitative approaches, including the findings from qualitative methods not being generalisable as they are unique to the participant group being studied and quantitative methods focusing solely on hypothesis testing (Johnson & Onwuegbuzie, 2004) (see chapter 3 for further details). The researcher took the view that quantitative and qualitative approaches provide complementary information in order to offer a more comprehensive understanding of breast cancer patients' experiences of treatment-related hair loss and their psychosocial support needs (Bishop, 2015). It meant that the limitations of quantitative methods were compensated by the advantages of qualitative methods, and vice versa. However, not all findings were found to be complementary, which is a challenge of mixed methods research. The qualitative HeadStrong findings along with those from the quantitative HeadStrong study and systematic review helped to guide the development of the expressive writing study, specifically the systematic review found that hospital interventions were the most beneficial, however, women in the HeadStrong study indicated that timing was an issue in attending support services at a hospital, which also served as a reminder of their cancer and participants wanted more emotional support. Therefore, a remote intervention was

deemed more appropriate. Also, the SR and HeadStrong studies identified a need for an intervention to help patients express their feelings and emotions, which the expressive writing intervention aimed to do.

A challenge of mixed methods research is the integration of the qualitative and quantitative methods during analysis and integration (Tariq & Woodman, 2010), however, a main reason for using a mixed methods approach was to enable triangulation for the HeadStrong study (Howe, 2012), allowing the exploration of breast cancer patients' experiences of treatment-related hair loss and preferences for psychosocial support through the use of different perspectives. Integration meant pondering over the findings, checking the fit of each new set of interpretations with developing understanding. A complete synthesis was not necessarily the aim of this research, therefore, meanings do not necessarily have to be consistent to be valid, they can be seen as multi-dimensional (Mason, 2006). Despite a qualitative approach being deemed more appropriate in exploring individual experiences of a phenomenon, the collection of quantitative data is equally important as it allowed the exploration of women's experiences of the HeadStrong service as they accessed it, whereas the qualitative study was asking people to reflect back on their experiences which may have been several months earlier.

To summarise, this program of research has demonstrated the usefulness of mixed methods research to examine psychosocial interventions to support breast cancer patients affected by treatment-related hair loss. The methodologies used in this program of research have produced a range of data that have complementary applications, permitting different kinds of understanding and knowledge. Whilst the feasibility of a quantitative, randomised controlled trial was worthy of consideration for the expressive writing study, qualitative methods were necessary to explore individuals' experiences of the HeadStrong service. Having completed this research program, the pragmatic approach undertaken is still considered the most appropriate for this applied research.

7.5.4 Reflection on patient and public involvement (PPI)

Patient involvement has played a vital role within this research. It was used for a number of reasons, including the hope of overcoming recruitment challenges (Jones et al., 2015). Whilst there are a number of advantages to PPI, which have been discussed in chapter 3, there are also limitations. The main limitation is that a PPI representative cannot represent the views of every other patient, if they are relying on their own experience to inform their views and advice to the research team. This is why it was important to not only rely on one patient advisor and why Breast Cancer Voices were also consulted both for the HeadStrong evaluation and expressive writing study. Also, it must be acknowledged that those who choose to be involved in research as PPI volunteers are highly motivated and may differ in this, and other ways, to those who choose not to be involved in research but might still be the recipients of future interventions and care that result from it.

Moving forward with PPI, it is important that researchers take time to explain each step of the research process if patients and service users acting as PPI representatives are unfamiliar with it. For example, a particular challenge of using PPI in this program of research was that service users did not like the wording used in some of the information sheets and instructions on the questionnaires used in the quantitative studies. It was therefore important to re-phrase some of the wording so they were more user friendly to participants. It is acknowledged that a lack of awareness or understanding about the research process can lead to unrealistic expectations (Wright et al., 2007), which is why it was important for the researcher to meet with the user representative on a regular basis, to build a rapport and to gain an understanding of the user representative's expectations.

7.6 Summary of the main findings

As discussed previously, the first stage of the research was to conduct a systematic review of the available evidence of the effectiveness of psychosocial interventions to support people affected by hair loss. The systematic review revealed several characteristics of the successful interventions; intervention delivery soon after hair

loss, information provision, individual based intervention; and an opportunity for individuals to express their concerns. The second stage of the research involved taking a mixed methods approach to evaluate the HeadStrong service. The findings suggest HeadStrong can be an important and helpful intervention for breast cancer patients affected by hair loss, but it does not necessarily meet all of their needs. It was highlighted that there is still potential to develop a range of interventions for this patient group. The third stage in this program of research considered the feasibility of an expressive writing intervention to support this patient group. Although the expressive writing was found to be appealing to some, based on the small sample size no definitive conclusions could be made. Please see appendix 20 for a list of conferences and research events were the findings from this program of research have been disseminated.

7.7 Conclusions

This program of research has explored psychosocial interventions to support breast cancer patients affected by treatment-related hair loss. It has contributed to the limited body of research in this area by highlighting the relevance of this issue to those affected, giving an overview of the psychosocial support needs of this particular group and of the psychosocial support currently available to them. Also, it has considered the acceptability and feasibility of an expressive writing intervention which has not previously been tested in this context. Whilst generalisations cannot be made due to the small sample sizes in each of the studies, the research provides a basis for further research in this area. Moreover, women's individual psychosocial support needs in relation to their hair loss need greater recognition and further research is advised to determine the most appropriate means of providing individualised, effective support to meet the needs of this patient group.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., … Takeda, F. (1993). For the European Organization on Research and Treatment of Cancer Study Group on Quality of Life. The European Organization on Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials. *Journal of the National Cancer Institute, 85*, 365-376.

Abraham, C., & Michie, S. (2008). A taxonomy of behavior change techniques used in interventions. *Health Psychology, 27*(3), 379-87. Doi: 10.1037/0278-6133.27.3.379

Agency for Healthcare Research and Quality. (2002). *Systems to Rate the Strength of Scientific Evidence*. Retrieved 20th September, 2012 from http://archive.ahrq.gov/clinic/epcsums/strengthsum.pdf

Alexander, S., Palmer, C., & Stone, P. C. (2010). Evaluation of screening instruments for depression and anxiety in breast cancer survivors. *Breast Cancer Research and Treatment, 122*(2), 573-578.

Alise, M. A., & Teddlie, C. (2010). A continuation of the paradigm wars? Prevalence rates of methodological approaches across the social/behavioral sciences. *Journal of Mixed Methods Research, 4*(2), 103-126.

All Party Parliamentary Group on Body Image (APPG. (2012). *Reflections on Body Image.* London: All Party Parliamentary Group on Body Image.

Altman, D. G., Schultz, K. F., Moher, D., Egger, M., Davidoff, F., Elbourne, D., … Lang, T. (2001). The revised CONSORT statement for reporting randomised trials: Explanation and elaboration. *Annals of Internal Medicine, 134*(8), 663-694.

Ambler, N., Rumsey, N., Harcourt, D., Khan, F., Cawthorn, S., & Barker, J. (1999). Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: comparing advocacy with a conventional approach. *Journal of Advanced Nursing, 29*(2), 445-453.

Amiel, P., Dauchy, S., Bodin, J., Cerf, C., Zenasni, F., Pezant, E., … DiPalma, M. (2009). Evaluating beauty care provided by the hospital to women suffering from breast cancer: qualitative aspects. *Support Cancer Care, 17*, 839-845.

Amir, Z, Scully, J. & Borrill, C. (2004). The professional role of breast cancer nurses in multi-disciplinary breast cancer care teams. *European Journal of Oncology Nursing, 8*(4), 306-14.

Anderson, B. O., Shyyan, R., Eniu, A. E., Smith, R. A., Yip, C., Bese, N. S., … Carlson, R. W. (2006). Breast cancer in limited resource countries: an

overview of the Breast Health Global Initiative 2005 guidelines. *The Breast Journal, 12*(suppl. 1), S3 –15.

Arain, M., Campbell, M. J., Cooper, C. L., & Lancaster, G. (2010). What is a pilot or feasibility study?: a review of current practice and editorial policy. *BMC Medical Research Methodology, 10*, 67. 10.1186/1471-2288-10-67.

Arch, J. J. & Mitchell, J. L. (2015). An acceptance and commitment therapy (ACT) group intervention for cancer survivors experiencing anxiety at re-entry. *Psycho-Oncology*, (early view) Doi: 10.1002/pon.3890

Arigo, D., & Smyth, J. M. (2012). The benefits of expressive writing on sleep difficulty and appearance concerns for college women. *Psychology & Health, 27*(2), 210-226.

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32, DOI: 10.1080/1364557032000119616

Armes, J., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., … Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology, 27(36)*, 6172–6179.

Armijo-Olivo, S., Stiles, S. R., Hagen, N. A., Biondo, P. D., & Cummings, G. G. (2012). Assessment of study quality for systematic reviews: a comparison of the Cochrane Collaboration Risk of Bias Tool and the Effective Public Health Practice Project Quality Assessment Tool: methodological research. *Journal of Evaluation in Clinical Practice, 18*, 12-18.

Arora, N. K., Johnson, P., Gustafson, D. H., McTavish, F., Hawkins, R. P., & Pingree, S. (2002). Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. *Patient Education and Counselling, 47*, 37–46.

Arving, C., Brandberg, Y., Feldman, I., Johansson, B., & Glimelius, B. (2014). Cost-utility analysis of individual psychosocial support interventions for breast cancer patients in a randomized controlled study. *Psycho-Oncology, 23*, 251-258.

Ashley, L., O'Connor, D. B., & Jones, F. (2011). Effects of emotional disclosure in caregivers: Moderating role of alexithymia. *Stress and Health, 27*, 376-387.

Ates, O., Soyle, C., Babacan, T., Sarici, F., Kertmen, N., Allen, D., Sever, A. R., & Altundag. (2016). Assessment of psychosocial factors and distress in women having adjuvant endocrine therapy for breast cancer: the relationship

among emotional distress and patient and treatment-related factors. *Springer Plus, 5:486*, 1-7. DOI 10.1186/s40064-016-2136-2

Attree, P., Morris, S., Clifton, M., Hinder, S., & Vaughan, S. (2009). *Exploring the Impact of User Involvement on Health and Social Care Services for Cancer in the UK. Final Report*. London, UK: Macmillan Cancer Support.

Auvinen, P. K., Mähönen, U. A., Soininen,K. M., Paananen, P. K., Ranta-Koponen, P. H., Saavalainen, I. E., & Johansson, R. T. (2010). The effectiveness of a scalp cooling cap in preventing chemotherapy-induced alopecia. *Tumori, 96*, 271-275.

Avis, N. E., Crawford, S., & Manuel, J. (2004). Psychosocial problems among younger women with breast cancer. *Psycho-oncology, 13*, 295-308. Doi: 10.1002/pon.744

Bagby, M. R., Parker, J. D. A., & Taylor, G. J. (1994). The twenty-item Atoronto Alexithymia Scale-I. Item selection and cross-validation of the factor structure. *Journal of Psychosomatic Research, 38*, 23-32.

Bagby, M. R., Taylor, G. J., & Parker, J. D. A. (1994). The twenty-item Toronto Alexithymia Scale- II. Convergent, discriminant, and concurrent validity. *Journal of Psychosomatic Research, 38*, 33-40.

Baikie, K. A. (2008). Who does expressive writing work for? Examination of alexithymia, splitting, and repressive coping style as moderators of the expressive writing paradigm. *British Journal of Health Psychology, 13*, 61-66.

Baildam, A., Keeling, F., Noblet, M., Thomson, L., Bundred, N., & Hopwood, P. (2002). Nurse led follow-up clinics for women treated for primary breast cancer: a randomised controlled trial. *European Journal of Cancer, 38* (suppl. 3), 136.

Banning, M. (2007). Advanced breast cancer: aetiology, treatment and psychosocial features. *British Nursing Journal, 16*(2), 86-90.

Barley, E. A., Haddad, M., Simmonds, R., Fortune, Z., Walters, P et al. (2012). The UPBEAT depression and coronary heart disease program: using the UK medical research council framework to design a nurse-led complex intervention for use in primary care. *BMC Family Practice, 13*(1), 1-13.

Batchelor, D. (2001). Hair and cancer chemotherapy: consequences and nursing care – a literature study. *European Journal of Cancer Care, 10(3)*, 147-163.

Batten, S. V., Follette, V. M., Hall, M. L. R., & Palm, K. M. (2002). Physical and psychological effect of written disclosure among sexual abuse survivors. *Behavior Therapy, 33*, 107-122.

Baucom, D. H., Porter, L. S., Kirby, J. S., Gremore, T. M., & Keefe, F. J. (2006). Psychosocial issues confronting young women with breast cancer. *Breast Disease, 23*, 103-113.

Baum, E. S., & Rude, S. S. (2013). Acceptance-enhanced expressive writing prevents symptoms in participants with low initial depression. *Cognitive Therapy and Research, 37*, 35-42.

Baxter, N. (1998). *The Body Image After Breast Cancer Questionnaire: The design and testing of a disease specific measure*. PhD Thesis. University of Toronto.

Baxter, N. N., Goodwin, P. J., Mcleod, R.S., Dion, R., Devins, G., & Bombardier, C. (2006). Reliability and validity of the Body Image After Breast Cancer Questionnaire. *The Breast Journal, 12*(3): 221 - 232.

Beck, A. T. (1961). *Beck depression inventory*. Philadelphia: Center for Cognitive Therapy.

Beckwith McGuire, K. M., Greenberg, M,. A., & Gevirtz, R. (2005). Autonomic effects of expressive writing in individuals with elevated blood pressure. *Journal of Health Psychology, 10*, 197-209.

Benjamin, B., Ziginskas, D., Harman, J., & Meakin, T. (2002). Pulsed electrostatic fields (ETG) to reduce hair loss in women undergoing chemotherapy for breast carcinoma: A pilot study. *Psycho-Oncology, 11*(3), 244-248.

Beresford, P. (2005) 'Service user': regressive or liberatory terminology? *Disability and Society, 20* (4), 469–477.

Beresford, P. (2007). User involvement, research and health inequalities: developing new directions. *Health and Social Care in the Community, 15*(4), 306-312.

Beresford, P. (2013). Beyond the usual suspects. Retrieved September 2014, from http://www.shapingourlives.org.uk/documents/BTUSReport.pdf

Bessell, A. (2009). *Facing up to visible difference: The design and evaluation of a new computer-based psychosocial intervention*. PhD Thesis. University of the West of England, Bristol, UK.

Bessell, A., Brough, V., Clarke, A., Harcourt, D., Moss, T. P., & Rumsey, N. (2012). Evaluation of the effectiveness of Face IT, a computer-based psychosocial intervention for disfigurement-related distress. *Psychology, Health & Medicine, 17*, (5), 565-577, DOI: 10.1080/13548506.2011.647701

Bessell, A., Clarke, A., Harcourt, D., Moss, T. P., & Rumsey, N. (2010). Incorporating user perspectives in the design of an online intervention tool

for people with visible differences: Face IT. *Behavioural and Cognitive Psychotherapy, 38,* 577-596.

Bessell A., & Moss, T. P. (2007). Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: A systematic review of the empirical literature. *Body Image, 4*, 227-238.

Bidstrup, P. E., Christensen, J., Mertz, B. G., Rottmann, N., Dalton, S. O., & Johansen, C. (2015). Trajectories of distress, anxiety and depression among women with breast cancer: looking beyond the mean. *Act Oncologica, 54*, 789-796.

Biondo, S., & Collins, F. E. (2003). Bad hair life 2: A proposed group psychological intervention for women with hair loss. *Australian Journal of Psychology*, *55*, 167.

Bird, G. F. (1992). Program writing as a method for increasing self-esteem, self-disclosure and coping skills. *Dissertation Abstracts International, 53,* 2536.

Bishop, F. L. (2015). Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British Journal of Health Psychology*, *20*, 5-20.

Blackmore, T., & Simmons, B. R. (2008). *Cornwall centre for independent living (CIL) focus group outcomes report*. Cornwall Disability Research Network.

Blackwood, B., O'Halloran, P. & Porter, S. (2010). On the Problems of Mixing RCTs with Qualitative Research: The Case of the MRC Framework for the Evaluation of Complex Healthcare Interventions. *Journal of Research in Nursing*, *15*(6), 511-521.

Bodor, N. Z. (2002). *The Health Effects of Emotional Disclosure for Individuals with Type 1 Diabetes*. Doctoral dissertation. Austin, Texas: University of Texas.

Boehmke, M. M., & Dickerson, S. S. (2005). Symptom, symptom experience, and symptom distress encountered by women with breast cancer undergoing current treatment modalities. *Cancer Nursing, 28*(5), 382-389.

Boinon, D., Sultan, S., Charles, C., Stulz, A., Guillemeau, C., Delaloge, S., & Dauchy, S. (2014). Changes in psychological adjustment over the course of treatment for breast cancer: the predictive role of social sharing and social support. *Psycho-Oncology, 23*, 291-298.

Bonito, A., Horowitz, N., McCorkle, R., & Chagpar, A. B. (2013). Do healthcare professional discuss the emotional impact of cancer with patients? *Psycho-Oncology, 22*, 2046-2050.

Boonzaier, A., Pollard, A., Ftanou, M., Couper, J. W., Schofield, P., Mileshkhin, L., & Henderson, M. (2010). The practical challenges of recruitment and retention when providing psychotherapy to advanced breast cancer patients. *Support Care Cancer, 18,* 1605-1613.

Booth, A. (2006). Using research in practice: Australian supermodel? A practical example of evidence-based library and information practice. *Health Info Library Journal, 23,* 69–72.

Borsellino, M., & Young, M. M. (2011). Anticipatory coping: taking control of hair loss. *Clinical Journal of Oncology Nursing, 15*(3), 311-315.

Bos, A. E. R., Schaalma, H. P., & Pryor, J. B. (2008). Reducing AIDS-related stigma in developing countries: The importance of theory- and evidence-based interventions, Psychology, Health & Medicine, 13(4), 450-460, Doi: 10.1080/13548500701687171

Botchkarev, V. (2003). Molecular mechanisms of chemotherapy-induced hair loss. *Journal of Investigative Dermatology Symposium Proceedings, 8*(3), 72–75.

Bottomley, A. (1997). To randomise or not to randomise, methods and psychology. In Richardson, T. E. (ed), *Handbook or qualitative research methods,* BPS Books, Leicester.

Boyatzis, R. E. (1998). *Transforming qualitative information. Thematic analysis and code development*. London: Sage.

Boyes, A. W., Girgis, A., D'Este, C., & Zucca, A. C. (2012). Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis a population-based cross-sectional study. *BMC Cancer, 12*(1), 1-10.

Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS- SF34). *Journal of Evaluation in Clinical Practice, 15*(4): 602-606.

Boykoff, N., Moieni, M., & Subramanian, S. K. (2009). Confronting chemobrain: an in-depth look at survivors' reports of impact on work, social networks, and health care response. *Journal of Cancer Survivorship,* 3, 223–32.

Boyle, D. A. (2006). Survivorship. *Clinical Journal of Oncology Nursing, 10*: 407-416.

Brandes, K., Linn, A. J., Butow P. N., & van Weert, J. C. M. (2015). The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. *Psycho-Oncology, 24,* 245-252.

Brennan, J. (2001). Adjustment to cancer-coping or personal transition? *Psycho-Oncology, 10,* 1-18.

Brannen, J. (2004). Working qualitatively and quantitatively. In C. Seale, G. Gobo, J.F. Gubrium, & D. Silverman (eds.), *Qualitative Research Practice*. London: Sage.

Brannen, J. (2005). Mixing methods: The entry of qualitative and quantitative approaches into the research process. *The International Journal of Social Research Methodology, Special Issue, 8*(3), 173-185.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Breast Cancer Care. (2014). *My body, myself Altered body image, intimacy and sex after breast cancer.* A policy report by Breast Cancer Care. Retrieved January 2015 from https://www.breastcancercare.org.uk/sites/default/files/files/my-body-myself-report.pdf

Brett, J., Staniszewska, S., & Mockford, C. (2010). *The PIRICOM Study. A Systematic Review of the Conceptualisation, Measurement, Impact and Outcomes of Patient and Public Involvement in Health and Social Care Research*. London: United Kingdom Clinical Research Collaboration.

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2012). 'Mapping the impact of patient and public involvement on health and social care research: a systematic review'. *Health Expectations, 17*(5), 637-650doi:10.1111/j.1369-7625-2012.00795.x

Brindle, S., Douglas, F., van Teijlingen, E., & Hundley, V. (2005). Midwifery research: questionnaire surveys. *Midwives, 8,* 4, 156-158.

British Psychological Society. (2009). *Code of ethics and conduc*t. Retrieved 18th June, 2014 from http://www.bps.org.uk/system/files/Public%20files/bps_code_of_ethics_2009.pdf

Broderick, J. E., Junghaenel, D. U., & Schwartz, J. E. (2005). Written emotional expression produces health benefits in fibromyalgia patients. *Psychosomatic Medicine, 67,* 326-334.

Broderick, J. E., Stone, A. A., Symth, J. M., & Kaell, A. T. (2004). The feasibility and effectiveness of an expressive writing intervention for rheumatoid arthritis via home-based videotape instructions. *Annual of Behavioural Medicine, 27*(1), 50-59.

Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDs stigma: What have we learned? *AIDS Education and Prevention, 15*(1), 49-69.

Brown, H. W. (2009). *African-American women's hair issues and engagement in physical activity–executive summary*. Washington, DC: American Association of Retired Persons.

Brown, D. R., Fouad, M. N., Basen-Engquist, K., & Tortolero-Luna, G. (2000). Recruitment and retention of minority women in cancer screening, prevention, and trials. *Annals of Epidemiology, 10*(8), S13-21.

Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology, 84(4)*, 822-848.

Brown, K. W., Ryan, R. M., & Creswell, J. D. (2007). Mindfulness: theoretical foundations and evidence for its salutary effects. *Psychological Inquiry, 18*, 211-237.

Bryman, A. (2006). Integrating quantitative and qualitative research: how is it done? *Qualitative Research, 6* (1), 97-113.

Buick, D. L., Petrie, K. J., Booth, R., Probert, J., Benjamin, C., & Harvey, V. (2000). Emotional and functional impact of radiotherapy and chemotherapy on patients with primary breast cancer. *Journal of Psychosocial Oncology, 18*(1), 39-62.

Burton, C. M., & King, L. A. (2008). Effects of (very) brief writing on health: the two-minute miracle. *British journal of Health Psychology, 13*, 9-14.

Cadogan, J. (2012). Changing provision of Healthcare settings in the United Kingdom. In N. Rumsey & D. Harcourt (Ed.), *The oxford handbook of the psychology of appearance* (486-501). Oxford: Oxford University Press.

Cameron, L. D. & Nicholls, G. (1998). Expression of stressful experiences through writing: Effects of a self-regulation manipulation for pessimists and optimists. *Health Psychology, 17*, 84-92.

Campbell, D., Khan, A., Rankin, N., Williams, P., & Redman, S. (2006). Are specialist breast nurses available to Australian women with breast cancer? *Cancer Nursing, 29,* 43–48.

Campbell, M. K., Snowdon, C., Francis, D., Elbourne, D., McDonald, A. M., Knight, R., … Grant, A. (2007). STEPS group: Recruitment to randomised trials: strategies for trial enrolment and participation study. The STEPS study. *Health Technology Assessment, 11*, 48-105.

Cancer Research UK. (2014). *About breast cancer chemotherapy*. Retrieved June, 2015, from http://www.cancerresearchuk.org/about-cancer/type/breast-cancer/treatment/chemotherapy/about-breast-cancer-chemotherapy

Cancer Research UK. (2015). *Breast Cancer incidence*. Retrieved June, 2015, from http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by- cancer-type/breast-cancer#heading-Zero

Carelle, N., Piotto, E., Bellanger, A., Germanaud, J., Thuillier, A., & Khayat D. (2002). Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer, 95*, 155–163.

Carnevale, F. A. (2007). Revisiting Goffman's stigma: the social experience of families with children requiring mechanical ventilation at home. *Journal of Child Health Care, 11*(1), 7-18.

Carpenter, D. M., Geryk, L. L., Chen, A. T., Nagler, R. H., Dieckmann, N. F., & Han, P. K. J. (2015). Conflicting health information: a critical research need. *Health Expectations*, 1-10. Doi: 10.1111/hex.12438

Carr, T., Moss, T., & Harris, D. (2005). The DAS24: A short form of the Derriford Appearance Scale (DAS59) to measure individual responses to living with problems of Appearance. *British Journal of Health Psychology, 10*(2), 285-298.

Carr, W., & Wolfe, S. (1979). Unmet needs as sociomedical indicators. *International Journal of Health Services, 6*, 417–429.

Carver, C. S., & Antoni, M. H. (2004). Finding Benefit in Breast Cancer During the Year After Diagnosis Predicts Better Adjustment 5 to 8 Years After Diagnosis. *Health Psychology, 23*(6), 595–598.

Carver, C. S. (2013). Sources of Social Support Scale (SSSS). *Measurement Instrument Database for the Social Science*. Retrieved July 2014 from www.midss.ie

Casellas-Grau, A., Font, A., & Vives, J. (2014). Positive psychology interventions in breast cancer. A systematic review. *Psycho-Oncology, 23*, 9-19.

Cash, T. F. (2001). The psychology of hair loss and it's implications for patient care. *Clinics in Dermatology, 19*, 161-166.

Cash, T. F. (2003). *Brief manual for the Appearance Schemas Inventory-Revised*. Unpublished manual. Department of Psychology Old Dominion University Norfolk, Virginia.

Cash, T. F., Melnyk, S. E., & Hrabosky, J. I. (2004). The assessment of body image investment: An extensive revision of the appearance schemas inventory. *International Journal of Eating Disorders, 35*(3), 305-316.

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., … Harris, J. (1993). The Functional Assessment of Cancer Therapy Scale: Development and validation of the general measure. *Journal of Clinical Oncology, 11*(3), 570 - 579.

Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care.* York , UK: Centre for Reviews and Dissemination.

Chamberlain, K. (2000). Methodology and qualitative health research. *Journal of Health Psychology, 5*(3), 285-296.

Chen, C. M., Cano, S. J., Klassen, A. F., King, T., McCarthy, C., Cordeiro, P. G., … Pusic, A. L. (2010). Measuring quality of life in oncologic breast surgery: A systematic review of patient-reported outcome measures. *The Breast Journal, 16*(6), 587 - 597.

Choi, E. K., Kim, I., Chang, O., Kang, D., Nam, S., Lee, J. E., … Cho, J. (2014). Impact of chemotherapy-induced alopecia distress on body image, psychosocial well-being, and depression in breast cancer patients. *Psycho-Oncology, 23*, 1103-1110.

Chua, A. S., DeSantis, S. M., Teo, I., & Fingeret, M. C. (2015). Body image investment in breast cancer patients undergoing reconstruction: Taking a closer look at the Appearance Schemas Inventory-Revised. *Body Image, 13*, 33-37.

Clarke, A. (1998). 'What happened to your face?' Managing facial disfigurement. *British Journal of Community Nursing*, 3(1): 13-16.

Clarke, A., & Cooper, C. (2001). Psychological rehabilitation after disfiguring injury or disease: Investigating the training needs of specialist nurses. *Journal of Advanced Nursing, 34*(1), 18-26.

Clarke, P., & Evans, S. (1990). New interactive TV program helps patients cope with hair loss. *Oncology, 4*(9),126.

Clarke, A., Thompson, A. R., Jenkinson, E., Rumsey, R., & Newell, R. (2013). *CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety due to Visible Difference*. London: Wiley-Blackwell.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98,* 310–357.

Collett, A., Al-Tameemi, W., Dunnill, C., Hussain, O., & Georgopoulos. N. (2014). The role of scalp cooling in the prevention of Chemotherapy Induced Alopecia. *European Journal of Clinical and Medical Oncology Special Edition*, 65–69.

Collins, B., Mackenzie, J., Stewart, A., Bielajew, C., & Verma, S. (2009). Cognitive effects of chemotherapy in post-menopausal breast cancer patients 1 year after treatment. *Psychooncology,18*(2), 134–143.

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO. The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research, 22,* 1435–1443.

Cooley, M. E., Sarna, L., Brown, J. K., Williams, R. D., Chernecky, C., Padilla, G., & Danao, L. L. (2003). Challenges of recruitment and retention in multisite clinical research. *Cancer Nursing, 26,* 376-384.

Cope, D. (2015). Conducting pilot and feasibility studies. *Oncology Nursing Forum, 42*(2), 196–197. Doi: 10.1188/15.ONF.196-197

Cosmetics, Toiletries and Fragrances Association. (2015). *Look good, feel better. Cosmetics,Toiletries and Fragrances Association*. Retrieved 1st July, 2015 from http://lookgoodfeelbetter.org/about-lgfb/our-mission

Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanlet, B., Sargeant, A., … Staley, K. (2010). Service user involvement in cancer care: the impact on service users. *Health Expectations, 14,* 159-169.

Coughlan, G., & Clarke, A. (2002). Shame & burns. In P. Gilbert, & J. Miles (Eds.), *Body shame* (pp. 155-170). Hove: Brunner-Routledge.

Craft, M. A., Davis, G. C., & Paulson, R. M. (2012). Expressive writing in early breast cancer survivors. *Journal of Advanced Nursing, 69*(2), 305-315.

Craig, P., Dieppe, P., Macintyre, S., Mitchie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions the new Medical Research Council guidance. *BMJ, 337,* 979- 983.

Craig, P., & Petticrew, M. (2013). Developing and evaluating complex interventions: Reflections on the 2008 MRC guidance. *International Journal of Nursing Studies, 50,* 585-592.

Creswell, J. D., Lam, S., Stanton, A. L., Taylor, S. E., Bower, J. E., & Sherman, D. K. (2007). Does Self-Affirmation, Cognitive Processing, or Discovery of Meaning Explain Cancer-Related Health Benefits of Expressive Writing? *Personality & Social Psychology Bulletin, 33,* 238-250.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research.* (2nd ed.) Thousand Oaks, CA: Sage.

Creswell, J. W., Plano Clark, V. L., & Garrett, A. L. (2008). Methodological issues in conducting mixed methods research designs. In M. M. Bergman (Ed.), *Advances in mixed methods research* (pp. 66–83). London: Sage.

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research design. In A. Tashakkori & C Teddlie (Eds.), *Handbook of mixed methods in social and behavioural sciences* (3rd ed.), Mahwah, NJ: Lawrence Erlbaum.

Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D. T. Gilbert & S. T. Fiske (Eds.), *The handbook of social psychology* (pp. 504–553). Boston: McGraw-Hill.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika, 16,* 297-334.

Cruickshank, S., Kennedy, C., Lockhart, K., Dosser, I., & Dallas, L. (2008). *Specialist breast care nurses for supportive care of women with breast cancer*. Retrieved from http://www2.cochrane.org/reviews /en/ab005634.html

Daigneault, P., & Jacob, S. (2014). Unexpected but most welcome: mixed methods for the validation and revision of the participatory evaluation measurement instrument. *Journal of Mixed Methods Research, 8*(1), 6-24.

Danoff-Burg, S., Mosher, C. E., Seawell, A. H., & Agee, J. D. (2010). Does narrative writing instruction enhance the benefits of expressive writing?. *Anxiety, Stress, & Coping, 23*(3), 341-352.

Daugherty, C., Ratain, M.J., Grochowski, E., Stocking, C., Kodish, E., Mick, R., Siegler, M. (1995). Perceptions of cancer patients and their physicians involved in phase 1 trials. *Journal of Clinical Oncology, 13*(5), 1062-1072.

Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health Research, 12*(2), 279-289.

Delamere, F. M., Sladden, M.J., Dobbins, H. M., & Leonardi-Bee, J. (2008). Interventions for alopecia areata. *Cochrane Database of Systematic Reviews,* Issue 2. Art. No: CD004413. Doi: 10.1002/14651858.

De Moor, C., Sterner, J., Hall, M., Warneke, C., Gilani, Z., Amato, R., & Cohen, L. (2002). A pilot study of the effects of expressive writing on psychological and behavioural adjustment in patients enrolled in a Phase II trial of vaccine therapy for metastatic renal cell carcinoma. *Health psychology, 21*, 615-619.

Den Heijer, M., Seynaeve, C., Vanheusden, K., Duivenvooren, H. J., Vos, J., Bartels, C. C. M., Menke-Pluymers, M. B.E., & Tibben, A. (2011). The contribution

of self-esteem and self-concept in psychological distress in women at risk of hereditary breast cancer. *Psycho-Oncology, 20*(11), 1170-1175.

Denieffe, S., & Gooney, M. (2011). A meta-synthesis of women's symptoms experience and breast cancer. *European Journal of Cancer Care, 20*(4), 424-435.

Denscombe, M. (2008). Communities of practice: A research paradigm for the mixed methods approach. *Journal of Mixed Methods Research, 2*, 270 - 283.

De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C., & Patel, V. (2014). Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials, 15*, 267. Doi:10.1186/1745-6215-15-267

Denzin, N. K., & Lincoln, Y. (2005). *Handbook of qualitative research*. Sage Publications, Thousand Oaks, CA.

Department of Health. (2005). *Creating a patient-led NHS. Delivering the NHS improvement plan*. Retrieved 16th May, 2015 From http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106506

Department of Health. (2006a). *Best Research for Best Health: A New National Health Research Strategy*. London, UK.

Department of Health. (2006b). *Reward and Recognition*. Department of Health, London.

Department of Health. (2007). *Cancer Reform Strategy*. London, UK.

Department of Health. (2011). *Improving outcomes: A strategy for cancer*. London: Department of Health.

Department of Health. (2012). *Quality of life of cancer survivors in England: Report on a pilot survey using Patient Reported Outcome Measures (PROMS)*. Retrieved 18th May from https://www.gov.uk/government/publications/cancer-survivors-give-their-views-in-pilot-survey

Department of Health, Macmillan Cancer Support & NHS improvement. (2013). *Living with & beyond Cancer: taking action to improve outcomes*. Retrieved 16th May 2015 from https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes

Dimoska, A., Butow, P. N., Lynch, J., Hovery, E., Agar, M., Beale, P., & Tattersall, M. H. N. (2012). Implementing patient question-prompt lists into routine cancer care. *Patient Education and Counseling, 86*, 252-258.

Donovan, J. L., Paramasivan, S., de Salis, I., & Toerien, M. (2014). Clear obstacles and hidden challenges: understanding recruiter perspective in six pragmatic randomised controlled trials. *Trials, 15*(5), 1-12.

Dougherty, L. (2006). Comparing methods to prevent chemotherapy-induced alopecia. *Cancer Nursing Practise, 5*(6): 25–31

Downey, L., & Engelberg, R. A. (2010). Quality-of-life trajectories at the end of life: Assessments over time by patients with and without cancer. *Journal of the American Geriatrics Society, 58*, 3, 472-479.

Downing, J., Knapp, C., Muckaden, M. A., Fowler-Kerry, S., & Marston, J. (2015). Priorities for global research into children's palliative care: results of an international Delphi study. *BMC Palliative Care, 14*(36), 1-10. DOI 10.11186/s12904-015-0031-1

Dugdale, S., Elison, S., Davies, G., Ward, J., & Dalton, M. (2016). *A comprehensive, multi-level investigation of the implementation of a novel digital substance misuse intervention, Breaking Free Online: conceptualising implementation processes within services using the MRC framework and health psychology theory*. Public Health. Conference Abstract: 2nd Behaviour Change Conference: Digital Health and Wellbeing. Doi: 10.3389/conf.FPUBH.2016.01.00053

Duncan, J., & Combia, J. (1987). Lessons learned while providing group counselling for adult patients with metastatic cancer. *The Journal for Specialists in Group Work, 12*, 70-75.

Dures, E., Rumsey, N., Morris, M., & Gleeson, K. (2011). Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal of Health Psychology,16,* 332–341. doi:10.1177/1359105310377537

Earnhardt, J. L., Martz, D. M., Ballard, M. E., & Curtin, L. (2002). A writing intervention for negative body image: Pennebaker fails to surpass the placebo. *Journal of College Student Psychotherapy, 17*, 19-35.

Eccles, S. A., Aboagye, E. O., Ali, S., Anderson, A. S., Armes, J., Berditchevski, F., …Thompson, A. M. (2013). Critical research gaps and translational priorities for the successful prevention and treatment of breast cancer. *Breast Cancer Research, 15*:R92.

Edvardsson, D., Sandman, P. O., & Rasmussen, B. (2014). Caring and uncaring-meanings of being in an oncology environment. *Journal of Advanced Nursing*, 55(2):188-197.

Efird, J. (2011). Block randomization with randomly selected block sizes. *International Journal of Environmental Research and Public Health, 8,* 15-20. Doi: 10.3390/ijerph8010015

Ehmann, J. L., Sheehan, A., & Decker, G. D. (1991). Intervening with alopecia: Exploring an entrepreneurial role for oncology nurses. *Oncology Nursing Forum, 18*(4), 769-773.

EPHPP. (2010). *Quality assessment tool for quantitative studies*. Retrieved January 2012 from http://www.ephpp.ca/PDF/Quality%20Assessment%20Tool_2010_2.pdf

Erni, T., Lotscher, K., & Modestin, J. (1997).Two-factor solution of the 20-item Toronto Alexithymia Scale confirmed. *Psychopathology, 30,* 335–340.

Esterling, B. A., Antoni, M. H., Fletcher, M. A., & Margulies, S. (1994). Emotional disclosure through writing or speaking modulates latent Espien-Barr virus antibody titers. *Journal of Consulting and Clinical Psychology, 62,* 130-140.

Etcoff, N. (1999). *Survival of the prettiest*: *The science of beauty*. New York: Doubleday.

Evans, C. J., Stone, K. A., Manthorpe, J., & Higginson, I. J. (2013). *MRC guidance on developing and evaluating complex interventions: Application to research on palliative and end of life care*. NIHR School for Social Care Research Methods Review.

Eveleigh, M. O., Blencowe, N. S., Mills, N., & Blazeby, J. M. (2011). Understanding the complexity of surgical procedures in RCTs: a pilot study to test the application of the MRC framework for evaluating complex healthcare interventions in the operating theatre. *Trials, 12*(1), A148. doi: 10.1186/1745-6215-12-S1-A148

Falk-Dahl, C., Reinertsen, K., Nesvold, I., Fossa, S., & Dahl, A. (2010). A study of body image in long-term breast cancer survivors. *Cancer, 116,* 3549–3557.

Fallowfield, L. (1992). Behavioural interventions and psychological aspects of care during chemotherapy. *European Journal of Cancer, 28,* 39–41.

Fawzy, F. I., Fawzy, N. W., Arndt, L. A., & Pasnau, R. O. (1995). Critical review of psychosocial interventions in cancer care. *Arch Gen Psychiatry, 50,*100-113.

Fawzy, N. W., Secher, L., Evans, S., & Giuliano, A. E. (1995). The Positive Appearance Center: An innovative concept in comprehensive psychosocial cancer care. *Cancer Practice, 3,* 233-238.

Fearon K, Strasser F, Anker SD, Bosaeus I, Bruera E, Fainsinger RL, et al. (2011). Definition and classification of cancer cachexia: an international consensus. *Lancet Oncology,12*(5), 489–495.

Feneck, O. R. (2009). Clinical research in anaesthesia: randomized controlled trial or observational studies? *European Journal of Anaesthesiology, 24,* 1–5.

Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving Integration in Mixed Methods Designs—Principles and Practices. *Health Services Research, 48*(6), 2134- 2156.

Fernandez-Taylor, S., & Bloom, J. R. (2011). Post-treatment regret among young breast cancer survivors. *Psycho-Oncology, 20,* 506-516.

Fernandez, M.E.R., Gregorio, M.A.P.S., Mas, M. B., & Rodriquez, A. M. (2012). The impact of breast reconstruction on self-esteem and body image in patients with breast cancer. *Universitas Psychologica, 11*(1), 25-41.

Feros, D. L., Lane, L., Ciarrochi, J., & Blackledge, J. T. (2013). Acceptance and commitment therapy (ACT) for improving the lives of cancer patients: a preliminary study. *Psycho-Oncology, 22,* 459-464.

Fingeret, M. C., Teo, I., & Epner, D. E. (2014). Managing body image difficulties of adult cancer patients: lessons from available research, *Cancer 120,* 633–641. doi:http://dx.doi.org/10.1002/cncr.28469.

Fiszer, C., Dolbeault, S., Sultan, S., & Brédart, A. (2014). Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psycho-Oncology, 23*(4), 361-374.

Fjorback, L. O., Arendt, M., Ørnbøl, E., Fink, P., & Walach, H. (2011). Mindfulness-based stress reduction and mindfulness-based cognitive therapy- a systematic review of randomized controlled trials. *Acta Psychiatrica Scandinavica, 124,* 102-119.

Fobair, P., Stewart, S., Chang, S., D'Onofrio, C., Banks, P., & Bloom, J. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology, 15,* 579–594.

Foster, C., Calman, L., Grimmett, C., Breckons, M., Cotterell, P., Yardley, L., … Richardson, A. (2015). Managing fatigue after cancer treatment:development of RESTORE, a web-based resource to support self-management. *Psycho-Oncology, 24*, 940-949.

Foster, C., Wright, D., Hill, H., Hopkinson, J., & Roffe, L. (2009). Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European Journal of Cancer Care, 18*(3), 223-247. doi:10.1111/j.1365-2354.2008.01001.x

Fox, J. (2003). Case study of alopecia universalis and web-based news groups. *British Journal of Nursing, 12*(9), 550-558.

Fuerstein, M., Todd, B. L., Moskowitz, M. C., Bruns, G. L., Stoler, M. R., Nassif, T., & Yu, X. (2010). Work in cancer survivors: a model for practice and research. *Cancer Survivorship, 4*(4), 415-437. doi: 10.1007/s11764-010-0154-6.

Francis, G. (2012). Publication bias and the failure of replication in experimental psychology. *Psychonomic Bulletin & Review, 19*, 975–991. doi:10.3758/s13423-012-0322-y

Francis, M. E., & Pennebaker, J. W. (1992). Putting stress into words: the impact of writing on physiological, absentee, and self-reported emotional well-being measures. *Stress Management, 6*, 280-287.

Frattaroli, J. (2006). Experimental disclosure and its moderators: A meta-analysis. *Psychological Bulletin, 132* (6), 823-865.

Free, C., Hoile, E., Robertson, S,, & Knight, R. (2010). Three controlled trials of interventions to increase recruitment to a randomized controlled trial of mobile phone based smoking cessation support. *Clinical Trials, 7*(3), 265-273.

Freedman, T. G. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing, 17*(4), 334-341.

Friedman, L. C., Kalidas, M., Elledge, R., Chang, J., Romero, C., Husain, I., … Liscum, K. R. (2006). Optimism, social support and psychosocial functioning among women with breast cancer. *Psychooncology,15*(7), 595-603.

Frisina, P. G., Borod, J. C., & Lepore, S. J. (2004). A meta-analysis of the effects of written emotional disclosure on the health outcomes in clinical populations. *Journal of Nervous and Mental Health, 192*, 629-634.

Frith, H., Harcourt, D., & Fussell, A. (2007). Anticipating an altered appearance: women undergoing chemotherapy treatment for breast cancer. *European Journal of Oncology Nursing, 11*(5), 385-391.

Gauthier, L. R., Rodin, G., Zimmermann, C., Warr, D., Librach, S. L., Moore, M., Sheperd, F. A., & Gagliese, L. (2012). The communal coping model and cancer pain: The roles of catastrophizing and attachment style. *The Journal of Pain, 13*(12), 1258-1268.

Gellaitry, G., Petters, K., Bloomfield, D., & Home, R. (2010). Narrowing the gap: the effects of an expressive writing intervention on perceptions of actual

and ideal emotional support in women who have completed treatment for early stage breast cancer. *Psycho-Oncology, 19*, 77-84.

Gelo, O., Braakmann, D., & Benetka, G. (2008). Quantitative and qualitative research: Beyond the debate. *Integrative Psychological and Behavioral Science, 42*, 266-290.

Germann, J. N., Leonard, ., Stuenzi, T. J., Pop, R. B., Stewart, S. M., & Leavey, P.J. (2015). Hoping is coping: A guiding theoretical framework for promoting coping and adjustment following pediatric cancer diagnosis. *J Pediatr Psychol, 40*(9), 846-855. doi: 10.1093/jpepsy/jsv027.

Gidron, Y., Peri, T., Connolly, J. F., & Shalev, A. Y. (1996). Written disclosure in posttraumatic stress disorder: Is it beneficial for the patient? *Journal of Nervous & Mental Disease, 184*, 505- 507.

Gillham, B. (2005). *Research interviewing: The range of techniques*. Berkshire: Open University Press.

Goffman E. (1963). *Stigma*. Englewood Cliffs, NJ: Prentice Hall.

Golant, M., Altman, T., & Martin, C. (2003). Managing cancer side effects to improve quality of life: a cancer psychoeducation program. *Cancer Nursing, 26*(1), 37-44.

Gómez-Campelo, P., Bragado-Álvarez, C., & Hernández-Lloreda, M. J. (2014). Psychological distress in women with breast and gynaecological cancer treated with radical surgery. *Psycho-Oncology, 23*, 459-466

Gorlick, A., Bantum, E. O., & Owen, J. E. (2014). Internet-based interventions for cancer-related distress: exploring the experiences of those whose needs are not met. *Psycho-Oncology, 23*, 452-458.

Gortner, E., Rude, S., & Pennebaker, J.W. (2006). Benefits of expressive writing in lowering rumination and depressive symptoms. *Behavior Therapy, 37*, 292-303.

Guest, G., Bunce, A., & Johnson, L. (2006). How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods, 18*, 59-82.

Gray, R., Fitch, M., Greenberg, M., & Shapiro, S. (1995). Consumer participation in cancer system planning. *Journal of Palliative Care, 11*, 27–33.

Green, J. D., & Sedikides, C. (2001). When do self-schemas shape social perception?. The role of descriptive ambiguity. *Motivation and Emotion, 25*(1), 67-83.

Greenberg, M. A., & Stone, A. A. (1992). Emotional disclosure about traumas and its relation to health: Effects of previous disclosure and trauma severity. *Journal of Personality and Social Psychology, 63*, 75-84.

Greenberg, M., A., Wortman, C. B., & Stone, A. A. (1996). Emotional expression and physical health: Revising traumatic memories or fostering self-regulation? *Journal of Personality and Social Psychology, 71*, 588-602.

Greene, J. C. (2008). Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods Research, 2*(1), 7–22.

Grevelman, E. G., & Breed, W. P. M. (2005). Prevention of chemotherapy-induced hair loss by scalp-cooling. *Annals of Oncology, 16*(3), 352-358.

Griggs, J. J., Sorbero, M. E., Mallinger, J. B., Quinn, M., Waterman, M., Brooks, B., … Shields, C. G. (2007). Vitality, mental health, and satisfaction with information after breast cancer. *Patient Education and Counseling, 66*(1), 58–66.

Gripsrud, B. H., Brassil, K. J., Summers, B., Søiland, H., Kronowitz, S., & Lode, K. (2016). Capturing the experience: Reflections of women with breast cancer engaged in an expressive writing intervention. *Cancer Nursing, 39*(4), E51-60. Doi: 10.1097/NCC.0000000000000300.

Hagen, N. A., Biondo, P. D., Brasher, P. M. A., & Stiles, C. R. (2011). Formal Feasibility Studies in Palliative Care: Why They Are Important and How to Conduct Them. *Journal of Pain and Symptom Management, 42*(2), 278-289.

Halkett, G., Arbon, P., Scutter, S., & Borg, M. (2006). The role of the breast care nurse during treatment for early breast cancer: the patient's perspective. *Contemporary Nurse, 23*(1):46-57.

Hanley, B. (2005). *Research as Empowerment? Report of a Series of Seminars Organised by the Toronto Group*. York: Joseph Rowntree Foundation.

Hansen, E & Clarke, A. (2009). Helping people with an unusual appearance. *The Psychologist, 21*(6), 496-498.

Harber, K. D., & Pennebaker, J. (1992). Overcoming traumatic memories. In S. A. Christianson (Ed.), *The handbook of emotion and memory* (pp.359-387). Hillsdale, NJ: Erlbaum.

Harcourt , D., & Frith, H. (2008). Women's experiences of an altered appearance during chemotherapy: an indication of cancer status. *Journal of Health Psychology, 13*(5), 597-606.

Harley, A. E., A. Odoms-Young, B. Beard, M. L. Katz, & C. A. Heaney. (2009). African American social and cultural contexts and physical activity:

Strategies for navigating challenges to participation. *Women & Health 49,* 84–100. doi:10.1080/03630240802690861

Harris, A. H. (2006). Does expressive writing reduce health care utilization? A meta-analysis of randomized trials. *Journal of Consulting and Clinical Psychology,74*, 243–252.

Harrison, D. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Journal of Supportive Care in Cancer, 17*(8): 1117–1128. doi: 10.1007/s00520-009-0615-5

Hartl, K., Janni, W., Kastner, R., Sommer, H., Strobl, B., Rack, B & Stauber, M. (2003). Impact of medical and demographic factor on long-term quality of life and body image of breast cancer patients. *Annals of Oncology, 14*(7), 1064–1071.

Hasson, F., Keeney, S., & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing, 32*(4), 1008-1015.

Hayes, N. (2000). *In Doing Psychological Research*. Buckingham: Open University Press.

Hayes, S. C. & Smith, S. (2005). *Get out of your mind into life*. Oakland, CA: New Harbinger Publications.

Hayes, S.C., Strosahl, K., Wilson, K. G., Bissett, R., Pistorello, J., Toarmino, D., … McCurry, S. M. (2004). Measuring experiential avoidance: a preliminary test of a working model. *Psychological Record, 54*, 553-578.

Health Research Authority. (2013). *Defining research*. Retrieved 20th June 2013, from http://www.hra.nhs.uk/documents/2013/09/defining-research.pdf

Heitzmann,C. A., & Kaplan, R. M. (1988). Assessment of Methods for Measuring Social Support. *Health Psychology, 7*(1), 75-109.

Helms, R. L., O'Hea, E. L., & Corso, M. (2008). Body image issues in women with breast cancer. *Psychology, Health & Medicine, 13*(3), 313-325.

Helmreich, R., Stapp, J., & Ervin, C. (1974). The Texas Social Behavior Inventory (TSBI): An objective measure of self-esteem or social competence. *Journal Supplement Abstract Service. Catalog of Selected Documents in Psychology, 4*, 79.

Henselmans, I., Helgeson, V. S., Seltman, H., de Vries, J., Sanderman, R., & Ranchor, A. V. (2010). Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. *Health Psychology, 29*(2):160–168.

Hesketh, P. J., Batchelor, D., Golant, M., Lyman, G. H., Rhodes, N., & Yardley, D. (2004). Chemotherapy-induced alopecia: psychosocial impact and therapeutic approaches. *Support Care Cancer,12*, 543–549

Hielscher, S. (2013). 'Good' and 'bad' shine: an examination of the material interactions in women's hair care in the UK. *Journal of Design History, 26* (3), 257-269.

Hilton, S., Hunt, K., Emslie, C., Salinas, S., & Ziebland, S. (2008). Have men been overlooked? A comparison of young men and women's experiences of chemotherapy-induced alopecia. *Psycho-Oncology, 17*(6), 577-583.

Hobfall, S. E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist, 44*, 513-524.

Holland, J. C., Andersen, B., Breitbart, W. S., Compas, B., Dudley, M. M., Fleishman, S. … Zevon, M. A. (2013). Distress management: Clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network, 11*,190–208.

Holmbeck, G. N. (2002). A developmental perspective of adolescent health and illness: An introduction to the special issues. *Journal of Pediatric Psychology, 27*(5), 409-416.

Hopwood, P., Fletcher, I., Lee, A & Al Ghazal, S. (2001). A body image scale for use with cancer patients. *European Journal of Cancer, 37*, 189 - 197.

Howe, K. R. (2012). Mixed methods, triangulation, and causal explanation. *Journal of Mixed Methods Research, 6*, 89-96. Doi:10.1177/1558689812437187

Hsieh, H. F., & Shannon, S. (2005) Three approaches to qualitative content analysis. *Qualitative Health Research 15*, 1277–1288.

Huitt, W., Hummel, J., & Kaeck, D. (1999). *Internal and external validity*. Retrieved 25th June 2013 from, http://edpsycinteractive.org/topics/intro/valdgn.html

Hulbert-Williams, N. J., Storey, L. & Wilson, K. G. (2015). Psychological interventions for patients with cancer: psychological flexibility and the potential utility of Acceptance and Commitment Therapy. *European Journal of Cancer Care, 24*, 15-27.

Hunt, N., & McHale, S. (2005). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma, 10*, 33-50.

Hunter, L. (2012). Challenging the reported disadvantages of e-questionnaires and addressing methodological issues of online data collection. *Nurse Researcher, 20*, 1, 11-20.

Husson, O., Mols, F., van de Poll-Franse, L. V. (2011). The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Annals of Oncology, 22*, 761-772.

Imrie, S., & Troop, N. A. (2012). A pilot study on the effects and feasibility of compassion-focused expressive writing in day hospice patients. *Palliative and Supportive Care, 10*, 115-122.

Independent Cancer Taskforce. (2015). *Achieving world-class cancer outcomes. A strategy for England 2015-2012*. Retrieved 5th August, from http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

INVOLVE. (2012). *Briefing notes for researchers: involving the public in NHS, public health and social care research*. INVOLVE, Eastleigh.

Irvine, A. (2011). Duration, dominance and depth in telephone and face-to-face interviews: a comparative exploration. *International Journal of Qualitative Methods, 10*(3),202-220.

Israelashvili, M. (2012). Should adjustment disorder be conceptualized as transitional disorder? In pursuit of adjustment disorders definition. *Journal of Mental Health, 21*(6):579-88. doi: 10.3109/09638237.2012.670881.

Iwamitsu, Y., Shimoda, K., Abe, H., Tani, T., Okawa, M., & Buck, R. (2005). Anxiety, emotional suppression, and psychological distress before and after breast cancer diagnosis. *Psychosomatics, 46*(1):19–24.

Janis, I. L., & Field, P. B. (1959). Sex differences and personality factors related to persuasibility. In C. I. Hovland & I. L. Janis (ed.), *Personality and Persuasibility* (55-68). New Heaven: Yale University Press.

Jarry, J. L., & Ip, K. (2005). The effectiveness of stand-alone cognitive-behavioural therapy for body image: A meta-analysis. *Body Image, 2*, 317–331.

Jenkinson, L. (2012). Therapeutic interventions: Evidence of effectiveness. In N. Rumsey & D. Harcourt (Ed.), *The oxford handbook of the psychology of appearance* (551-567). Oxford: Oxford University Press.

Jennings, S., Philip, E. J., Nelson, C., Schuler, T., Starr, T., Jandorf, L., Temple, L., Garcia, E., Carter, J., & DuHamel, K. (2014). Barriers to recruitment in psycho-oncology: unique challenges in conducting research focussing on sexual health in female survivorship. *Psycho-Oncology, 23*, 1192-1195.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research Paradigm whose time has come. *Educational Researcher 3*(7), 14-26.

Johnson, R. B., Onwuegbuzie, A. J & Turner, L. A. (2007). Towards a definition of mixed methods research. *Journal of Mixed Methods Research, 1* (2): 112 - 133.

Jones, R. D. (2001). Depression and anxiety in oncology: the oncologist's perspective. *Journal of Clinical Psychiatry, 62*(suppl 8):52-55.

Jones, S., Murphy, F., Edwards, M., & James, J. (2008). Doing things differently: advantages and disadvantages of web questionnaires. *Nurse Researcher, 15*, 4, 15-26

Jones, E. L., Williams-Yesson, B. A., Hackett, R. C., Staniszewska, S. H., Evans, D., & Francis, N. K. (2015). Quality of reporting on patient and public involvement within surgical research: a systematic review. *Annals of Surgery*, *261*(2), 243-250.

Kacar, S. D., Ozuguz1, P., Bagcioglu, E., Coskun, K. S., Polat, S., Karaca, S., & Ozbulu, O. (2016). Frequency of body dysmorphic disorder among patients with complaints of hair loss. *International Journal of Dermatology, 55*, 425-429.

Kaiser, N. C., Hartoonia, N., & Owen, J. E. (2010). Toward a cancer-specific model of psychological distress: population data from the 2003-2005 National Health Interview Surveys. *Journal of Cancer Survivorship, 4*, 291-302.

Kalabokes, V. D. (2011). Alopecia areata: Support groups and meetings – how can it help your patient? *Dermatologic Therapy, 24*, 302-304.

Kanatas, A., Lowe, D., Velikova, G., Roe, B., Horgan, K., Shaw, R. J., & Rogers, S. N. (2014). Issues patients would like to discuss at their review consultation in breast cancer clinics - a cross-sectional survey. *Tumori, 100*(5), 568-79. Doi: 10.1700/1660.18184

Karekla, M., & Constantinou, M. (2010). Religious coping and cancer: proposing an Acceptance and Commitment Therapy Approach. *Cognitive and Behavioral Practice, 17*, 371-381.

Katsimbri, P., Bamias, A., & Palidis, N. (2000). Prevention of chemotherapy-induced alopecia using an effective scalp cooling system. *European Journal of Cancer 36*, 766–71.

Katz, N., Fernandez, K., Chang, A., Benoit, C., & Butler, S. F. (2008). Internet-based survey of nonmedical prescription opioid use in the United States. *The Clinical Journal of Pain, 24*, 6, 528-535.

Kaur, G., Hutchison, I., Mehanna, H., Williamson, P., Shaw, R., & Smith, C. T. (2013). Barriers to recruitment for surgical trials in head and neck oncology:

a survey of trial investigators. *BMJ Open, 3*(4*)*, 1-10. Doi:10.1136/bmjopen-2013-002625

Kavoc, S. H., & Range, L. M. (2002). Does writing about suicidal thoughts and feelings reduce them? *Suicide and Life-Threatening Behaviour, 32*, 428-440.

Kelle, U. (2006). Combining qualitative and quantitative methods in research practise: purposes and advantages. *Qualitative Research in Psychology, 3*, 293-311.

Kelley J.E., Lumley M.A., Leisen J.C. (1997). Health effects of emotional disclosure in rheumatoid arthritis patients. *Health Psychology, 16*, 331-340.

Kendrick, K. (2008). 'Normalizing' female cancer patients: Look good, feel better and other image programs. *Disability & Society, 23*(3), 259-269. Doi: 10.1080/09687590801954042

Kent, G. (2000). Understanding the experiences of people with disfigurements: An integration of four models of social and psychological functioning. *Psychology, Health & Medicine, 5*(2), 117-129. Doi: 10.1080/713690187

Kent, G., & Thompson, A. R. (2002). Models of disfigurement: Implications for treatment. In P. Gilbert & J. Miles (eds.) *Understanding body shame*, (pp. 106-116). Hover: Brunner-Routledge.

Kettles, A. M., Creswell, W., & Zhang, W. (2011). Mixed methods research in mental health nursing. *Journal of Psychiatric and Mental Health Nursing, 18*(6), 535–542.

Klein, K., & Boals, A. (2001). Expressive writing can increase working memory capacity. *Journal of Experimental Psychology: General, 130*, 520-533.

Kienle, G. S., Glockmann, A., Schink, M., & Kiene, H. (2009). Viscum album L. extracts in breast and gynaecological cancers: a systematic review of clinical and preclinical research. *Journal of Experimental & Clinical Cancer Research, 11*, 28:79. Doi: 10.1186/1756-9966-28-79.

King, L. A. (2001). The health benefits of writing about life goals. *Personality and Social Psychology Bulletin, 27*, 798-807.

King, L. A. (2002). Gain without pain? Expressive writing and self-regulation. In S. J. Lepore & J. M. Smyth (Eds.), *The writing cure: How expressive writing promotes health and emotional well-being* (pp. 119-134). Washington, DC: American Psychological Association.

King, L. A., & Miner, K. N. (2000). Writing about the perceived benefits of traumatic events: Implications for physical health. *Personality and Social Psychology Bulletin, 26,* 220- 230.

Kissane, D., McKenzie, M., Block, S., Moskowitz, C., McKenzie, D., & O'Neil, I. (2006). Family focussed grief therapy: a randomized, controlled trial in palliative care and bereavement. *American Journal of Psychiatry, 163*, 1208-1218.

Knobf, M. T. (2007). Psychosocial responses in breast cancer survivors. *Seminars in Oncology Nursing, 23* (1): 71 - 83.

Knowles, E. D., Wearing, J. R., & Campos, B. (2011). Culture and the health benefits of expressive writing. *Social Psychological and Personality Science, 2*(4), 408-415.

Köhle, N., Drossaert, C. H. C., Schreurs, K. M. G., Hagedorn, M., Verdonck, I. M. V., & Bohlmeijer, E. T. (2015). A web-based self-help intervention for partners of cancer patients based on Acceptance and Commitment Therapy: a protocol of a randomized controlled trial. *BMJ Public Helath,15*(303), 1-13 Doi: 10.1186/s12889-015-1656-y

Koole, S. L., & van Knippenberg, A. (2007). Controlling your mind without ironic consequences: Self-affirmation eliminates rebound effects after thought suppression. *Journal of Experimental Social Psychology, 43,* 671– 677. Doi:10.1016/j.jesp.2006.07.001

Koszalinski, R. S., & Williams, C. (2012). Embodying identity in chemotherapy-induced alopecia. *Perspectives in Psychiatric Care, 48,* 116-121.

Kovačič, T., & Kovačič, M. (2011). Impact of Relaxation Training According to Yoga in Daily Life® System on Self-Esteem after Breast Cancer Surgery. *The journal of alternative and complementary medicine, 17*(12), 1157-1164.

Kraus, P. L. (1999). Body image, decision making, and breast cancer treatment. *Cancer Nursing, 22*(6), 421-427.

Laccetti, M. (2007). Expressive writing in women with advanced breast cancer. *Oncology Nursing Forum, 34*(5), 1019-1024.

Lakshman, R., Griffin, S., Hardeman, W., Schiff, A., & Ong, K. K. (2012). Using the MRC framework for complex interventions to develop a childhood obesity prevention trial: the baby milk trial. *Archives of Disease in Childhood, 97,* 181-182. Doi: 10.1136/archdischild-2012-301885.425

Lamb, B. W., Allchorne, P., Sevdalis, N., & Green, J. S. A. (2011). The role of the urology clinical nurse specialist in the multidisciplinary team meeting. *International Journal of Urological Nursing 5*, 59–64.

Land, S. R., Wickerham, D. L., Costantino, J. P., Ritter, M. W., Vogel, V. G., Lee, M., … Ganz, P. A. (2006). Patient reported symptoms and quality of life during treatment with tamoxifen or raloxifene for breast cancer prevention: The NSABP study of tamoxifen and raloxifene (STAR) P-2 trial. *Journal of the American Medical Association, 295,* 2742 - 2751.

Leary, M. R. (1983). A brief version of the Fear of Negative Evaluation Scale. *Personality and Social Psychology Bulletin, 9*, 371-376.

Ledesma, D., & Kumano, H. (2009). Mindfulness-based stress reduction and cancer: a meta-analysis. *Psycho-Oncology, 18*(6), 571-579.

Lee, H. S., & Cohn, L. D. (2010). Assessing coping strategies by analysing expressive writing samples. *Stress and Health, 26*, 250-260.

Lee, C., & Rowlands, I. J. (2015). When mixed methods produce mixed results: Integrating disparate findings about miscarriage and women's wellbeing. *British Journal of Health Psychology, 20*, 36-44.

Lemieux, J., Forget, G., Brochu, O., Provencher, L., Cantin, G., Desbiens, C., Doyle, C., Poirier, B., Camden, S. & Durocher, M. (2014). Evaluation of eligibility and recruitment in breast cancer clinical trials. *The Breast Journal, 23*, 385-392.

Lemieux, J., Maunsell, E., & Provencher, L. (2008). Chemotherapy-induced alopecia and effects on quality of life among women with breast cancer: a literature review. *Psycho-Oncology, 17*(4), 317-328.

Lengacher, C. A., Reich, R. R., Paterson, C. L., Jim, H. S., Ramesar, S., Alinat, C. B., … Kip, K. E. (2015). The effects of mindfulness-based stress reduction on objective and subjective sleep parameters in women with breast cancer: a randomized controlled trial. *Psycho-Oncology, 24*, 424-432.

Lepore, S. J. (1997). Expressive writing moderates the relation between intrusive thoughts and depressive symptoms. *Journal of Personality and Social Psychology, 73*, 1030-1037.

Lepore, S. J., Greenberg, M. A., Bruno, M., & Smyth, J. M. (2002). Expressive writing and health: Self-regulation of emotion-related experience, physiology, and behaviour. In S. J. Lepore and J. M. Smyth (Eds.), *The writing cure. How expressive writing promotes health and emotional well-being*. (pp. 99-117). Washington, DC: American Psychological Press.

Lepore, S., & Smyth, J. (2002). *The writing cure: How expressive writing promotes health and emotional well-being*. Washington, DC: American Psychological Association press.

Leung, J., Pachana, N. A., & McLaughlin, D. (2014). Social support and health-related quality of life in women with breast cancer: a longitudinal study. *Psycho-Oncology, 23*, 1014-1020.

Lieberman MA, Golant M, Giese-Davis J, et al. Electronic support groups for breast carcinoma: a clinical trial of effectiveness. Cancer 2005;15:920–925.

Loas,G., Otmani, O., Verrier, A., Fremaux, D., & Marchand, M. P. (1996).Factor analysis of the French version of the 20-item Toronto Alexithymia Scale (TAS-20). *Psychopathology, 29* (2), 139–144

Look Good Feel Better. (2014). *Look Good Feel Better*. Retrieved 10th April 2014 from www.lookgoodfeelbetter.org

Looney, S., & Jones, P. (2003). A method for comparing two normal means using combined samples of correlated and uncorrelated data. *Statistics in medicine,22*, 1601-1610.

Loscalzo, J. (2009). Pilot trials in clinical research: Of what value are they? *Circulation, 119*, 1694-1696.

Love, A. W., Kissane, D. W., Bloch, S. & Clarke, D. M. (2002). Diagnostic efficiency of the Hospital Anxiety and Depression Scale in women with early stage breast cancer. *Australian and New Zealand Journal of Psychiatry, 36*, 246-250.

Low, C. A., Stanton, A. L., Bower, J. E., & Gyllenhammer, L. (2010). A randomized controlled trial of emotionally expressive writing for women with metastatic breast cancer. *Health Psychology, 29*(4), 460-466.

Low, C. A., Stanton, A. L., & Danoff-Burg, S. (2006). Expressive disclosure and benefit finding among breast cancer patients: Mechanisms for positive health effects. *Health Psychology, 25*(2), 181-189.

Lubberding, S., Uden-Kraan, C. F. V., Te Velde, E. A., Cuijpers, P., Leemans, C. R., & Leeuw, I. M. V. (2015). Improving access to supportive cancer care through an eHealth application: a qualitative needs assessment among cancer survivors. *Journal of Clinical Nursing, 24*, 1367-1379.

Lumley, M. A. (2004). Alexithymia, emotional disclosure, and health: A program of research. *Journal of Personality, 72*, 1271-1300.

Macduff, C., Mackenzie, T., Hutcheon, A., Melville, L., & Archibald, H. (2003). The effectiveness of scalp cooling in preventing alopecia for patients receiving epirucin and docetaxel. *European Journal of Cancer Care, 12*(2), 154-161.

Macmillan. (2014). *Cancer in the UK 2014*. Retrieved 19th May from http://www.macmillan.org.uk/Documents/AboutUs/WhatWeDo/CancerintheUK2014.pdf…..

Macmillan Cancer Support. (2006). *Worried Sick – the Emotional Impact of Cancer*. Macmillan Cancer Support, London.

MacNaughton, G. (2001). Action research. In G. MacNaughton, S. Rolfe, & I. Siraj-Blatchford (Eds.), *Doing early childhood research: International perspectives on theory and practice, (pp. 208-223).* Crows Nest NSW: Allen & Unwin.

Manning, J. (2011). The Sociology of Hair: Hair Symbolism Among College Students. *Social Sciences Journal, 10*(1), 35-48.

Manning, D. L., & Dickens, C. (2007) Cancer Information and Support Centres: fixing parts cancer drugs cannot reach. *European Journal of Cancer Care, 16*, 33–38.

Manning, D. L., & Quigley, P. (2002) Understanding the needs of people using a cancer information service in Northern Ireland. *European Journal of Cancer Care 11*, 139– 142.

Maslin-Prothero, S. (2003). Developing user involvement in research. *Journal of Clinical Nursing, 12*, 412-421.

Mason, J. (2006). 'Mixing Methods in a Qualitatively-Driven Way'. *Qualitative Research, 6*(1), 9-26.

Maxcy, S. (2003). Pragmatic threads in mixed methods research in the social sciences: the search for multiple modes of inquiry and the end of the philosophy of formalism. In Tashakord, A. & Teddlie, C. (Eds), *Handbook of mixed methods in social and behavioural research* (pp.51-90). Thousand Oaks, CA: Sage.

Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *BMJ, 320*, 50-52.

Mays, N. Roberts, E. Popay, J. (2001) Synthesising Research Evidence. In Fulop, N. Allen, P. Clarke, A. Black, N. (eds) *Methods for studying the delivery and organisation of health services*. Hove: Brunner-Routledge.

McConochie, L., & Pearson, E.(2006). Development of a nurse-led skin camouflage clinic. *Nursing Standard,* 20, 74-80.

McDaid, C., Hodges, Z., Fayter, D., Stirk, L., & Eastwood, A. (2006). Systematic review of interventions to increase participation of cancer patients in randomised controlled trials, *Trials, 17*:16.

McDonald, A. M., Knight, R. C., Campbell, M. K., Entwistle, V. A., Grant, A.M., Cook, J. A. M., … Snowdon, C. (2006). What influences recruitment to randomised controlled trials? A review of trials funded by two UK funding agencies. *Trials, 7*, 9.

McGarvey, E. L., Baum, L. D., Pinkerton, R. C., & Rogers, L. M. (2001). Psychological sequelae and intervention for treatment-induced alopecia among female cancer patients. *Cancer Practice, 9*(6), 283-289.

McGarvey, E. L., Leon-Verdin, M., Baum, L. D., Bloomfield, K., Brenin, D. R., Koopman, C., Acton, S., Clark, B., & Parker, B. E. (2010). An evaluation of a computer-imaging program to prepare women for chemotherapy- related alopecia. *Psycho-Oncology,19*(7), 756-766.

McKenna, H. P. (1994) The Delphi technique: a worthwhile approach for nursing? *Journal of Advanced Nursing 19*, 1221-1225.

McMillan, S. C., & Weitzner, M. A. (2003). Methodologic issues in collecting data from debilitated patients with cancer near end of life. *Oncology Nursing Forum, 30*, 123-129.

McNair, D. M., Lorr, M & Droppleman, L. F (1971). *Profile of Mood States manual*. San Diego: Education & Industrial Testing Service.

McNees, P., Dow, K., & Loerzel, V. (2005). Application of the CuSum Technique to evaluate changes in recruitment strategies. *Nursing Research, 54*, 399-405.

Mehnert, A., Berg, P., Henrich, G., & Herschback, P. (2009). Fear of cancer progression and cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncology, 18*(12), 1273-1280.

Merz, E. L., Fox, R. S., & Malcarne, V. L. (2014). Expressive writing interventions in cancer patients: a systematic review. *Health Psychology Review, 8*(3), 339-361.

Metcalfe, K. A., Esplen, M. J., Goel, V., & Narod, S. A. (2004). Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy. *Psycho-Oncology, 13*, 14 - 25.

Meyer, A., Coroiu, A., & Korner, A. (2015). One-to-one peer support in cancer care: a review of scholarship published between 2007 and 2014. *European Journal of Cancer Care 24*, 299–312.

Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology, 11*(5), 799-808.

Miller, G. E., & Cohen, S. (2001). Psychological interventions and the immune system: A meta-analytic review and critique. *Health Psychology, 20*(1), 47-63.

Mills M. (2000). *Regional Multi-professional Audit of the Cancer Services in Northern Ireland*. NHSPPS, Belfast, Northern Ireland, UK.

Mitchell, A. J., Meader, N., & Symonds, P. (2010). Diagnostic validity of the Hospital Anxiety and Depression Scale (HADS) in cancer and palliative settings: a meta-analysis. *Journal of Affective Disorders,126*(3), 335-48. doi: 10.1016/j.jad.2010.01.067

Mogk, C., Otte, S., Reinhold-Hurley, B., & Kroner-Herwig, B. (2006). Health effects of expressive writing on stressful or traumatic experiences—a meta-analysis. *Psycho-social medicine, 3*, 1-9.

Montazeri, A. (2008). Health-related quality of life in breast cancer patients: A bibliographic review of the literature from 1974 to 2007. *Journal of Experimental and Clinical Cancer Research*, 27, 32. Doi: 10.1186/1756-9966-27-32

Monti, D. A., Kash, K. M., Kunkel, E. J., Moss, A., Mathews, M., Brainard, G., … Newberg, A. B. (2013). Psychosocial benefits of a novel mindfulness intervention versus standard support in distressed women with breast cancer. *Psycho-Oncology*, *22*, 2565-2575.

Moran-Ellis, J., Alexander, V. D, Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research, 6*, 45-59.

Morahan-Martin, J., & Schumacher, P. (2003). Loneliness and social uses of the internet. *Computers in Human Behavior, 19*(6), 659–671.

Moravcsik, A. (2014). Transparency: The revolution in qualitative research. *American Political Science Association*, *47*(1), 48-53. Doi:10.1017/S1049096513001789

Moreira, H., & Canavarro, M. C. (2012). The association between self-consciousness about appearance and psychological adjustment among newly diagnosed breast cancer patients and survivors: The moderating role of appearance investment. *Body Image, 9*, 209-215.

Moreira, H., Silva, S., Marques, A & Canavarro, M. C. (2009). The Portuguese version of the Body Image Scale (BIS) – Psychometric properties in a sample of breast cancer patients. *European Journal of Oncology Nursing, 14*(2), 111-118.

Moreira, H., Silva, S., & Canavarro, M. C. (2010). The role of appearance investment in the adjustment of women to with breast cancer. *Psycho-Oncology, 19*, 959-966.

Morgan, D. (2007). Paradigms lost and pragmatism regained. *Journal of Mixed Methods Research, 1*(1), 48-76.

Morgan, D. L. (2014). *Integrating qualitative and quantitative methods : a pragmatic approach*. California: Sage Publications.

Morrow, E., Ross, F., Grocott, P., & Bennett, J. (2010). A model and measure for quality service user involvement in health research. *International Journal of Consumer Studies, 34*, 532-539.

Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research, 40*(1), 120-123.

Morse, J. M. (2003). Principles of mixed methods and multimethod research design. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social & behavioral research* (pp. 189-208). Thousand Oaks, CA: Sage.

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research, 25*(9), 1212-1222.

Mosher, C. E., Johnson, C., Dickler, M., Norton, L., Massie, M. J., & DuHamel, K. (2013). Living with metastatic breast cancer: A qualitative analysis of physical, psychological and social sequelae. *The Breast Journal, 19*(3), 285-292.

Moss, T. P. (2005). The relationship between subjective and objective ratings of disfigurement severity and psychological adjustment. *Body Image, 2*, 151-159.

MRC. (2000). *A framework for the development and evaluation of RCTs for complex interventions to improve health*. London: Medical Research Council

MRC (2008) *Developing and evaluating complex interventions: new guidance*. London: Medical Research Council.

Mulders, M., Vingerhoets, A., & Breed, W. (2008). The impact of cancer and chemotherapy: Perceptual similarities and differences between cancer patients, nurses and physicians. *European Journal of Oncology Nursing, 12*(2), 97-102.

Mundy, E. A., DuHamel, K. N., & Montgomery, G. H. (2003). The efficacy of behavioral interventions for cancer treatment-related side effects. *Seminars in Clinical Neuropsychiatry 8,* 253– 275.

Münstedt, K., Manthey, N., Sachsse, S., & Vahrson, H. (1997). Changes in self-concept and body image during alopecia induced cancer chemotherapy. *Supportive Care Cancer, 5*, 139-143.

Murray, M., & Chamberlain, K. (1998). Qualitative research in health psychology developments and directions. *Journal of Health Psychology, 3*(3), 291-295.

Murray, E. (2012). Web-Based Interventions for Behavior Change and Self-Management: Potential, Pitfalls, and Progress. *Medicine, 1*(2):e3. Doi: 10.2196/med20.1741

Murchiea, P., Hannaforda, P. C., Wykeb, S., Nicholson, M. C., & Campbell, N. C. (2007). Designing an integrated follow-up program for people treated for cutaneous malignant melanoma: a practical application of the MRC framework for the design and evaluation of complex interventions to improve health. *Family Practice, 24*(3), 283-292.

Musanti, R. (2012). A study of exercise modality and physical self-esteem in breast cancer survivors. *Medicine & Science in Sports & Exercise, 44*(2), 352-361.

Muscarella, F., & Cunningham, M. R. (1996). The Evolutionary Significance and Social Perception of Male Pattern Baldness and Facial Hair. *Ethology and Sociobiology, 17*, 99-117.

Myers, J. S. (2009). Chemotherapy-related cognitive impairment: neuroimaging, neuropsychological testing, and the neuropsychologist. *Clinical Journal of Oncology Nursing, 13*, 413–21.

National Cancer Research Network. (2015). *UK: NIHR*. Retrieved from http:www.crncc.nihr.ac.uk/oktoask/oktoask_campaign.htm

Naus, M. J., Ishler, M. D., Parrott, C. E., & Kovacs, S. A. (2009). Cancer survivor adaptation model: Conceptualizing cancer as a chronic illness. *Journal of Clinical Psychology, 65*(12), 1350-1359.

Neumark, D. E., Stommel, M., Given C. W., & Given, B. A. (2001). Research design and subject characteristics predicting nonparticipation in a panel survey of older families with cancer. *Nursing Research, 50*, 363-368.

NHS Executive. (1996). *Improving Outcomes in Breast Cancer*. Clinical Outcomes Group. Department of Health, London.

NICE. (2002). *Guidance on cancer services. Improving outcomes in breast cancer: manual update*. NICE, London.

NICE. (2007). *Drug misuse – psychosocial interventions*. Retrieved 10 April, 2015 from http://www.nice.org.uk/guidance/CG51

NICE. (2009). *Early and locally advanced breast cancer: Diagnosis and treatment*. Cardiff: National Collaborating Centre for Cancer.

NICE. (2011). *Commissioning stepped care for people with common mental health disorders*. Retrieved March 2015 from https://www.nice.org.uk/guidance/cmg41/resources/non-guidance-commissioning-stepped-care-for-people-with-common-mental-health-disorders-pdf

NICE. (2012). *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*. Retrieved 16th May 2015 from http://www.nice.org.uk/guidance/CG138

NICE. (2014). *Early and locally advanced breast cancer. Diagnosis and treatment*. Retrieved 18th May From http://www.nice.org.uk/Guidance/CG80

NIHR Cancer Research Network. (2013). *Annual report 2012-2013*. Retrieved 21st April 2015, from http://www.crn.nihr.ac.uk/wp-content/uploads//crnadmin/Cancer-NCRNAnnualReport2012-13.pdf

Nolte, S., Donnelly, J., Kelly, S., Conley, P., & Cobb, R. (2006). A randomized clinical trial of a videotape intervention for women with chemotherapy-induced alopecia: A gynaecological oncology group study. *Oncology Nursing Forum, 33*(2), 305-311.

Norman, G. (2010). Likert scales, levels of measurement and the "laws" of statistics. *Advances in Health Sciences Education, 15*(5), 625-632.

Normal, S., Lumley, M., Dooley. J., & Diamond, M.. (2002). For whom does it work? Moderators of the effects of written emotional disclosure in a randomized trial among women with chronic pelvic pain. *Psychosomatic Medicine, 66*, 174-183.

Northouse, L., Rosset, T., Phillips, L., Mood, D., Schafenacker, A., & Kershaw, T. (2006). Research with families facing cancer: the challenges of accrual and retention. *Research in Nursing & health, 29*, 199-211.

Nozawa, K., Ichimura, M., Oshima, A., Tokunaga, E., Masuda, N., Kitano, A., Fukuuchi, A., & Shinji, O. (2015). The present state and perception of young women with breast cancer towards breast reconstructive surgery. *International Journal of Clinical Oncology, 20*, 324-331.

Nystuen, P., & Hagen, K. B. (2004). Telephone reminders are effective in recruiting nonresponding patients to randomized controlled trials. *Journal of Clinical Epidemiology, 57*, 773-776.

O'Cathain A, Murphy E, & Nicholl J. (2007). Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. *BMC Health Services Research, 7*, 85.

O'Connor, M., Allen, J. J. B., & Kaszniak, A. W. (2005). Emotional disclosure for whom? A study of vagal tone in bereavement. *Biological Psychology, 68*, 135-146.

O'Connor, D. B., & Ashley, L. (2008). Are alexithymia and emotional characteristics of disclosure associated with blood pressure reactivity and psychological distress following written emotional disclosure? *British Journal of Health Psychology, 13*(3), 495-512.

O'Connor, D., Green, S., & Higgins, J. P. T. (2008). Defining the review question and developing criteria for including studies. In J. P. T. Higgins & S. Green (Eds.), *Cochrane handbook for systematic reviews of interventions*. Retrieved March 2012 from www.cochrane-handbook.org

O'Connor, D. B., Hurling, R., Hendrickx, H., Osborne, G., Hall, J., Walklet, E., Whaley, A., & Wood, H. (2010). Effects of written emotional disclosure on implicit self-esteem and body image. *British Journal of Health Psychology, 16*, 488-501.

Odgaard-Jensen, J., Vist, G. E., Timmer, A., Kunz, R., Akl, E. A., Schünemann, H., … Oxman, A. D. (2011). Randomisation to protect against selection bias in healthcare trials. *Cochrane Database For Systematic Reviews, 13*(4): :MR000012. Doi: 10.1002/14651858.MR000012.pub3.

Oliver, S., & Buchanan, P. (1997). *Examples of lay involvement in research and development*. EPI-centre, Social Science Research Unit, London University Institute of Education: London.

Ong, L. M., Visser, M. R., Lammes, F. B., van Der Velden, J., Kuenen, B. C., & de Haes, J. C. (2000). Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall, and quality of life: a randomized, double-blind study. *Journal of Clinical Oncology, 18*, 3052–3060.

O'Reilly, M., & Parker, N. (2013). 'You can take a horse to water but you can't make it drink': Exploring children's engagement and resistance in family therapy. *Contemporary Family Therapy, 35*(3), 491-507.

Osborn, R. L., Demoncada, A. C., & Feuerstein, M. (2006). Psychosocial interventions for depression, anxiety, and quality of life in cancer survivors: meta-analyses. *The International Journal of Psychiatry in Medicine, 36*(1), 13-34.

Osborne, R. H., Elsworth, G. R., Sprangers, M. A. G., Oort, F. J., & Hopper, J. L. (2004). The value of the Hospital Anxiety and Depression Scale (HADS) for comparing women with early onset breast cancer with population-based reference women. *Quality of Life Research, 13*(1), 191-206.

Őstlund, U., Kidd, L., Wengström, Y., & Rowa-Dewar, N. (2011). Combining qualitative and quantitative research within mixed method research designs: A methodological review. *International Journal of Nursing Studies, 48,* 369–383. doi:10.1016/j.ijnurstu.2010.10.005

Orford, J. (2008). Asking the right questions in the right way: the need for a shift in research on psychological treatments for addiction. *Addiction, 103,* 875–85.

Ott, N. J., Norris, R. L. & Bauer-Wu, S. M. (2006). Mindfulness meditation for oncology patients: a discussion and critical review. *Integrative Cancer Therapies, 5*, 98-108.

Oyedemi, T. (2016). Beauty as violence: 'beautiful' hair and the cultural violence of identity erasure. Social Identities, 22(5), 537-553. DOI: 10.1080/13504630.2016.1157465

Owen, J. E., Klapow, J. C., Roth, D. L., Shuster, J. I., Bellis, J., Meredith, R., & Tucker, D. C. (2005). Randomized pilot of a self-guided internet coping group for women with early-stage breast cancer. *Annals of Behavioral Medicine, 30,* 54–64.

Page, S. J., & Persch, A. C. (2013). Recruitment, retention, and blinding in clinical trials. *American Journal of Occupational Therapy, 67*, 154-161.

Pallant, J. (2010). *SPSS Survival manual*. (4th ed). Magraw-Hill: Maidenshead.

Pandey, R., Mandal, M. K., Taylor, G.J., & Parker, J. D. (1996).Cross-cultural alexithymia: development and validation of a Hindi translation of the 20-item Toronto Alexithymia Scale. *Journal of Clinical Psychology, 52*(2), 173–176.

Park, C. L., & Blumberg, C. J. (2002). Disclosing trauma through writing: testing the meaning-making hypothesis. *Cognitive Therapy and Research, 26*, 597-616.

Park, H. Y., Kim, J. H., Choi, S., Kang, E., Oh, S., Kim, J. Y., & Kim, S. W. (2015). Psychological effects of a cosmetic education program in patients with breast cancer. *European Journal of Cancer Care, 24*, 493-502.

Parker, J. D. A., Taylor, G. J., & Bagby, R. M. (2003). The 20-item Toronto Alexithymia Scale III: Reliability and factorial validity in a community population. *Journal of Psychosomatic Research, 55*, 269 – 275. doi:10.1016/S0022-3999(02)00578-0

Pauwels, E., De Bourdeaudhuij, I., Charlier, C., Lechner, L., & Van Hoof, E. (2012). Psychosocial Characteristics Associated with Breast Cancer Survivors' Intimate Partners' Needs for Information and Support After Primary Breast Cancer Treatment. *Psychosocial Oncology, 30*(1), 1-20.

Peck, H., Mitchell, H., & Stewart, A. (2000) Evaluating the efficacy of scalp cooling using the Penguin cold cap system to reduce alopecia in patients undergoing chemotherapy for breast cancer. *European Journal of Oncology Nursing 4*(4), 246–8.

Pennebaker, J. W. (1989). Confession, inhibition, and disease. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 22, pp. 211-244). Orlando, FL: Academic Press.

Pennebaker, J. W. (1993). Confession, inhibition, and disease. In L. Berkowitz (Ed.), *Advances in experimental social psychology*. (pp. 211-244). New York: Academic Press.

Pennebaker, J. W., & Beall, S. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of Abnormal Psychology, 95*, 274-281.

Pennebaker, J. W., Colder, M., & Sharp, L. L. (1990). Accelerating the coping process. *Journal of Personality and Social Psychology, 58*, 528-537.

Pennebaker, J., & Francis, M. (1996). Cognitive, emotional and language processes in disclosure. *Cognition and Emotion, 10*, 601-626.

Pennebaker, J., Francis, M., & Booth, R. (2001). *Linguistic Inquiry and Word Count (LIWC): LIWC 2001*. Mahwah, NJ: Erlbaum.

Pennebaker, J. W., Kiecolt-Glaser, J. K., & Glaser, R. (1988). Disclosure of traumas and immune function: Health implications for psychotherapy. *Journal of Consulting and Clinical, 56*, 239-245.

Pennebaker, J., Mayne, T., & Francis, M. (1997). Linguistic predictors of adaptive bereavement. *Journal of Personality and Social Psychology, 72*, 863-871.

Petersen, S., & Ritz, T. (2010). Dependency of illness evaluation on the social comparison context: Findings with implicit measures of affective evaluation of asthma. *British Journal of Health Psychology, 15*(2), 401-416. doi: 10.1348/135910709x466676

Petrie, K. J., Booth, R. J., Pennebaker, J. W., & Davidson, K. P. (1995). Disclosure of trauma and immune response to a hepatitis B vaccination program. *Journal of Consulting and Clinical Psychology, 63*, 787-792.

Pickard-Holley, S. (1995). The symptom experience of alopecia. *Seminars in Oncology Nursing, 11*(4), 235-258.

Pidgeon, N. (1996). Grounded theory: theoretical background. In Richardson, J. T. E. (ed), *Handbook of qualitative research methods for psychology and the social sciences*. Leicester: The British Psychological Society.

Pilarska, A. (2016). How do self-concept differentiation and self-concept clarity interrelate in predicting sense of personal identity? *Personality and Individual Differences, 102*, 85-89.

Pollard, K.C. and Evans, D. (2013), 'Theorising service user involvement from a researcher perspective'. In Staddon, P. (ed.) *Mental Health Service Users in Research, Policy Press* (pp.39-51). Bristol.

Poon, A., & Danoff-Burg, S. (2011). Mindfulness as a moderator in expressive writing. *Journal of Clinical Psychology, 67*(9), 881-895.

Pope, C., & Mays, N. (1995). Qualitative research: researching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BAIU, 311*(6996), 42-45.

Power, S., & Condon, C. (2008) Chemotherapy-induced alopecia: a phenomenological study. *Cancer Nursing Practice, 7*(7): 44–7.

Pozo-Kaderman, C., Kaderman, R. A., & Toonkel, R. (1999). The psychosocial aspects of breast cancer. *Nurse Practitioner Forum, 10*, 165-174.

Protière, C., Evans, K., Camerlo, J., d'Ingrado, M. P., Macquart-Moulin, G., Viens, P., … Genre, D. (2002). Efficacy and tolerance of a scalp cooling system for prevention of hair loss and the experience of breast cancer patients treated by adjuvant chemotherapy. *Support Care Cancer 10*: 529–37

Pruitt, R., & Privette, A. B. (2001). Planning strategies for the avoidance of pitfalls in intervention research. *Journal of Advanced Nursing, 35*, 514-520.

Przezdziecki, A., Alcorso, J., & Sherman, K. A. (2016). My changed body: background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer. *Patient Education and Counseling, 99*(5), 870-874.

Przezdziecki, A., & Sherman, K. A. (2016). Modifying affective and cognitive responses regarding body image difficulties in breast cancer survivors using a self-compassion-based writing intervention. *Mindfulness, 7*(5), 1142-1155. doi:10.1007/s12671-016-0557-1

Przezdziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: breast cancer, body image, distress and self-compassion. *Psycho-oncology*, *22*, 1872-1879.

Puts, M. T. E., Monette, J., Girre, V., Wolfson, C., Monette, M., Batist, G., & Bergman, H. (2009). Participation of older newly-diagnosed patients in an observational prospective pilot study: an example of recruitment and retention. *BMC Cancer*, *9*:277. Doi: 10.1186/1471-2407/9/277

Quality Health. (2014). *National Cancer Patient Experience Survey 2014 National Report*. Retrieved 1st June, 2015 from https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385 - 401.

Raingruber, B. (2011). The effectiveness of psychosocial interventions with cancer patients: an integrative review of the literature (2006-2011). *ISRN Nursing, 2011*, 1-12. Doi:10.5402/2011/638218

Randall, J., & Ream, E. (2005). Hair loss with chemotherapy: at a loss over it's management? *European Journal of Cancer Care, 14*(3), 223-231.

Rayner, L., Price, A., Hotopf, M., & Higginson, I. J. (2011). The development of evidence-based European guidelines on the management of depression in palliative cancer care. *European Journal of Cancer, 47*, 702–712.

Razavi, D., Merckaert, I., Marchal, S., Libert, Y., Conradt, S., Boniver, J., … Delvaux, N. (2003). How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post training consolidation workshops. *Journal of Clinical Oncology, 21*, 3141–3149.

Ream, E., & Richardson, A. (1996). The role of information in patients' adaptation to chemotherapy & radiography: a review. *European Journal of Cancer Care, 5*(3), 131-138.

Redman, S., Turner, J., & Davis, C. (2003). Improving supportive care for women with breast cancer in Australia: the challenges of modifying health systems. *Psycho-Oncology*, *12*, 521-531.

Redmond, J. L. (2014). Understanding and Addressing Barriers to Recruitment. *The American Journal of Managed Care, 20*(5), 1.

Reinfold, M. (1960). Relationship of stress to the development of symptoms in alopecia areata and chronic urticaria. *British Medical Journal, 19,* 846-849.

Reynolds, J. S., & Perrin, N. A. (2004). Mismatches in social support and psychosocial adjustment to breast cancer. *Health Psychology, 23*(4), 425-430.

Richards, J. M., Beal, W. E., Seagal, J., & Pennebaker, J. W. (2000). Effects of disclosure of traumatic events on illness behaviour among psychiatric prison inmates. *Journal of Abnormal Psychology, 109,* 156-160.

Ristevski, E., Regan, M., Jones, R., Breen, S., Batson, A., & McGrail, M. R. (2013). Cancer patient and clinician acceptability and feasibility of a supportive care screening and referral process. *Health Expectations, 18*(3), 406-418. Doi: 10.1111/hex.12045

Rise, M. B., Solbjor, M., Lara, M. C., Westerlund, H., Grimstad, H., & Steinsbekk, A. (2013). Same description, different values. How service users and providers define patient and public involvement in health care. *Health Expectations, 16*(3), 266–276.

Ridderheim, M., Bjurbergm, M., & Gustavsson, A. (2003). Scalp hypothermia to prevent chemotherapy-induced alopecia if effective and safe: a pilot study of a new digitalized scalp-cooling system used in 74 patients. *Support Care Cancer11*: 371–7.

Rivkin, I., Gustafson, J., Weingarten, I., & Chin, D. (2006). The effects of expressive writing on adjustment to HIV. *AIDS and Behaviour, 10*(1), 13-26.

Roark, L. (2008). Look Good ... Feel Better Helps People Battling Cancer Help Themselves. *Journal of Oncology Practice, 4*(5), 262.

Robert, C. S., Piper, L., Denny, J., & Cuddeback, G. (1997). A support group intervention to facilitate young adults' adjustment to cancer. *Health & Social Work, 22*(2)133-140.

Robinson, E., Rumsey, N., & Partridge, J. (1996). An evaluation of the social skills interaction skills workshops for people with disfiguring conditions. *British Journal of Plastic Surgery, 49,* 281-289.

Rodgers, J., Martin, C. R., Morse, R. C., Kendell, K. & Verrill, M. (2005). An investigation into the psychometric properties of the Hospital Anxiety and Depression Scale in patients with breast cancer. *Health and Quality of Life Outcomes, 3*(41), 1-12.

Roe, H. (2011). Chemotherapy-induced alopecia: advice and support for hair loss. *British Journal of Nursing, 20*(10), S4-S11.

Rogers, S. N., El-Sheikha, J., & Lowe, D. (2009). The development of a patients concerns inventory (PCI) to help reveal patients concerns in the head and neck clinic. *Oral Oncology, 45*, 555-561.

Ron, I. G., Kalmus, Y., Kalmus, Z., Inbar, M., & Chaitchik, S. (1997). Scalp cooling in the prevention of alopecia in patients receiving depilating chemotherapy. *Support Care Cancer, 5*, 136-138.

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Rosman, S. (2004). Cancer and stigma: experience of patients with chemotherapy-induced alopecia. *Patient Education and Counselling, 52*(3), 333-339.

Ross, S., Grant, A., Counsell, C., Gillespie, W., Russell, I., & Prescott, R. (1999). Barriers to participation in randomised controlled trials: a systematic review. *Journal of Clinical Epidemiology, 52*, 1143-1156.

Rost, A. D., Wilson, K. G., Buchanan, E., Hildebrandt, M. J. & Mutch, D. (2012). Improving psychological adjustment among late-stage ovarian cancer patient: examining the role of avoidance in treatment. *Cognitive and Behavioral Practice, 19*, 508-517.

Rothwell, P. M. (2005). External validity of randomized controlled trials: 'To whom do the benefits apply? *Lancet 365*, 82–93.

Rumsey, N., & Harcourt, D. (2005). *The Psychology of Appearance*. Open University Press: Maidenhead.

Rumsey, N., & Harcourt, D. (2012). *The Oxford handbook of the psychology of appearance*. Oxford University Press: Oxford.

Russ, D. A. (1992). The use of program writing as a treatment for anxiety. *Dissertation Abstracts International, 53*, 3165-3166.

Saboonchi, S., Petersson, L., Wennman-Larsen, A., Alexanderson, K., Brännström, R., & Vaez, M. (2014). Changes in caseness of anxiety and depression in breast cancer patients during the first year following surgery: Patterns of transiency and severity of the distress response. *European Journal of Oncology Nursing, 18*, 598-604.

Salmon, P., Clark, L., McGrath, E. & Fisher, P. (2015). Screening for psychological distress in cancer: renewing the research agenda. *Psycho-Oncology, 24*, 262-268.

Salonen, P., Tarkka, M., Kellokumpu-Lehtinen, P., Koivisto., A., Astedt-Kurki, P., & Kaunonen, M. (2011). Individual face-to-face support and quality of life in

patients with breast cancer. *International Journal of Nursing Practise, 17*, 396-410.

Sandok, B. A. (1964). Alopecia Areata: An apparent relationship to psychic factors. *The American Journal of Psychiatry, 121,* 184-185.

Santin, O., Mills, M., Treanor, C. & Donnelly, M. (2012). A comparative analysis of the health and well-being of cancer survivors to the general population. *Support. Care Cancer* 20, 2545–2552.

Sarwer, D. B., & Crerand, C. E. (2004). Body image and cosmetic medical treatments. *Body Image, 1*(1), 99-111.

Sax, L. J., Gilmartin, S. K & Bryant, A. N. (2003). Assessing response rates and non-response bias in web and paper surveys. *Research in Higher Education, 44*(4), 409-432.

Schaefer, C., Coyne, J. C., & Lazarus, R. S. (1981). The health-related functions of social support. *Journal of Behavioral Medicine, 4*, 381. Doi:10.1007/BF00846149

Schwer, R. K., & Daneshvary, R. (2000). Keeping up one's appearance: Its importance and the choice of type of hair-grooming establishment. *Journal of Economic Psychology 21*, 207-222.

Schofield, P., Ugalde, A., Carey, M., Mileshkin, L., Duffy, M., Ball, D., & Aranda, S. (2008). Lung cancer: challenges and solutions for supportive care intervention research. *Palliative Support Care, 6,* 281-287.

Schoutrop, M. J. A., Lange, A., Brosschot, J., & Everaerd, W. (1997). Overcoming traumatic events by means of writing assignments. In A. Vingerhoets, F. van Bussel, & J. Boelhouwer (Eds.), *The (Non)expression of emotions in health and disease.* (pp 279-289). Tilburg, The Netherlands: Tilburg University Press.

Schoutrop, M. J. A., Lange, A., Hanewald, G., Davidovich, U., & Salomon, H. (2002). Structured writing and processing major stressful events: A controlled trial. *Psychotherapy and Psychosomatics, 71*, 151-157.

Schroevers, M & Brandsma, R. (2010). Is learning mindfulness associated with improved affect after mindfulness-based cognitive therapy? *British Journal of Health Psychology, 101*, 95-107.

Schain, W. S. (1994). Barriers to clinical trials: Part II: knowledge and attitudes of potential participants. *Cancer, 74*, 2666-2671.

Sears, S. R., Stanton, A. L., Kwan, L., Krunnick, J. L., Rowland, J. H., Meyerowitz, B. E., & Ganz, P. A. (2003). Recruitment and retention challenges in

breast cancer survivorship research: Results from a multisite, randomized intervention trial in women with early stage breast cancer. *Cancer Epidemiology, Biomarkers & Prevention*, *12*, 1087-1090.

Sealed Envelope Ltd. (2015). *Create a blocked randomisation list*. Retrieved July 2015 from https://sealedenvelope.com/simple-randomiser/v1/lists.

Shapiro, S. L., Lopez, A. M., Schwartz, G. E., Bootzin, R., Figueredo, A. J., Braden, C. J., & Kurker, S. F. (2001). Quality of life and breast cancer: Relationship to psychosocial variables. *Journal of Clinical psychology*, 57(4), 501-519.

Shapiro, J., Wiseman, M., & Liu, H. (2000). Practical management of hair loss. *Canadian Family Physician, 46*(7), 1469-1477.

Sheppard, L. A., & Ely, S. (2008). Breast cancer and sexuality. *The Breast Journal*, 14(2): 176-181.

Sheppard, V. B., Harper, F. W. K., Davis, K., Hirpa, F., & Makambi, K. (2014). The importance of contextual factors and age in association with anxiety and depression in black breast cancer patients. *Psycho-Oncology, 23*, 143-150.

Sherman, D. K., Nelson, L. D., & Steele, C. M. (2000). Do messages about health risks threaten the self? Increasing the acceptance of threatening health messages via self- affirmation. *Personality and Social Psychology Bulletin, 26*, 1046 –1058. doi:10.1177/01461672002611003

Sherman, A., Pennington, J., Latif, U., Farley, H., Arent, L., & Simonton, S. (2007). Patient preferences regarding cancer group psychotherapy interventions: a view from inside. *Psychosomatics, 48*, 426-432.

Sheese, B. E., Brown, E. L., & Graziano, W. G. (2004). Emotional expression in cyberspace: Searching for moderators of the Pennebaker disclosure effect via email. *Health Psychology, 23*, 457-464.

Shuy, R.W. (2003). In-person versus telephone interviewing. *In Inside interviewing: New lenses, new concerns*, Holstein J.A & Gubrium J.F (ed.). Thousand Oaks: Sage Publications; 175-193.

Siddons, H. M., Wooten, A. C., & Costello, A. J. (2013). A randomised, wait-list controlled trial: evaluation of a cognitive-behavioural group intervention on psycho-sexual adjustment for men with localised prostate cancer. *Psycho-Oncology, 22*, 2186-2192.

Silverman, D. (2000). *Doing qualitative research*. Sage publications: London

Simons, D. J. (2014). The value of direct replication. *Perspectives on Psychological Science, 9*, 76–80. Doi:10.1177/1745691613514755

Simpson, J. S., Carlson, L. E., Beck, C. A., & Patten, S. (2002). Effects of a brief intervention on social support and psychiatric morbidity in breast cancer patients. *Psycho-Oncology. 11*(4), 282–294.

Sloan, D. M., Feinstein, B. A., & Marx, B. P. (2009). The durability of beneficial health effects associated with expressive writing. *Anxiety, Stress & Coping, 22*(5), 509-523.

Sloan, D. M., & Marx, B. P. (2004). Taking pen to hand: Evaluating theories underlying the written disclosure paradigm. *Clinical Psychology: Science and Practise, 11,* 121-137.

Small, M. L. (2011). How to conduct a mixed methods study: Recent trends in a rapidly growing literature. *Annual Review of Sociology, 37,* 57-86.

Smith, J. A. (2003). *Qualitative psychology*: *A practical guide to research methods.* Thousand Oaks, CA: Sage.

Smith, C., Dickens, C., & Edwards, S. (2005). Provision of information for cancer patients: an appraisal and review. *European Journal of Cancer Care, 14*(3), 282-288.

Smith, S. K., Herndon, J. E., Lyerly, H. K., Coan, A., Wheeler, J. L., Staley, T., & Abernethy, A. P. (2011). Correlates of quality of life-related outcomes in breast cancer patients participating in the Pathfinders pilot study. *Psycho-oncology, 20,* 559-564. Doi: 10.1002/pon.1770

Smith, J. E., Richardson, J., Hoffman, C. & Pilkington, K. (2004). Mindfulness-based stress reduction as supportive therapy in cancer care: systematic review. *Journal of Advanced Nursing, 52,* 315-327.

Smyth, J. M. (1998). Written emotional expression: Effect sizes, outcome types, and moderating variables. *Journal of Consulting & Clinical Psychology, 66,* 174-184.

Smyth, J. M., Hockemeyer, J. R., & Tulloch, H. (2008). Expressive writing and post-traumatic stress disorder: Effects on trauma symptoms, mood states, and cortisol reactivity. *British Journal of Health Psychology, 13,* 85-93.

Smyth, J., & L'Abaté, L. (2000). Using workbooks to promote health: Examining their efficacy. In L'Abaté L, Torem M (eds), *Distance Writing and Computer Assisted Intervention in Psychiatry and Mental Health* (pp77-92). Westport, CT: Ablex.

Smyth, J. M., & Pennebaker, J. W. (2008). Exploring the boundary conditions of expressive writing: In search of the right recipe. *British Journal of Health Psychology, 13,* 1-7.

Smyth, J. M., Stone, A. A., Hurewitz, A., & Kaell. (1999). Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis: A randomized trial. The *Journal of the American Medical Association, 281*(14), 1304- 1309.

Smyth, J., True, N., & Souto, J. (2001). Effects of writing about traumatic experiences: The necessity for narrative structure. *Journal of Social & Clinical Psychology, 20,* 161-172.

Snyder, C. F., Blackford, A. L., Brahmer, J. R., Carducci, M. A., Pili, R., Stearns, V., … Wu, A. W. (2010). Needs assessments can identify scores on HRQOL questionnaires that represent problems for patients: an illustration with the Supportive Care Needs Survey and the QLQ-C30. *Quality of Life Research, 19,* 837–845.

Snyder, C. F., Garrett-Mayer, E., Blackford, A. L, Brahmer, J. R., Carducci, M. A., Pili, R., … Wu, A. W. (2009). Concordance of cancer patients' function, symptoms, and supportive care needs. *Quality of Life Research, 18,* 991–998.

Snyder, C. R., & Lopez, S. J. (2008). *Handbook of Positive Psychology*. New York, NY: Oxford University Press.

Solano, L., Donati, V., Pecci, F., Persichetti, S., & Colaci, A. (2003). Postoperative course after papiloma resection: Effects of written disclosure of the experience in subjects with different alexithymia levels. *Psychosomatic Medicine, 65,* 477-484.

Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). Quality in Qualitative Evaluation: A framework for assessing research evidence. *Social Research, 108,* 1-20.

Spera, S., Buhrfeind, E., & Pennebaker, J. W. (1994). Expressive writing and coping with job loss. *Academy of Management Journal, 3,* 722-733.

Spiegel, D. (1997). Psychosocial aspects of breast cancer treatment. Retrieved June 2013 from http:// www. bencium.hu/onkopszicholgia

Sprangers, M. A., Groenvold, M., Arraras, J. I., Franklin, J., Te Velde, A., et al. (1996). The European Organization for Research and Treatment of Cancer breast cancer-specific quality-of-life questionnaire module: first results from a three-country field study. *Journal of Clinical Oncology, 14,* 2756 - 68.

Stablein, T., Hall, J. L., Pervis, C., & Anthony, D. L. (2015). Negotiating stigma in health care: disclosure and the role of electronic health records. *Health Sociology Review, 24*(3), 227-241.

Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., Swaorowski, L. A., & Twillman, R. (2000). Emotionally expressive

coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting Psychology, 68*, 875-882.

Stanton, A. L., Danoff-Burg, S., Sworowski, L. A., Collins, C. A., Branstetter, A. D., Rodriguez-Hanley, A., Kirk, S. B., & Austenfeld, J. L. (2002). Randomization, controlled trial of written emotional expression and benefit finding in breast cancer patients. *Journal of Clinical Oncology, 20*(20), 4160-4168.

Stanton, A. L., Revenson, T. A., Tennen, H. (2007). Health psychology: psychological adjustment to chronic disease. *Annual Review Psychology, 58*, 565–592.

Stapel, D. A., & Van der Linde, L. A. J. G. (2011). What drives self-affirmation effects? On the importance of differentiating value affirmation and attribute affirmation. *Journal of Personality and Social Psychology, 101*(1), 34-45.

Stevens, T., Wilde, D., Hunt, J., & Ahmedzai, S. H (2003). Overcoming the challenges to consumer involvement in cancer research. *Health Expectations, 6*, 81-88.

Stevenson, C., & Cooper, N. (1997). Qualitative and quantitative research. *The Psychologist, 10*(4), 159-160.

Stilson, J. (2009). *Good Hair*. New York, NY: HBO Films.

Stommel, M., Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2004). A longitudinal analysis of the course of depressive symptomatology in geriatric patients with cancer of the breast, colon, lung, or prostate. *Health Psychology, 23*, 564-573.

Stroebe, M., Strobe, W., Scut, H., Zech, E., & van den Bout, J. (2002). Does disclosure of emotion facilitate recovery from bereavement? Evidence from two prospective studies. *Journal of Consulting and Clinical Psychology, 70*, 169-178.

Swash, B. Hulbert-Williams, N., & Bramwell, R. (2014). Unmet psychosocial needs in haematological cancer: a systematic review. *Support Care Cancer, 22*, 1131– 1141. Doi: 10.1007/s00520-014-2123-5

Taggart, L. R., Ozolins, L., Hardie, H., & Nyhof-Young, J. (2009). Look Good Feel Better Workshops: A "Big Lift" for women with cancer. *Journal of Cancer Education, 24*, 94-99.

Talley, A., Molix, L., Schlegel, R. J., & Bettencourt, A. (2010). The influence of breast cancer survivors' perceived partner social support and need satisfaction on depressive symptoms: a longitudinal analysis. *Psychology of Health, 25*(4),433–449.

Tashakkori, A. M., & Teddlie, C. B. (2010). *SAGE handbook of mixed methods in social and behavioural research*. London: Sage Publications.

Tatrow, k., & Montgomery, G. H. (2006). Cognitive behavioural therapy techniques for distress and pain in breast cancer patients: a meta-analysis. *Journal of Behavioural Medicine, 29*(1), 17-27.

Tariq, S., & Woodman, J. (2010). Using mixed methods in health research. *Journal of the Royal Society of Medicine Short Reports, 0*, 1-8. Doi: 10.1177/2042533313479197

Taylor, G. J., Bagby, R. M., & Parker, J. D. A. (1997). *Disorders of a affect regulation: Alexithymia in medical and psychiatric illness*. Cambridge: Cambridge University Press.

Taylor, G. J., Bagby, R. M., & Parker, J. D. A. (2003). The 20-item Toronto Alexithymia scale IV. Reliability and factorial validity in different languages and cultures. *Journal of Psychosomatic Research, 55*, 277-283.

The Appearance Research Collaboration (ARC). (2009). *Identifying the psychosocial factors and processes contributing to successful adjustment to disfiguring conditions*. Bristol: ARC.

Thompson, A., Brennan, K., Cox, A., Gee, J., Harcourt, D., Harris, A.,… Streuli, C. (2008). Evaluation of the current knowledge limitations in breast cancer research: gap analysis. *Breast Cancer Research, 10*(2), 1-25.

Thompson, A., & Kent, G. (2001). Adjusting to disfigurement: process involved in dealing with being visibly different. *Clinical Psychology Review*, 21(5): 663-682.

Tierney, A. J., Taylor, J., Closs, S. J. (1992). Knowledge, expectations and experiences of patients receiving chemotherapy for breast cancer. *Scandinavian Journal of Caring Science, 6*, 75–80.

Tiggemann, M., & Kenyon, S. J. (1998). The hairlessness norm: The removal of body hair in women. *Sex Roles, 39*(11), 873-885. Doi: 10.1023/A:1018828722102

Town, J. M., Abbass, A., & Hardy, G. (2011). Short-Term Psychodynamic Psychotherapy for Personality Disorders: A Critical Review of Randomized Controlled Trials. *Journal of Personality Disorders, 25*(6), 723-740.

Townsley, C. A., Chan, K. K., Pond, G. R., Marquez, C., Siu, L. L., & Straus, S. E. (2006). Understanding the attitudes of the elderly towards enrolment into cancer clinical trials. *BMC Cancer, 6*:34.

Treweek, S., Mitchell, E., Pitkethly, M., Cook, J., Kjeldstrøm, M., Taskila, T., Johansen, M., Sullivan, F., Wilson, S., Jackson, C., & Jones, R. (2010). Strategies to improve recruitment to randomised controlled trials. *Cochrane Database of Systematic Reviews,1*, MROOOO13.

Treweek, S., Lockhart, P., Pitkethly, M., Cook, J. A., Kjeldstrøm, M., Johansen, M., Taskila, T. K., Sullivan, F. M., Wilson, S., Jackson, C., Jones, R., & Mitchell, E. D. (2013). Methods to improve recruitment to randomised controlled trials: Cochrane systematic review and meta-analysis. *BMJ Open, 3*, e002360. Doi: 10.1136/bmjopen-2012-0023600

Trier-Bieniek, A. (2012). Framing the telephone interview as a participant-centred tool for qualitative research: a methodological discussion. *Qualitative research,* 12(6), 630-644.

Trüeb, R. M. (2009). Chemotherapy-induced alopecia. *Seminars in Cutaneous Medicine and Surgery, 28*(1), 11-14.

Tsaousis, I., Taylor, G. J., Quilty, L., Georgiades, S., Stavrogiannopolous, M., & Bagby, R. M. (2010). Validation of the Greek adaptation of the 20-item Toronto Alexithymia *Scale. Comprehensive Psychiatry, 51*, 443– 448. doi:10.1016/j.comppsych.2009.09.005

Ucok, O. (2005). The meaning of appearance in surviving breast cancer. *Human Studies, 28*(3), 291-316.

Ullrich, P., & Lutgendorf, S. (2002). Journaling about stressful events: Effects of cognitive processing and emotional expression. *Annals of Behavioural Medicine, 24*, 244-250.

Vahdaninia, M., Omidvari, S., & Montazeri, A. (2010). What do predict anxiety and depression in breast cancer patients? A follow-up study. *Social Psychiatry and Psychiatric Epidemiology, 45*(3), 355-361.

Vandegrift, K. V. (1994). The development of an oncology alopecia wig program. *Journal of Intravenous Nursing, 17*(2), 78-82.

Villagran, M. M., & Lucke, J. F. (2005). Translating communication measures for use in Non-English-Speaking Populations. *Communication Research Reports, 22*(3), 247-251.

Vogel, B. A., Bengel, J., & Helmes, A. W. (2008). Information and decision making: patients' needs and experiences in the course of breast cancer treatment. *Patient Education and Counseling, 71*, 79-85.

Voigt, B., Grimm, A., Loßack, M., Klose, P., Schneider, A., & Richter-Ehrenstein, C. (2011). The breast care nurse: the care specialist in breast centres. *International Nursing Review* 58, 450–453

Wagner, K. D., Davidson, P. J., Pollini, R. A., Strathdee, S. A., Washburn, R., Lawrence, A., & Palinkas, L. A. (2012). Reconciling incongruous qualitative and quantitative findings in mixed methods research: Exemplars from research with drug using populations. *International Journal of Drug Policy, 23*, 54-61. doi:10.1016/j.drugpo.2011.05.009

Walker, L., Nail, L. M., & Croyle, R. T. (1999). Does emotional expression make a difference in reactions to breast cancer? *Oncology Nursing Forum, 26*(6), 1025-1032.

Wang, F., Liu, J. J., Liu, L. Y., Ma, Z. B., Gao, D. Z., Zhang, Q., &Yu, Z. G. (2014). The status and correlates of depression and anxiety among breast-cancer survivors in Eastern China: a population-based, cross-sectional case-control study. *BMC Public Health, 14*(326), 1-6.

Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C., & Robertson, B., (1988). Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychological Medicine 18*, 203-209.

Watson, D., & Friend, R. (1969). Measurement of social-evaluative anxiety. *Journal of Consulting and Clinical Psychology*, *33*, 448–457.

Watson, E. K., Rose, P. W., Neal, R. D., Hulbert-Williams, N., Donnelly, P., Hubbard, G., … Wilkinson, C. (2012). Personalised cancer follow-up: risk stratification, needs assessment or both? *British Journal of Cancer 106*(1), 1–5

Watson, M., Greer, S., Young, J., Inayat, G., Burgess, C., & Robertson, B. (1988). Development of A Questionnaire Measurement Of Adjustment: The MAC Scale. *Psychological Medicine, 8*, 203-209.

Watson, M., White, C., Davolls, S., Mohammed, A., Lynch, A., & Mohammed, K. (2013). Problem-focussed interactive telephone therapy for cancer patients: a phase ll feasibility trial. *Psycho-Oncology*, *22*, 1485-1491.

Wefel, J. S., Lenzi, R., Theriault, R. L., Davis, R. N., Meyers, C. A. (2004). The cognitive sequelae of standard-dose adjuvant chemotherapy in women with breast carcinoma: results of a prospective, randomized, longitudinal trial. *Cancer, 100*, 2292–9.

Weinsman, J., Ebrecht, M., Scott, S., Walburn, J., & Dyson, M. (2008). Enhanced wound healing after emotional disclosure intervention. *British Journal of Health Psychology, 13*, 95-102.

Weiss, G. I., & Lonnquist, L. E. (2000). *The sociology of health, healing and illness*. Prentice Hall: Upper Saddle River, NJ.

Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: A qualitative study. *Body Image, 6*, 194-200.

Wetherell, M. A., Bryne-Davis, L., Dieppe, P., Donovan, J., Brookes, S., Byron, M., … Miles, J. (2005). Effects of emotional disclosure on psychological and physiological outcomes in patients with rheumatoid arthritis: an exploratory home-based study. *Journal of Health Psychology, 10*(2), 277-285.

Whelan, J. M., Griffith, C. D., & Archer, T. (2006). Breast cancer multidisciplinary teams in England: much achieved but still more to be done. *Breast Journal, 15*(1), 119-122.

Whelan, T. J., Rath, D., Willan, A.,Neimanis, M., Czukar, D., & Levine, M. (1998). Evaluation of a patient file folder to improve the dissemination of written information materials for cancer patients. *Cancer, 83*(8), 1620-1625. Doi: 10.1002/(SICI)1097- 0142(19981015)83:8<1620::AID-CNCR18>3.0.CO;2I

White, C. A. (2000). Body image dimensions and cancer: A heuristic cognitive behavioural model. *Psycho-Oncology, 9*(3), 183-192.

White, C.A. (2002). Body image issues in oncology, in T.F. Cash and T. Pruzinsky (eds) *Body Image: A Handbook of Theory, Research and Clinical Practice.* London: Guilford Press.

Wiggins, S., Moore-Millar, K., & Thomson, A. (2014). Can you pull it off? Appearance modifying behaviours adopted by users with alopecia in social interactions. *Body Image,* 11, 156-166.

Williamson, G. R. (2003). Misrepresenting random sampling? A systematic review of research papers in the Journal of Advanced Nursing. *Journal of Advanced Nursing, 44*(3), 278–288.

Willemsen, R., Haentjens, P., Roseeuw, D., & Vanderlinden, J. (2011). Hypnosis and Alopecia Areata: Long-term beneficial effects on psychological well-being. *Acta Dermato Venereologica, 19*, 35-39.

Willemsen, R., & Vanderlinden, J. (2008). Hypnotic approaches for alopecia areata. *International Journal of Clinical and Experimental Hypnosis, 56*(3), 318-333.

Willemsen, R., Vanderlinden, J., Deconinck, A., & Roseeuw, D. (2006). Hypnotherapeutic management of alopecia areata. *Journal of the American Academy of Dermatology, 55*, 233-237.

Williams, J., Wood, C., & Cunningham-Warbuton, P. (1999). A narrative study of chemotherapy-induced alopecia. *Oncology Nursing Forum, 26*(9), 549-565.

Wright, D. N. M., Corner, J.L., Hopkinson J. B., & Foster, C. L. (2007). The case for user involvement in research: the research priorities of cancer patients. *Breast Cancer Research, 9*(suppl 2). Doi:10.1186/bcr1801.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*, 215-228.

Yardley, L., & Bishop, F. L. (2007). Mixing qualitative and quantitative methods. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 352– 369). London, UK: Sage.

Yardley, L., & Bishop, F. L. (2015). Using mixed methods in health research: Benefits and challenges. *British Journal of Health Psychology, 20*, 1-4.

Yardley, L., & Nyman, S. R. (2007). Internet provision of tailored advice on falls prevention activities for older people: a randomized controlled evaluation. *Health Promotion International, 22*(2), 122-128. Doi:10.1093/heapro/dam007

Yeager, C. E., & Olsen, E. A. (2011). Treatment of chemotherapy-induced alopecia. *Dermatologic Therapy, 24*, 432-442.

Zachariae, R., & O'Toole, M. S. (2015). The effect of expressive writing intervention on psychological and physical health outcomes in cancer patients – a systematic review and meta-analysis. *Psycho-Oncology, 24*, 1349-1359. DOI: 10.1002/pon.3802

Zakowski, S. G., Ramati, A., Morton, C., Johnson, P., & Flanigan, R. (2004). Written emotional disclosure buffers the effects of social constraints on distress among cancer patients. *Health Psychology, 23*(6), 555-563.

Zannini, L., Verderame, F., Cucchiara, G., Zinna, B., Alba, A., & Ferrara, M. (2012). 'My wig has been my journey's companion': perceived effects of an aesthetic care program for Italian women suffering from chemotherapy-induced alopecia. *European Journal of Cancer Care,21(5)*, 650-660.

Zhang, Y., Liu, C & Jin, F. (2011). Psychological evaluation of patients after breast cancer surgery and care strategies improvement. *Journal of Clinical Oncology, 10* (10), 584 - 587.

Zhou, C., Wu, Y., An, S., & Li, X. (2015). Effect of expressive writing intervention on health outcomes in breast cancer patients: A systematic review and meta-analysis of randomized controlled trials. PLoS ONE, 10(7): e0131802. DOI:10.1371/journal.pone.0131802

Zierler, S., Cunningham, W. E., Anderson, R., Shapiro, M. F., Nakazono, T., Morton, S., Crystal, S., Stein, M., Turner, B., St. Clair, P., & Bozette, S. A. (2000). Violence victimization after HIV infection in a US probability sample of adult atients in primary care. *American Journal of Public Health, 90*(2), 208-215.

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale, *Acta Psychiatrica Scandinavica, 67*(6), 361-370.

Appendices

Appendix 1. Outline of the search strategy and search terms used for the systematic review

Stage 1. Terminology:-

Appearance/body image: body image, physical appearance, disfigurement, visible difference, alopecia, hair-loss/hair loss

Psychosocial Interventions: therapeutic interventions, patient teaching, education, advice, communication, camps, exercise, social skills training, wigs, headwear, scarves, CBT/Cognitive Behavioural Therapy, behavioural therapy, counselling, social support, social support networks, group therapy, peer support, hair consultant, nurse practitioner, oncology nurse, specialist nurse, cancer resource program, couple based interventions, nursing care, psycho-social support, information provision.

Psychosocial Intervention is defined as any program that incorporates techniques that aim to reduce psychosocial distress by reducing anxiety and depression and increasing social activities.

Cancer: oncology, cancer, tumour, chemotherapy

Stage 2. Identification of databases to search:-

- AMED – Allied and Complementary Medicine
- ASSIA – Applied Social Sciences Index and Abstracts
- BNI – British Nursing Index
- CAMPBELL COLLABORATION – Systematic reviews of the effects of social interventions
- CINAHL – Cumulative Index to Nursing and Allied Health Literature
- EMBASE- Psychiatry and Pharmacology
- MEDLINE – Biomedicine and Health
- PUBMED – Clinical Science and Biomedicine
- PSYCHINFO – Psychology
- SCIENCE DIRECT – Social Sciences
- SCIENCE CITATION INDEX – Medicine, Psychiatry
- SOCIAL SCIENCES CITATION INDEX – Psychology
- UK PUBMED CENTRAL – Biomedical and life sciences

Stage 3. Identification of 'grey' literature:-

- WEB OF KNOWLEDGE **–** ISI Web of Science and ISI Proceedings
- ZETOC (BRITISH LIBRARY) **–** Conference papers/proceedings

- CONFERENCE POSTERS – Review of abstract publications, attendance at International Psycho-Oncology Conference
- CONTACTS & EXERTS: –
    - Dr. Clarke
    - Dr. Collins
- ORGANISATIONS – website search of cancer charities: Breast Cancer Campaign, Breast Cancer Care, Breast Cancer UK, Tenovus, Cancer UK
- HAND SEARCH of Bibliographies – of those studies selected for systematic review and those identified as highly relevant during first screening of abstracts.

Stage 4. Systematic Consideraion of Concept/MeSH Terminology:-

To ensure that the chances of capturing all relevant papers are maximised, the first search for each database will be conducted with just the two concepts ‘psychosocial intervention’ and ‘hair loss’ for each. If the number of articles retrieved is high or if the relevance of the articles retrieved is low, the next concept ‘cancer’ will be entered with each database MeSH term.

The following searches were conducted with no limit on year of publication:

Database	Intervention	Hair loss/Appearance
AMED (EBSCO) Searched 9/2/12 & 10/2/12	Psychological intervention$ Psychological adj1 intervention$ Psychological adj2 intervention$ Psychological adj3 intervention$ Psycho-social intervention$ Psycho-social adj1 intervention$ Psycho-social adj2 intervention$ Psycho-social adj3 intervention$ Psychosocial intervention$ Psychosocial adj1 intervention$ Psychosocial adj2 intervention$ Psychosocial adj3 intervention$ Therapeutic intervention$	Hair loss Alopecia Bald* Appearance* Visible difference* Body image* Self-concept Body awareness
British Nursing Index (ProQuest) Searched 10/2/12	Patient teaching Patient adj1 teaching$ Patient adj2 teaching$ Education Exercise Advice Communication Camp$ Social skill$ training Camouflage Wigs Scarves	(Same hair loss/Appearance search terms as above)
CINAHL (EBSCO) Searched 12/2/12 & 13/2/12	Cognitive behavio?ral therapy Behavio?ral therapy Cognitive therapy CBT Counselling Social support Social support networks Group therapy Peer support Outreach program$ Couple-based intervention$ Nursing care	(Same hair loss/Appearance search terms as above)

	Nursing care-plan$ Psychological care	
EMBASE (OVID) Searched 13/2/12	(Same search terms used as above)	
MEDLINE (OVID) Searched 14/2/12	(Same search terms used as above)	
PSYCHINFO (EBSCO) Searched 14/2/12	(Same search terms used as above)	
INDEX/SOCIAL SCIENCES CITATION INDEX (WEB OF SCIENCE) Searched 14/2/12 & 15/2/12	(Same search terms used as above)	
ASSIA Searched 15/2/12	Psychological intervention$ Psychological adj1 intervention$ Psychological adj2 intervention$ Psychological adj3 intervention$ Psycho-social intervention$ Psycho-social adj1 intervention$ Psycho-social adj2 intervention$ Psycho-social adj3 intervention$ Psychosocial intervention$ Psychosocial adj1 intervention$ Psychosocial adj2 intervention$ Psychosocial adj3 intervention$	Alopecia Hair loss Baldness Physical appearance Visible difference$ Disfigure$ Body image$ Self-concept Body awareness
CAMPBELL COLLABORATION	Psychological intervention$ Psycho-social intervention$	Hair loss Alopecia

Searched 15/2/12	Psychosocial intervention$ Therapeutic intervention$ Psychological care Appearance Visible difference$ Disfigure$ Body image$	Baldness
UK PUBMED CENTRAL Searched 15/2/12	Psychosocial Psycho-social Appearance Visible difference	Hair loss Alopecia Baldness
COCHRANE LIBRARY Searched 15/2/12	Psychological intervention$ Psychological adj1 intervention$ Psychological adj2 intervention$ Psychological adj3 intervention$ Psycho-social intervention$ Psycho-social adj1 intervention$ Psycho-social adj2 intervention$ Psycho-social adj3 intervention$ Psychosocial intervention$ Psychosocial adj1 intervention$ Psychosocial adj2 intervention$ Psychosocial adj3 intervention$ Therapeutic intervention$ Patient teaching Patient adj1 teaching$ Patient adj2 teaching$ Education Exercise Advice Communication Camp$ Social skill$ training Camouflage Wigs Scarves Cognitive behavio?ral therapy Behavio?ral therapy Cognitive therapy CBT Counselling	Hair loss Alopecia Physical appearance Physical adj1 appearance Physical adj2 appearance Physical adj3 appearance Visible difference$ Visible adj1 difference Visible adj2 difference Visible adj3 difference Body image Body adj1 image Body adj2 image Body adj3 image Baldness Self-concept Body awareness Body adj awareness Body adj2 awareness Body adj3 awareness

	Social support	
	Social support networks	
	Group therapy	
	Peer support	
	Outreach program$	
	Couple-based intervention$	
	Nursing care	
	Nursing care-plan$	
	Psychological care	

Grey Literature Search

WEB OF KNOWLEDGE Searched 14/2/12	Psycho* intervention Appearance Body image$ Visible difference Self-concept Body awareness Disfigure$	Hair loss Alopecia Baldness
ZETOC (combined conference and journal search) Searched 16/2/12	Psycho* Appearance Body image Visible difference Self-concept Body awareness	Hair loss Alopecia Baldness

Search Record:

Search 1.a Hair Loss and intervention were included in all Ovid databases: AMED, British Nursing Index, CINAHL, EMBASE, MEDLINE, PSYCHINFO, Index/Social Science Citation Index: **8960** articles found and imported to Refworks.

Search 1.b ASSIA: Hair loss and intervention search terms run on this database and **463** articles were found and imported to Refworks.

Search 1.c UK PUBMED: Hair loss and intervention terms run on this database and**13** articles were found and imported to Refworks.

Search 1.d Cochrane Collaboration: Hair loss and intervention run on this database and **1456** articles found and imported to Refworks.

Search 1.e Web of Knowledge: Hair loss and intervention run on this database and **1183** articles found and imported to Refworks.

Search 1.f Zetoc: Hair loss and intervention run on this database and **378** articles found and imported to Refworks.

Once duplicates removed from Refworks: 5182 articles left for first review.

Appendix 2. Participant information sheet for the qualitative HeadStrong service evaluation

An evaluation of Breast Cancer Care's HeadStrong Service: Information Sheet

You are being invited to take part in a study. Please read this information carefully and contact us if you have any questions about it. Thank you.

What is the purpose of the study?

This study is interested in people's experiences of hair loss due to cancer treatment and their opinions about Breast Cancer Care's HeadStrong service. The study is being carried out by Melissa Pilkington, a PhD researcher from the Centre for Appearance Research (CAR) which is based at the University of the West of England (UWE), Bristol

Why have I been chosen?

You are being invited to take part because you have previously attended a Breast Cancer Care HeadStrong session. Anyone who has previously attended the HeadStrong service is eligible to take part. We are looking for a total of 25 people to take part

Do I have to take part?

No, taking part is voluntary. You do not have to take part if you do not want to and, if you do take part, you can withdraw from the study up to a month after taking part. Whether or not you take part will not make any difference to your care, now or in the future.

What will I have to do if I take part?

If you decide that you would like to take part in the study, you will be interviewed to explore your reasons for accessing HeadStrong, what you anticipated HeadStrong would provide and whether you think HeadStrong helped you in the long term. Interviews will be conducted via telephone. It is anticipated that interviews may last up to an hour maximum and we would like to record your interview if you are happy for us to do so.

What are the possible benefits of taking part?

We do not expect that you will personally benefit from taking part in this study, but you might be pleased to think that your feedback will be used to inform HeadStrong and other support services for people experiencing hair loss in the future

Will my identity be protected?

Yes, your identity will be protected. During the interview you will be asked about your diagnosis and hair loss, however, in order to protect your identity only a summary of this information will be reported during the write up if the evaluation.

What will happen with the results of the interview?

The results of the study will be given to Breast Cancer Care, so that they can use them to plan HeadStrong and other support services in the future. Your individual answers will not be passed on to Breast Cancer Care, they will only receive a summary of the study findings overall

How will the findings be shared with other people?

The overall findings will be published in a journal, presented at conference presentations and written up as part of a PhD. Also, a summary of the findings will be made available to both participants and to Breast Cancer Care for them to present at meetings.

Who has reviewed the study?

The study has been approved by the University of the West of England (UWE) Research Ethics Committee. It has also been approved by Breast Cancer Care. The study is funded by Breast Cancer Campaign.

Your right to withdraw from the study

You have the right to withdraw from the study up to a month after you have taken part. If you wish to withdraw from the study, please contact the researcher and your interview and all your information will be withdrawn from the study and destroyed.

What do I do now?

If you would like to take part in the study, please complete the consent form attached.

If you have any further questions, please contact, Melissa Pilkington at:-

Email:- Melissa.Pilkington@UWE.ac.uk

Telephone No:- (0117) 3283882

Or you can contact Melissa's supervisor, Dr Diana Harcourt at:-

Diana2.Harcourt@uwe.ac.uk

Telephone No:- (0117) 3283967

If you do want any more information about cancer-related hair loss, or would like to discuss any concerns you have, you might like to contact any of the following organisations that specialise in support for people affected by cancer:-

Breast Cancer Care:-

www.breastcancercare.org.uk

Peer Support Team Telephone No:- 0845 0771893

Peer Support Team Email:- ukpeersupportteam@breastcancercare.org.uk

Breast Cancer Care's Free Helpline for one-to-one support:- 0808 800 6000

Maggie's Centre:-

http://www.maggiescentres.org/

To arrange face-to-face support with a support specialist:-

Email:- enquiriesatmaggiescentres.org

Telephone No:- 0300 123 1801

Macmillan:-

www.macmillan.org.uk

If you have any questions, would like support or someone to talk to:-

Cancer Support Specialist Telephone No:- 0808 808 00 00

Appendix 3. Participant consent form for the qualitative HeadStrong service evaluation

An evaluation of Breast Cancer Care's HeadStrong Service: Consent Form

This study is interested in patients' experiences of Breast Cancer Care's HeadStrong service. Taking part in the study will involve either a face-to-face or telephone interview to discuss your experiences of HeadStrong. The interview should take no longer than an hour.

I would like to record the interview, with your permission. In order to protect your identity only a summary of the information you provide will be reported during the write up if the evaluation. You do not have to take part and you have the right to withdraw from the study up to a month after taking part.

If you give your consent to take part in the study, please sign below and return this form using the pre-paid envelope provided.

Print your name……. ***Date……..***

Your Signature..... Date.....

Contact Telephone Number.....

Or

Email.....

Thank you for your time.

Appendix 4. Interview schedule for the qualitative HeadStrong service evaluation

Interview schedule

Before we start, I would like to remind you that you do not have to answer any questions that you don't want to and if you choose not to answer a question, you don't have to tell me why. Also, you are free to stop the interview anytime if you feel you don't want to continue. The types of questions I ask do not have a right or wrong answer. I'm interested in finding out what you think and feel about things. I would like you to be open and honest when answering the questions. You will be asked to make up a false name for yourself and any information that you give will be treated as confidential. Are you happy to start? Do you have any questions before we start?

- Where did you attend your HeadStrong session?
- Why did you decide to go to a HeadStrong Session?
- How did you hear about HeadStrong?
- How many HeadStrong sessions did you attend?
- Did you attend HeadStrong prior to losing your hair or had you already started to lose your hair? (hair loss anticipation, hair loss moment, coping with hair loss, hair re-growth?)
- Did you use any other service to help with your hair loss?
- Where you offered any other support by your multidisciplinary team?
- How did losing your hair make you feel?
- Were some situations more difficult to handle than others?

- How did you try to manage the situation and how did you feel? Etc etc.

- What did you hope HeadStrong would achieve?

- What were your expectations of HeadStrong?

- Were your expectations met?

- What did you think it would be like at the session?
- Did HeadStrong help you with certain aspects of your life?

- To manage the impact that hair loss had on your overall appearance? Body image? Concern about hair loss? Quality of Life? Confidence in managing hair loss i.e. use of camouflage? Managing the reactions of other people?
- Has HeadStrong changed how you feel about hair loss?
- How do you feel about hair loss since going to the HeadStrong session?
- Have you used what was covered in the HeadStrong session since? For how long? Can you give me an example of a time or a situation when you've used it?
- What did you like about HeadStrong?
- Would you change the HeadStrong session in any way? If yes, how?
- Are there any aspects of hair loss that the session hasn't helped you with?
- Would you recommend HeadStrong to other people experiencing hair loss? Why, or why not?
- Is there anything else you would like to add?

Appendix 5. Invitation letter posted to eligible participants for the qualitative HeadStrong service evaluation

Printed on Breast Cancer Care Letter Headed paper

Date:

Dear

Invitation to take part in a study exploring people's experiences of the HeadStrong service.

I am writing to everyone who has attended a HeadStrong session, to tell them about a piece of research that is taking place and to invite them to take part. The research is investigating the emotional impact of hair loss and in particular people's experiences of the HeadStrong service. It will help us to ensure that Breast Cancer Care provides the best possible appropriate support for people affected by hair loss.

The research is being carried out by Melissa Pilkington, a PhD researcher from the Centre for Appearance Research (CAR) which is based at the University of the West of England (UWE), Bristol.

Please read the information sheet that has been sent to you with this letter and decide if you would like to take part. If you have any questions about the research, please do not hesitate to contact the researcher whose contact details are at the bottom of this letter.

If you do decide that you would like to take part, please note that any information that you give to the researcher will be treated as confidential. You are free to withdraw from the research up to a month after taking part and you will not be required to give a reason for withdrawing.

If you wish to take part, please read the enclosed information sheet and sign the consent form and return to Melissa Pilkington by using the pre-paid envelope enclosed.

If you would like more information please contact Melissa Pilkington:-
Email: Melissa.Pilkington@uwe.ac.uk

Telephone: 0117 3283882.

The Centre for Appearance Research
Room 2L13
University of the West of England, Bristol
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY

Thank you for reading this letter and for considering taking part in the study. Your support is much appreciated.

Yours Faithfully,

Breast Cancer Care

Appendix 6. Letter from NRES confirming REC review was not required for the HeadStrong service evaluation

ENQUIRY TO NRES

Dear Melissa,

Thank you for your email and summary seeking clarity on whether your project should be classified as research requiring ethical review.
As you will be aware, the new harmonised UK-wide edition of the Governance Arrangements for Research Ethics Committees (GAfREC) came into effect on 01 September 2011; detailed changes in the harmonised GAfREC can be found here on the NRES website.

There two key elements are whether:

i. your project is research? (The leaflet, "*Defining Research*", will help you to distinguish between research, audit or service evaluation and public health surveillance.) OR
ii. your project is research requiring ethical review? The algorithm, "*Does my project require review by a Research Ethics Committee?*", is designed to assist researchers, sponsors and R&D offices in determining whether a project requires ethical review by a Research Ethics Committee under the UK Health Departments. It encompasses the requirements for ethical review under both the policy of the UK Health Departments and legislation applying to the UK as a whole, or to particular countries of the UK.
The **Supplementary notes** section, in particular, outlines the types of research that do not normally require review by a REC within the UK Health Departments' Research Ethics Service.

Advisor's Comments:
Based on the information provided I would agree that this evaluation doesn't require REC review.

However, if you are undertaking the project within the NHS, you should check with the relevant NHS care organisation(s) what other review arrangements or sources of advice apply to projects of this type. Guidance may also be available from the clinical governance office.

Where the Research Governance Framework for Health and Social Care applies, the research will continue to require management permission from host care organisations ("R&D approval"). Within the Integrated Research Application System (IRAS), it is possible to indicate in the Filter that a research project requires review by NHS R&D only. Where a project raises potential ethical concerns, NHS organisations may require ethical review and, exceptionally, NRES would be willing to undertake this review. For student research, most universities will require such a review as part of their normal institutional processes.

All types of study involving human participants should, however, be conducted in accordance with basic ethical principles, such as informed consent and respect for the confidentiality of participants. Also, in processing identifiable data there are legal requirements under the Data Protection Act 2000. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation.

This response should not be interpreted as giving a form of ethical approval or any endorsement to your project, but it may be provided to a journal or other body as evidence that ethical approval is not a requirement.

Regards
NRES Queries Line REF 04/26/50

Appendix 7. Confirmation of UWE ethical approval for the qualitative HeadStrong service evaluation

University of the West of England
BRISTOL

Faculty of Health & Life Sciences
Glenside Campus

Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

Our ref: JW/lt

15th November, 2012

Melissa Pilkington
The Centre for Appearance Research
Department of Psychology
Faculty of Health & Life Sciences
UWE
Frenchay Campus

Dear Melissa

Application number: HLS/12/10/115
Application title: Evaluation of Breast Cancer Care's HeadStrong Service: A qualitative approach

Your ethics application was considered by the Faculty Research Ethics Committee and based on the information provided was given ethical approval to proceed with the following conditions:

Question 1 - The ethics application states the non-profit organization (Headstrong of Breast Cancer Care) have agreed to allow this research focussed on participants' experience of this service. However there is no documentary evidence to this effect; this should be part of the ethics application.
There is no discussion about how consent processes will work for telephone participants. There are no consent forms etc for the participants who are recruited because they did not use the Headstrong service.
Question 2 and 4 - The category of vulnerable participants includes those 'who are severely ill or have terminal illness' which can apply to breast cancer sufferers. Their status as people with cancer also makes them in our view 'vulnerable' so this part of the form should be amended. Recognition of

this fact increases the onus on the researchers to protect the participants so we would suggest that the research team should consider whether the degree of protection offered is sufficient. Also, are there any participants the researcher would ethically seek to exclude?
Question 5 (and also question 3) – the information sheet states:
Yes, your results will be kept completely confidential. This means that nobody other than the researchers will know that you have taken part and what you have told us.
This statement should be amended since presumably write-ups of the research will include quotations [*what you have told us*] which participants could recognise.
Also you should probably tell participants all the ways you are planning to disseminate the research findings (item 10 of the ethics application) so they are fully informed.
Are you planning to collect demographic information and/or information about illness status/progression etc? If so this should be clear to participants and you should probably tell them how you will protect their identity (i.e. only report aggregated demographic and illness status data?)
We also think the information sheet should have a line about who participants can contact if they are unhappy with any aspect of the research; should this also include reference to FREC?
The information sheet should probably also have a few sentences at the start about what taking part in the study involves (e.g. a 1-hour phone or in-person interview which will be digitally recorded).
The information about the right to withdrawn, how to do so and the 4-week deadline needs to be mentioned in the information sheet – since this is the paper that they take away (not the consent form).
Question 6 – it would potentially be helpful to identify the process in case there are issues – e.g. if the researcher is concerned about a participant, is there a potential to inform HeadStrong? Has one supervisor been identified formally as a clinical lead (this seems to be implied)?
Question 9 - researcher protection; the measures sound fine. Does the applicant also need to do a health and safety form however?
Please address the issues above. In particular, it would be worth looking at the advice on writing information and consent forms which is available through the university ethics pages:
http://rbi.uwe.ac.uk/internet/Research/ethics/default.asp
If you look in particular at:
http://rbi.uwe.ac.uk/internet/Research/ethics/ifa.asp there is a link on the right hand side for ‘consent’ – the word document provides the university guidance on this topic.

If these conditions include providing further information please do not proceed with your research until you have full approval from the committee. You must notify the Faculty Research Ethics Committee in advance if you wish to make any significant amendments to the original application.

If you have to terminate your research before completion, please inform the Faculty Research Ethics Committee within 14 days, indicating the reasons.

Please notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Any changes to the study protocol, which have an ethical dimension, will need to be approved by the Faculty Research Ethics Committee. You should send details of any such amendments to the committee with an explanation of the reason for the proposed changes. Any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

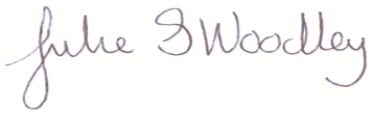
Please note that all information sheets and consent forms should be on UWE headed paper.

Please be advised that as principal investigator you are responsible for the secure storage and destruction of data at the end of the specified period. A copy of the 'Guidance on Managing Research Records' is enclosed for your information.

Please note: The University Research Ethics Committee (UREC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

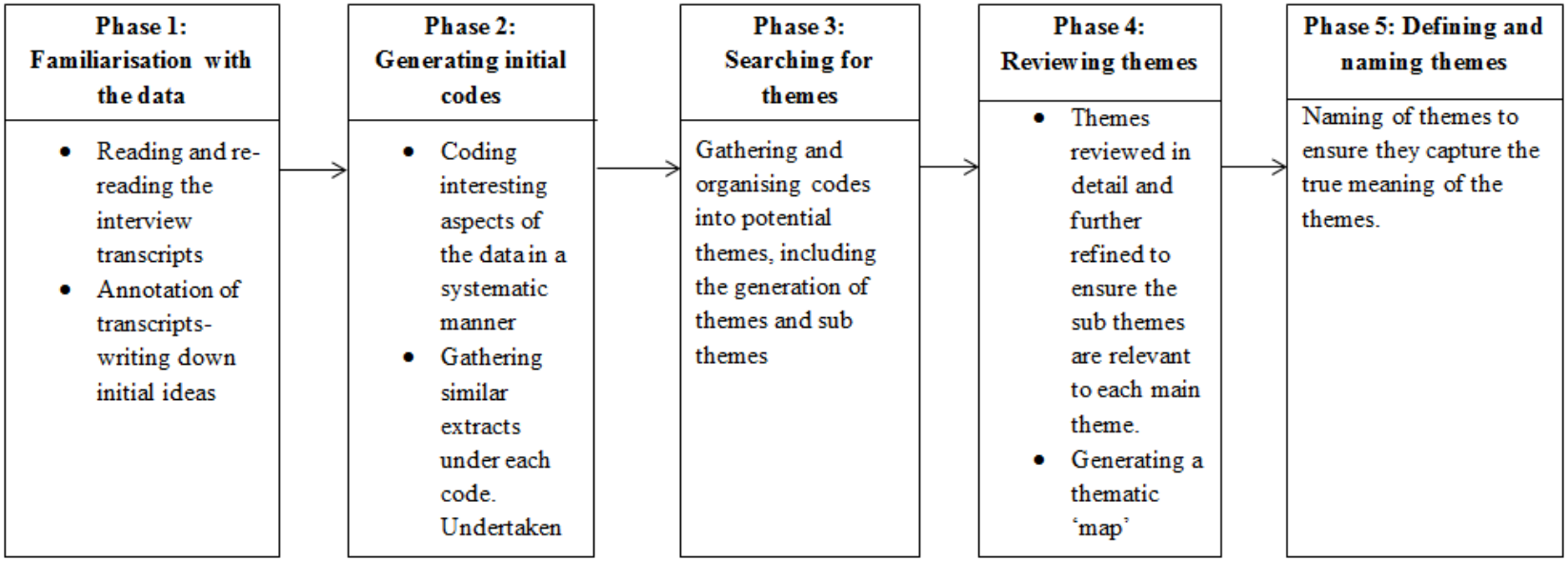
Yours sincerely

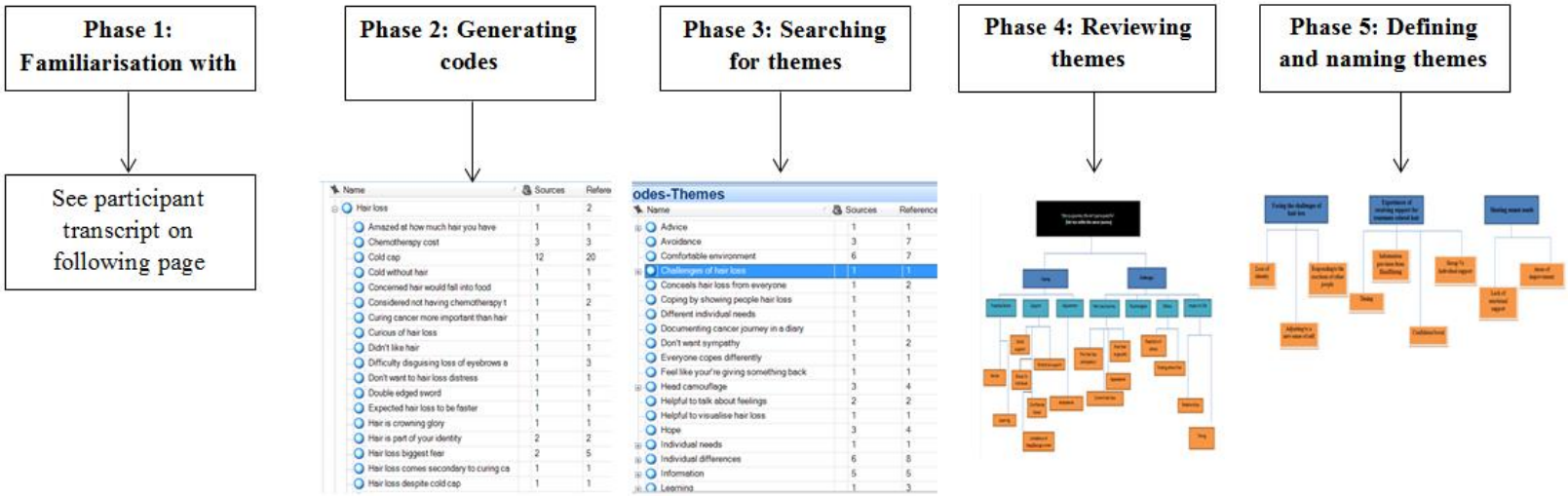


Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. Di Harcourt
Tim Moss

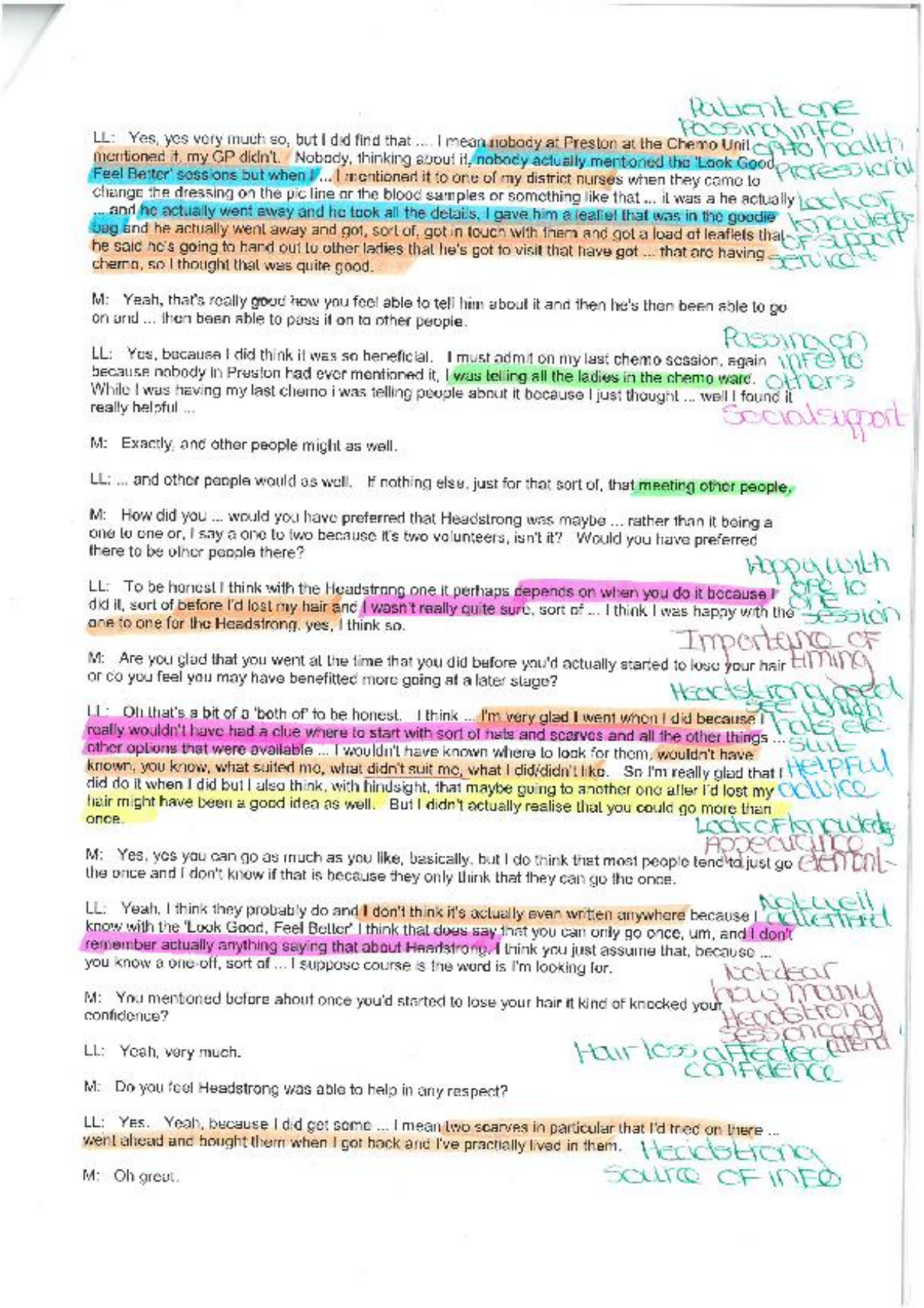
Appendix 8. Braun and Clarke's (2006) thematic analysis used to analyse the qualitative interviews.





Appendix 9. Applying Braun and Clarke's (2006) thematic analysis

Appendix 10. Participant transcript



LL: Yes, yes very much so, but I did find that ... I mean nobody at Preston at the Chemo Unit mentioned it, my GP didn't. Nobody, thinking about it, nobody actually mentioned the 'Look Good Feel Better' sessions but when I ... I mentioned it to one of my district nurses when they came to change the dressing on the pic line or the blood samples or something like that ... it was a he actually ... and he actually went away and he took all the details, I gave him a leaflet that was in the goodie bag and he actually went away and got, sort of, got in touch with them and got a load of leaflets that he said he's going to hand out to other ladies that he's got to visit that have got ... that are having chemo, so I thought that was quite good.

M: Yeah, that's really good how you feel able to tell him about it and then he's then been able to go on and ... then been able to pass it on to other people.

LL: Yes, because I did think it was so beneficial. I must admit on my last chemo session, again because nobody in Preston had ever mentioned it, I was telling all the ladies in the chemo ward. While I was having my last chemo I was telling people about it because I just thought ... well I found it really helpful ...

M: Exactly, and other people might as well.

LL: ... and other people would as well. If nothing else, just for that sort of, that meeting other people,

M: How did you ... would you have preferred that Headstrong was maybe ... rather than it being a one to one or, I say a one to two because it's two volunteers, isn't it? Would you have preferred there to be other people there?

LL: To be honest I think with the Headstrong one it perhaps depends on when you do it because I did it, sort of before I'd lost my hair and I wasn't really quite sure, sort of ... I think I was happy with the one to one for the Headstrong, yes, I think so.

M: Are you glad that you went at the time that you did before you'd actually started to lose your hair or do you feel you may have benefitted more going at a later stage?

LL: Oh that's a bit of a 'both of' to be honest. I think ... I'm very glad I went when I did because I really wouldn't have had a clue where to start with sort of hats and scarves and all the other things ... other options that were available ... I wouldn't have known where to look for them, wouldn't have known, you know, what suited me, what didn't suit me, what I did/didn't like. So I'm really glad that I did do it when I did but I also think, with hindsight, that maybe going to another one after I'd lost my hair might have been a good idea as well. But I didn't actually realise that you could go more than once.

M: Yes, yes you can go as much as you like, basically, but I do think that most people tend to just go the once and I don't know if that is because they only think that they can go the once.

LL: Yeah, I think they probably do and I don't think it's actually even written anywhere because I know with the 'Look Good, Feel Better' I think that does say that you can only go once, um, and I don't remember actually anything saying that about Headstrong. I think you just assume that, because ... you know a one-off, sort of ... I suppose course is the word is I'm looking for.

M: You mentioned before about once you'd started to lose your hair it kind of knocked your confidence?

LL: Yeah, very much.

M: Do you feel Headstrong was able to help in any respect?

LL: Yes. Yeah, because I did get some ... I mean two scarves in particular that I'd tried on there ... went ahead and bought them when I got back and I've practically lived in them.

M: Oh great.

LL: I mean, I've got quite a few scarves and, sort of, obviously because it was through winter that I was having the chemo, I've got quite a few hats and things but I do tend to find myself going back to the two scarves that I actually found through Headstrong. Yeah, yeah, just the ones that I feel most comfortable in and ... feel that they do suit me and, so yeah, that was definitely ... it was about finding what ... because you could spend an absolute fortune and then get home and get it on the internet and think "Oh my God that's awful" ...

M: That's it and then it arrives and you just think "No, that's not me".

LL: Yeah, that just doesn't ... yeah, whereas Headstrong gives you the chance to find out what sort of thing you're looking for before you actually commit to spending any money. So that's really good.

M: That's always a good thing isn't it?

LL: Yeah, very much so because, again, I have done that since. I've ordered stuff on the internet and then though mmm, no, not sure about this, this is not quite right, so ... yeah, at least with the ones that I found through Headstrong I knew that I liked them before I even bought them so that's really, really good.

M: That's great. Did you find there was ... once you started to lose your hair was there some situations that you found your hairloss affected you more maybe like confidence wise? Is there certain things that you did beforehand that you maybe felt you didn't want to do as much once you'd lost your hair?

LL: Yeah very much so. I know ... I think it was about 10 days before my hair really, really did come out rapidly - I'd had it cut very short but it was very long and it had been very long for years and years and years and years and years. I hated myself with short hair ... I liked my long hair and so trying to sort of obviously minimise the impact ... a lot of people had said it might be a good idea to get it cut short and make it easier when the hairloss did start, which I did ... and in ... in most ways I am actually glad I did it because when it actually did come out, if it had still been long that would have just been even worse than it was. But I must admit that the day after I'd had my hair cut really short I literally went to pieces, um, wouldn't even stand in front of a window, I didn't want anybody to see me, I wouldn't leave the house. I had some guys round that were doing some work on the garden at the front and I actually ended up sticking a notice on the door before they were due to arrive in the morning just saying if you needed anything to go to my next door neighbours because I'd had to go out for the day. Just because I just didn't, I couldn't ...

M: You couldn't ... just didn't want to see anyone?

LL: ... I couldn't face anybody. So I literally did fall apart the day after the haircut and then 10 days later the hair ... it started literally within a couple of days so that was why I was sort of ... timing wise think I'd got it right because it started coming out a couple of days after the hair cut but it was about a week later and I was in the bath and I was washing it and what was left was just coming out in absolutely massive handfuls. It was really, really upsetting and, as I say, again with hindsight, the haircut was probably a good thing because if it'd still been long that would've been even worse.

M: Yep.

LL: And then for the next couple of days you're obviously sort of shedding and it's getting into everything, you know, it's getting into your clothes and ... it just makes you feel really ... well you're itchy anyway, your scalp's itchy, but then obviously your hair's in everything else so it makes you the rest of you feel really itchy and it's an awful awful experience and it did very much ... not at ... surprisingly not just in terms of appearance but overall confidence. Just overall it's ... even, I'm even nervous driving now and I've driven all over the country, I've driven for years, I've always been very confident and now I'm not confident in the car. I'm not confident. I'm not too bad going to places where people don't know me...

M: Yes.

LL: ... but when I have to go to, you know, to sort of places where people do know me I'm very uncomfortable. I'm sort of ... I'm going to have to have a meeting with my boss in a couple of weeks and we'll probably be meeting up in ... I work for a company that has hotels, it's a hotel chain, so we'll probably meet up in one of the hotels and I'm dreading it. I'm absolutely dreading it because I'll have to go into the Accounts Office and I'll have to see all the people that know me and I'm just ...

M: And that's what you're not looking forward to is it?

LL: Yeah.

M: People that you know, yeah?

LL: People that know me and sort of, because obviously my eyelashes have gone now and my eyebrows have gone and my face just looks completely different and I just...

M: Yep. So you're worried that they're going to see you differently to what you used to look like? Yeah.

LL: Yes, yeah and it is ... it's very, very hard to explain because .. it's not ... it's nothing to do with vanity it's just that you look in the mirror and you're not there anymore.

M: Yes, it kind of ... does it feel like it's kind of someone looking back you?

LL: Yeah like it's just a complete, sort of, stranger and you don't like, you know, what you're seeing looking back at you and obviously that gets worse as things go along because this sort of ... you lose your eyelashes, your eyebrows so then you can't wear your eye make-up. So you can't even, sort of, make yourself feel better in that respect. And it does still seem to knock on into ... or for me it has anyway ... it's sort of had a knock-on effect into just about everything really. The only person that's actually seen me without anything on my head is my partner. I just can't face ... I don't want to see me with nothing on my head so I don't want anybody else to. I mean, my partner's been really good um ... He's been absolutely fantastic. I said I'd found an alternative to the aqueous cream with the essential oils so he does me a little head massage very night with the oils ...

M: That's fantastic.

LL: ... so hopefully it'll stimulate the hair growth and ... but yeah, he has he's been really supportive.

M: Oh that's good. It's really good that you've got that support.

LL: Very much so, definitely. At least there is somebody that, you know, you sort of feel "oh yeah, it's o.k. for him to see, it's o.k. for him" but ... and he just says ... he keeps saying I look lovely and that's perhaps how you see it but I'm seeing something completely different and I can't help it it is just the way I feel and see myself.

M: Yes.

LL: So yes I just can't wait for it all to come back now!

M: Have you ... I was going to say like did you, was your GP ... were they quite good in kind of explaining to you that the chances that you may lose your hair?

LL: Oh yeah everybody ... I mean because it was breast cancer and because it was a particular ... it was the FEC, the FEC ... and so yeah everybody said. I mean, my um ... I think the first person that told me was obviously my oncologist at my first meeting with my oncologist and then, obviously the chemo nurses. The chemo nurses actually told me to within a day of when it would come out. With FEC they literally know to within sort of a few days when your hair's going to come out um ...

M: Were they correct as well?

LL: Yes, yes, absolutely. They basically tell you, because you're on a 3 week cycle and they

basically tell you that with round about sort of day 20 your hair'll be gone ... and it was. It was literally ... I think ... as I said it'd started a week earlier and it'd shed slowly but that weekend, the weekend before I had my second cycle was when it just came out in big, big handfuls.

M: Right.

LL: So they literally can tell you with that particular type of chemotherapy that that's going to happen very, very accurately.

M: Yes. Do you think that ... I was going to say do you think that helped that they were able to be so accurate or not really?

LL: In the sense that I know when to get my hair cut and ...

M: You can try to prepare.

LL: ... yes, yeah. And obviously it's nice to think that there's something that you have got control over because there's so little ... you know, once you get the diagnosis you just feel like you've no control over anything so little things like that - like buying scarves, like organising your wig, you know, being able to get your hair cut at the right time, are just little things that you've got some control over. But what, unfortunately, you don't have any control over is the way you react when your hair goes because, obviously, nobody can prepare you for that. They can tell you it's going to happen but nobody can tell you how you are going to feel about it personally.

M: And I guess you don't know yourself how you are going to feel until it actually happens.

LL: No. I mean, I knew I was absolutely dreading it because, as I say, I've had long hair for years and I like it that way and, you know ... I've never been sort of ... I've never chopped and changed my hairstyle, I've never really coloured it, I just like it long and just ... it was just there and I was quite happy with it so I didn't feel any need to change it and so ... I was, yeah I was, I was absolutely devastated with the hairloss and then ... you think that's sort of, the rock bottom but then your eyelashes and your eyebrows go and you realise that actually yes it still can get worse in terms of your appearance, yeah.

M: It's even more to contend with.

LL: Yeah, Yes. So hopefully now there's nothing else that can fall out!

M: Yes! Have they been able to predict how long it may be before you hair will start to grow back?

LL: They say within six weeks you should start getting some ... sorry within six weeks of your last chemo session you should start getting some, you know some growth back, which I have got a little bit of fuzz on top of my head - it's just getting a little bit fuzzy, it's not completely shiny and bald anymore - and then they say within two months you should have about an inch of hair. But then it can come back curly if it was straight, or it can come back straight if it was curly - it can come back a different colour, it can come back ... so they do warn you that, you know, don't expect it to come back the same way as it was because it might not. And to be honest, I don't care what colour it comes back as long as there's lots of it!

M: Yeah, as long as it does come back.

LL: Yeah, Yeah. But that's what I'm really looking forward to now.

M: Yes. I was going to ask, would you ... based on your experience of Headstrong would you recommend it to someone else do you think?

LL: Yes. Yeah. I'd recommend it to everybody but certainly with that particular sort of chemo combination, the FEC where, you know, they are going to guarantee that you're going to lose your hair ... I think, I mean, people use a cold cap and some are successful but it's very hit and miss with the cold cap and it does prolong the amount of time that you spend on the chemo unit and so it ... I

Appendix 11. Pre-HeadStrong service evaluation questionnaire

Create Your Own ID Code

You have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code, please enter the first three letters of your first name and the day of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

Demographic Information

The following information will be used to understand the sample of data collected and will be used for statistical purposes only, not to identify you. Please remember that all responses are anonymous. (*All questions are optional).*

A: About you (*please tick the relevant box or write your answer in the space provided*):

1. Are you male or female? (*please tick one box*)

☐ Male ☐ Female

2. Please state your age _____

3. How would you describe your ethnic group? (*please tick one box*)

White

☐ English/Welsh/Scottish/Northern Irish/British

☐ Irish

☐ Gypsy or Irish Traveller

☐ Any other white background

please write in _____

Mixed/multiple ethnic groups

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other Mixed/multiple ethnic background

please write in _____

Asian/Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

please write in _____

Black/African/Caribbean/Black British

☐ African

☐ Caribbean

☐ Any other Black/African/Caribbean background

please write in _____

Other ethnic group

☐ Arab

☐ Any other ethnic group

please write in _____

Or

☐ Prefer not to answer

4. Are you currently in education or employed? (*please tick one box*)

☐ School

☐ College

☐ University

☐ Working Full time

☐ Working Part time

☐ Unemployed

☐ Other (please state) _____

5. Which area do you live in? (*please tick one box*)

☐ England

☐ Scotland

☐ Wales

☐ Northern Ireland

☐ Ireland

☐ Outside UK and Ireland

please state which country _____

B: About your cancer and hair loss

1. Which type of cancer were you diagnosed as having? (*please tick one box*)

☐ Breast Cancer

☐ Other (*Please specify*) _____

2. How long ago were you given your diagnosis?_____ years _____ months

3. What type of treatment, if any, did you receive? (*Please tick all that apply*)

☐ Chemotherapy ☐ None ☐ Other (*Please specify*) _____

☐ Radiotherapy ☐ Not sure

☐ Surgery (*Please specify*) _____

4. At the moment, have you experienced any hair loss due to cancer treatment? (*please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, how long after starting treatment did you start to lose your hair? _____

5. If you have experienced/are experiencing hair loss, please place a vertical mark on the line below to indicate your extent of hair loss.

No hair loss |——————————————————————| Complete hair loss

C: HeadStrong

1. Is this your first visit to HeadStrong? (*please tick one box*)

☐ Yes

☐ No (*Please state how many times you have attended HeadStrong*)_____

2. How did you hear about HeadStrong? _____

3. In order of importance to you, please state below up to four reasons why you wish to attend a HeadStrong session? i.e. for help in preparing for the possibility of hair loss

1)_____

2)_____

3)_____

4)_____

4. Place a vertical mark on the line below to indicate how confident you feel in managing the consequences of hair loss.

Not at all |——————————————————| confident Very confident

5. Place a vertical mark on the line below to indicate how confident you feel in coping with the reactions of others to your hair loss.

Not at all |——————————————————| confident Very confident

6. Place a vertical mark on the line below to indicate how confident you feel in using scarves and other headwear to cope with your hair loss.

Not at all confident ⊢——————————————————⊣ Very confident

D: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					
When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					

When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the first time, I wonder what they think about how I look.					
In my everyday life, lots of things happen that make me think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasise about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to explore whether you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present, my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my hair loss:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine or masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my feature:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How "normal" do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your hair loss?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My hair loss causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always .... N/A ....

My hair loss limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ... N/A ....

E: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

F: Your Health and Wellbeing

Below is a list of statements that other people with your illness have said are important. Please tick one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					
I feel ill.					
I am forced to spend time in bed.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next section.* I am satisfied with my sex life.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I feel sad.					
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					
I worry that my condition will get worse.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am able to work (include work at home).					
My work (include work at home) is fulfilling.					
I am able to enjoy life.					
I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

G: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how typical it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I am making on someone.					
I am afraid that others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's opinions of me do not					

bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate your thoughts by ticking the box the relevant box.

	Yes Definitely	Yes Sometimes	No, Not Much	No Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				
I get palpitations, or sensations of 'butterflies' in my stomach or chest.				

I have a good appetite.				
I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

Please place any further comments you would like to make in the box below.

Thank you for taking part!

Please return the questionnaire in the pre-paid envelope provided.

Appendix 12. Two week follow-up HeadStrong service evaluation questionnaire

Create Your Own ID Code

You have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code, please enter the first three letters of your first name and the day of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

All questions are optional.

A: About your hair loss (*please tick the relevant box or write your answer in the space provided*):

1. At the moment, have you experienced any hair loss due to cancer treatment? (*Please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, how long after starting treatment did you lose your hair? _____

2. If you have experienced/are experiencing hair loss, please place a vertical mark on the line below to indicate your extent of hair loss.

No hair loss |_____|

Complete hair loss

B: HeadStrong

1. At what point did you attend a HeadStrong session? (*Please tick one box*)

☐ Prior to losing your hair

☐ After you had started to lose your hair

2. Where did you attend your HeadStrong session? _____

3. In order of importance to you, please state below up to four reasons why you chose to attend a HeadStrong session? i.e. for help in preparing for the possibility of hair loss

1) _____

2) _____

3) _____

4)_____

4. Please state below your expectations of HeadStrong?

1)_____

2)_____

3)_____

4)_____

5)_____

5. Place a vertical mark on the line below to indicate the extent to which your expectations that you have listed above were met.

Expectation 1)

Not met ├──────────────────────────────────┤

at all Completely met

Expectation 2)

Not met ├──────────────────────────────────┤

at all Completely met

Expectation 3)

Not met ├──────────────────────────────────┤

at all Completely met

Expectation 4)

Not met ├──────────────────────────────────┤

at all Completely met

Expectation 5)

Not met ├──────────────────────────────────┤

at all Completely met

6. Place a vertical mark on the line below to indicate how useful you found HeadStrong in helping manage your hair loss.

Not at all ⊢——————————————————————⊣

useful Very useful

7. Place a vertical mark on the line below to indicate how confident you feel in managing the consequences of hair loss.

Not at all ⊢——————————————————————⊣

confident Very confident

8. Place a vertical mark on the line below to indicate how confident you feel in coping with the reactions of others to your hair loss.

Not at all ⊢——————————————————————⊣

confident Very confident

9. Place a vertical mark on the line below to indicate how confident you feel in using the techniques you learned at HeadStrong to manage your hair loss.

Not at all ⊢——————————————————————⊣

confident Very confident

10. Would you recommend HeadStrong to someone else who is experiencing hair loss? (*Please tick one box*)

☐ Yes ☐ No ☐ Not Sure

11. Do you think the techniques and information you gained from HeadStrong will help you to manage your hair loss in the future? (*Please tick one box*)

☐ Yes ☐ No ☐ Not Sure

C: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					
When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					
When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the first time, I wonder what they think about how I look.					

In my everyday life, lots of things happen that make me think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasise about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to explore whether you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present, my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my hair loss:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine or masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my hair loss:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A ..... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How "normal" do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your hair loss?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My hair loss causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always .... N/A ....

My hair loss limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ... N/A ....

D: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

E: Your Health and Well-Being

Below is a list of statements that other people with your illness have said are important. Please tick one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					
I feel ill.					
I am forced to spend time in bed.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next section.* I am satisfied with my sex life.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I feel sad.					
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					
I worry that my condition will get worse.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am able to work (include work at home).					
My work (include work at home) is fulfilling.					
I am able to enjoy life.					
I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

F: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how typical it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I am making on someone.					
I am afraid others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's opinions of					

me do not bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate your thoughts by ticking the relevant box.

	Yes Definitely	Yes Sometimes	No, Not Much	No Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				

I get palpitations, or sensations of 'butterflies' in my stomach or chest.				
I have a good appetite.				
I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

Please place any further comments you would like to make about your experience(s) of HeadStrong in the box below.

Thank you for taking part!

Please return the questionnaire in the pre-paid envelope provided.

Appendix 13. Three month follow-up HeadStrong service evaluation questionnaire

Create Your Own ID Code

You have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code, please enter the first three letters of your first name and the day of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

All questions are optional.

A: About your hair loss (*please tick the relevant box or write your answer in the space provided*):

1. At the moment, have you experienced any hair loss due to cancer treatment? (*Please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, how long after starting treatment did you lose your hair? _____

2. If you have experienced/are experiencing hair loss, please place a vertical mark on the line below to indicate your extent of hair loss.

No hair loss |——————————————————| Complete hair loss

B: HeadStrong

1. Place a vertical mark on the line below to indicate how useful you found HeadStrong in helping you to manage your hair loss.

Not at all |——————————————————|

useful Very useful

2. Place a vertical mark on the line below to indicate how confident you feel in managing the consequences of hair loss.

Not at all |——————————————————|

confident Very confident

3. Place a vertical mark on the line below to indicate how confident you feel in coping with the reactions of others to your hair loss.

Not at all |——————————————————|

confident Very confident

4. Place a vertical mark on the line below to indicate how confident you feel in using the techniques you learned at HeadStrong to manage your hair loss.

Not at all ⊢——————————————————⊣

confident Very confident

5. Would you recommend HeadStrong to someone else who is experiencing hair loss?

☐ Yes ☐ No ☐ Not Sure

6. Do you think the techniques and information you gained from HeadStrong will help you to manage your hair loss in the future? (*Please tick one box*)

☐ Yes ☐ No ☐ Not Sure

C: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					

When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					
When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the first time, I wonder what they think about how I look.					
In my everyday life, lots of things happen that make me think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasise about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to explore whether you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present, my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my hair loss:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine or masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my hair loss:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my
mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How "normal" do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your hair loss?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My hair loss causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always .... N/A ....

My hair loss limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ... N/A ....

D: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

E: Your Health and Well-Being

Below is a list of statements that other people with your illness have said are important. Please tick one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					

I feel ill.					
I am forced to spend time in bed.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next section.* I am satisfied with my sex life.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I feel sad.					
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					
I worry that my condition will get worse.					

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am able to work (include work at home).					
My work (include work at home) is fulfilling.					
I am able to enjoy life.					
I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

F: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how typical it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I am making on someone.					
I am afraid that others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's					

opinions of me do not bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate your thoughts by ticking the relevant box.

	Yes Definitely	Yes Sometimes	No, Not Much	No Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				
I get palpitations, or sensations of 'butterflies' in my stomach or chest.				
I have a good appetite.				

I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

Please place any further comments you would like to make about your experience(s) of HeadStrong in the box below.

Thank you for taking part!

Please return the questionnaire in the pre-paid envelope provided.

Appendix 14. UWE ethical approval for the quantitative HeadStrong service evaluation

University of the West of England
BRISTOL

Faculty of Health & Life Sciences
Glenside Campus

Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

Our ref: JW/lt

17 February 2017
23rd November, 2012

Melissa Pilkington
The Centre for Appearance Research
Department of Psychology
Faculty of Health & Life Sciences
UWE
Frenchay Campus

Dear Melissa

Application number: HLS/12/10/116
Application title: Evaluation of Breast Cancer Care's HeadStrong Service: A quantitative approach

Your ethics application was considered by the Faculty Research Ethics Committee and based on the information provided was given ethical approval to proceed.

You must notify the Faculty Research Ethics Committee in advance if you wish to make any significant amendments to the original application.

If you have to terminate your research before completion, please inform the Faculty Research Ethics Committee within 14 days, indicating the reasons.

Please notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Any changes to the study protocol, which have an ethical dimension, will need to be approved by the Faculty Research Ethics Committee. You should send details of any such amendments to the committee with an explanation

of the reason for the proposed changes. Any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

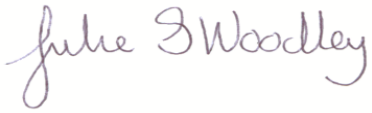
Please note that all information sheets and consent forms should be on UWE headed paper.

Please be advised that as principal investigator you are responsible for the secure storage and destruction of data at the end of the specified period.

Please note: The University Research Ethics Committee (UREC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely



Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. Di Harcourt
Tim Moss

Appendix 15. List of HeadStrong centres including number of patients seen at each HeadStrong centre per annum

Site	No of patients seen per annum
Scotland	60
Wrexham	75
Liverpool	140
Chester	60
London	100
Southend	80

Appendix 16. Participant information sheet for the quantitative HeadStrong service evaluation

An evaluation of Breast Cancer Care's HeadStrong Service: Information Sheet

You are being invited to take part in a study. Please read this information carefully and do not hesitate to contact me with any questions that you may have. Thank you.

What is the purpose of the study?

This study is evaluating Breast Cancer Care's HeadStrong service, by exploring individuals experiences of the service and how it helps them to manage the emotional impact of hair loss. The study is being carried out by Melissa Pilkington, a PhD researcher from the Centre for Appearance Research (CAR) which is based at the University of the West of England (UWE), Bristol

Why have I been chosen?

You are being invited to take part because you have expressed an interest in attending a Breast Cancer Care HeadStrong session at one of the centres in which this study is taking place. Everyone approaching the HeadStrong service at these centres is being invited to take part. We are looking for a total of 84 people to take part

Do I have to take part?

No, taking part is voluntary. You do not have to take part if you do not want to and, if you do take part, you can withdraw from the study up to a month after taking part. Whether or not you take part will not make any difference to your HeadStrong session.

What will I have to do if I take part?

You will be asked to complete a questionnaire prior to attending a HeadStrong session, another questionnaire two weeks after attending the session and one more, 3 months later. We expect that each questionnaire will take no more than 30 minutes to

complete. If you would prefer to complete the questionnaires online, please click on the link below.

What are the possible benefits of taking part?

You will not personally benefit from taking part in this study, however the results of the study will inform plans for the provision of HeadStrong and other support services for people affected by hair loss in the future.

Will my identity be protected?

Yes, your identity will be protected. During the questionnaires you will be asked for about your diagnosis and hair loss, however, in order to protect your identity only a summary of this information will be reported during the write up of the evaluation.

What will happen with the results of the study?

The results of the study will be given to Breast Cancer Care, so that they can use them to plan HeadStrong and other support services in the future. Your individual questionnaires will not be passed on to Breast Cancer Care, they will only receive a summary of the study findings overall.

How will the findings be shared with other people?

The overall findings will be published in a journal, presented at conference presentations and written up as part of a PhD thesis. Also, a summary of the findings will be made available to both participants and to Breast Cancer Care for them to present at meetings.

Who has reviewed the study?

The study has been approved by the University of the West of England (UWE) Research Ethics Committee. It has also been approved by Breast Cancer Care. The study is funded by Breast Cancer Campaign.

Your right to withdraw from the study

You have the right to withdraw from the study up to a month after taking part. If you wish to withdraw from the study, please contact the researcher and all your information will be withdraw from the study and destroyed.

What do I do now?

If you would like to take part in the study, please complete the questionnaire and return it to Melissa Pilkington, together with the consent form, in the envelope provided. You do not need to put a stamp onto the envelope. Alternatively, you can complete the questionnaires online at **http://www.tinyurl.com/Pre-HeadStrong**

If you have any further questions please contact, Melissa Pilkington at:-

Email:- Melissa.Pilkington@uwe.ac.uk

Telephone No:- (0117) 3283882

Work Mobile Telephone No:- 07972733919

Or you can contact Melissa's supervisor, Prof. Diana Harcourt at:

Diana2.Harcourt@uwe.ac.uk

Telephone No:- (0117) 3283967

If you would like any more information about cancer-related hair loss, or have any concerns that you would like to discuss, you might like to contact any of the following organisations that specialise in support for people affected by cancer:-

Breast Cancer Care:-

www.breastcancercare.org.uk

Peer Support Team Telephone No:- 0845 0771893

Peer Support Team Email:- ukpeersupportteam@breastcancercare.org.uk

Breast Cancer Care's Free Helpline for one-to-one support:- 0808 800 6000

Maggie's Centre:-

http://www.maggiescentres.org/

To arrange face-to-face support with a support specialist:-

Email:- enquiriesatmaggiescentres.org

Telephone No:- 0300 123 1801

Macmillan:-

www.macmillan.org.uk

If you have any questions, would like support or someone to talk to:-

Cancer Support Specialist Telephone No:- 0808 808 00 00

Appendix 17. Participant consent form for the quantitative HeadStrong service evaluation

An evaluation of Breast Cancer Care's HeadStrong Service: Consent Form

This study is interested in patients' experiences of Breast Cancer Care's HeadStrong service. Taking part in the study will involve completing a questionnaire on 3 different occasions, either on paper or online.

In order to protect your identity only a summary of the information you provide will be reported during the write up of the evaluation. Your completed questionnaires will be stored securely and only accessible to the research team. You do not have to take part and you have the right to withdraw from the study up to a month after taking part.

If you give your consent to take part in the study please complete this form and return it with the completed questionnaire in the pre-paid envelope provided.

Print your name.....

Date.....

Your Signature.....

Date.....

Telephone number .....

Please indicate below how you would prefer to receive the later questionnaires.

☐ **Post**

☐ **Email**

***Address*.....**

.....

.....

.....

.....

***Email address*.....**

Thank you for your time!

Appendix 18. Looney and Jones (2003) Z-score test statistic

$$Z_{corrected} = \frac{\overline{x}_1 - \overline{x}_2}{\sqrt{\frac{s_1^2}{n_a + n_c} + \frac{s_2^2}{n_b + n_c} - \frac{(2n_c)s_{12}}{(n_a + n_c)(n_b + n_c)}}}$$

n_a = number of subjects with observations exclusive to sample 1

n_b = number of subjects with observations exclusive to sample 2

n_c = number of subjects with observations in both samples (i.e. paired)

$\bar{x}_1$ = mean of observations in sample 1 (i.e. in n_a and n_c)

$\bar{x}_2$ = mean of observations in sample 2 (i.e. in n_b and n_c)

s_1 = standard deviation of sample 1 (i.e. in n_a and n_c)

s_2 = standard deviation of sample 2 (i.e. in n_b and n_c)

s_{12} = covariance between the paired observations only (i.e. in n_c)

Using the Standard Normal tables reject H if the observed values of the test statistic are $Z \geq 1.96$.

Appendix 19. List of expressive writing studies

Reference	Measures	Inclusion Criteria	Exclusion Criteria	Methodology	Control Group	Findings	Criticisms of Studies
Craft, M. A., Davis, G. C., & Paulson, R. M. (2013) Expressive writing in early breast cancer survivors. *Journal of Advanced Nursing, 69*(2), 305-315.	Functional assessment of Cancer Therapy Breast Cancer Version	*Diagnosis of breast cancer, either invasive or non-invasive *Definitive treatment *Time from diagnosis less than 2 years *Able to speak and write English * Physically able to write either by hand or with a word processor for 20-min periods	*Individuals with recurrent or metastatic breast cancer * If mental status precluded pts * If been diagnosed and/or treated for clinical depression	*120 pts randomised into one of four groups; control group (no writing), one of three EW groups; breast cancer, trauma, any self-selected trauma, and facts related to breast cancer. *Pts wrote for 20 minutes a day for 4 consecutive days. *QOL was measured at baseline, 1	No writing	* An ANOVA determined no important differences in QOL among the four groups of pts at baseline. * MANOV analysed the combined effect of time and group assignment on the outcome variable * EW about about one's breast cancer, breast cancer trauma; and facts related to breast cancer,	* Convenience sample limits generalisability of findings * Varying previous exposure to journaling and variance in attrition in the different groups which may indicate a preference for one way of writing over another

				month and 6 months after writing.	sig improved the QOL outcome * Changes in QOL over the three time periods were analysed using t-tests * Multiple regression was used to explore whether or not EW contributed to QOL * Intention to treat analysis (ITT) was used due to the high dropout rate between T1 and T2 assessment periods and due to the possibility of

					group diffs arising after randomisation to the intervention	
O'Connor, D. B., & Ashley, L. (2008). Are alexithymia and emotional characteristics of disclosure associated with blood pressure reactivity and psychological distress following written emotional disclosure. *British Journal of Health Psychology, 13*, 495-512.	* Toronto Alexithymia Scale (TAS-20) 20-item measure that assess three dimensions of alexithymia; difficulty identifying feelings (DIF), difficulty describing feelings (DDF) and externally oriented thinking (EOT) * 28-item General Health Questionnaire (GHQ),	* Good general health * Currently not taking any blood pressure medication * Having systolic and diastolic blood pressure levels within normal range * No evidence of psychiatric problems	See inclusion criteria	* 87 pts wrote about their most stressful life experience or about a non-stressful experience, for 15 mins, over 3 consecutive days * Emotional characteristics of the disclosure essays were analysed with the linguistic Inquiry and Word Count program and	* No evidence of support found in the main effects of disclosure on cardiovascular responses to stress or on emotional distress. * Alexithymia found to moderate the impact of writing such that non-alexithymic pts in the experimental condition reported significant	* Floor effects may have accounted for the negative findings i.e. many pts may not have experienced a sig traumatic stressor * Follow-up period of 2 weeks was relatively short - health related improvements may not have emerged in this short period

was used to assess emotional distress		alexithymia was assessed at baseline using the Toronto Alexithymia scale-20.	lower emotion distress 2 weeks later. * Alexithymic pts who disclosed a greater no of negative when compared to positive emotion words exhibited reduced systolic and diastolic responses to stress. * Analysis used included an ANOVA for main effects * Series of hierarchical regressions were used to	* No measure of neuroticism/ negative affectivity.

						analyse the main and interactive effects of alexithymia on the three outcome variables	
O'Connor, D. B., Hurling, R., Hendricks, H., Osborne, G., Hall, J., Walklet, E., Whaley, A., & Wood, H. (2010). Effects of written emotional disclosure on implicit self-esteem and body image. *British Journal of Health*	* Rosenberg self-esteem scale - gives a global estimate of self-esteem * Body Image Avoidance Questionnaire - 19-item measure of avoidance behaviours from situations that may cause anxiety to someone with negative body image. * Body Checking	N/A	N/A	* 162 pts were randomised into one of three experimental groups; written emotional disclosure condition, writing about body image success stories (WSS) or a control condition * WED- pts asked to write about their deepest	* Pts in the control group were asked to write for 15mins on 3 consecutive days about what they had had done the previous day.	* Levels of self-esteem were improved 4 weeks later in the WED condition * Implicit self-esteem was found to be greater following WED compared to the control condition, but not following WSS	* May have found clearer and more substantive results may have emerged if we had recruited pts who were currently experiencing body image disturbance issues or if more detailed measure of body image and self-

Psychology, 16, 488-501.	Questionnaire- 23-item measure of body checking behaviours that consist of three subscales: overall appearance checking, checking specific body parts, idiosyncratic checking * The Body Parts Satisfaction Scale - 25 item scale	emotions and thoughts about a stressful or traumatic issues/event in terms of their body or body related experiences for 15mins on 3 consecutive days. * Pts in the WSS condition were given 6 diff body image success stories vignettes before completing two writing exercises. The vignettes were adapted from the Body	esteem were used * A larger sample size would have provided more power to explore the moderating role of individual differences variables such as Alexithymia or perfectionism.

	measuring satisfaction with body parts as well as global body satisfaction. * Center for Epidemiological Studies Short Depression Scale - 10-item scale that measures depression			Image Workbook. Pts were presented with two diff vignettes for the current age group. Pts read the success stories and then were asked to complete two writing tasks. This condition was timed to last 15mins on each of the three days.			
Stanton, A. L., Danoff-Burgy, S., Sworowski, L. A., Collins, C. A., Branstetter, A. D., Rodrigueq-Hanley,	* Psychological adjustment- The Profile of Mood States (POMS) - Measure of negative and positive affect	* First diagnosis of stage one or two cancer * 20 weeks after completion of medical	* Diagnosis of recurrent or metastatic disease and inability to read or write	* Researcher rang all pts on medical treatment completion to describe trial and schedule participation.	Fact control group (CTL)	* EMO writing was relatively effective for women low in avoidance * Induced POS writing was more useful for	* Primary reliance on pt self-report * Lack of generalisability of findings- pts evidenced more positive

A., Kirk, S. B., & Austenfeld, J. L. (2002).	frequently used in studies of cancer patients.	treatment	English	Pts were mailed informed consent form and baseline questionnaire. *	women high in avoidance * Compared with CTL pts at 3 months, the EMO group reported sig	psychological
Randomised, Controlled trial of written emotional expression and benefit finding in breast cancer patients. *Journal of Clinical Oncology, 20* (20), 4160-4168.	* Physical health-related outcomes- Negative somatic symptoms were assessed on a measure developed by Pennebaker * Cancer-related avoidance- COPE			Randomisation was through a computerised random number generator. * EMO group- pts asked to write about their deepest thoughts and feelings regarding experience with breast cancer. * POS group- pts asked to write about positive	decreased physical symptoms * The EMO and POS pts had sig fewer medical app for cancer related morbidities.	adjustment than other samples * Small sample size

				thoughts and feelings regarding her experience with breast cancer * CTL group- pts asked to write about facts regarding cancer and its treatment.			
Gellaitry, G., Peters, K., Bloomfield, D., & Home, R. (2010). Narrowing the gap: the effects of an expressive writing intervention on perceptions of actual and ideal emotional	* Significant others scale- used to measure pts level of support across a range of key individuals * QOL- assessed using the Functional Assessment of Cancer Therapy- Breast * Psychological	* Pt attending their last radiotherapy app at the outpatient clinic	* Unable to write for the duration of 20 mins * Unable to speak, read or write English * Defined psychiatric disorder	* Pts recruited for the study in their last week of treatment * 93 pts were randomised * Pts in the writing group, wrote for 20 mins on four consecutive days. *Postal follow-ups at	* Control group received normal care	* Sig effect of group on women's perceptions of social support with those in the intervention group being more satisfied with their emotional support they received	* Sample did not demonstrate cultural or ethnic diversity- limiting the generalisability of findings * Sample consisted of pts with early stage breast cancer

support in women who have completed treatment for early stage breast cancer. *Psycho-Oncology, 19,* 77-84.	well-being- assessed using the Profile of Mood States		1, 3, 6 months	* Satisfaction with their emotional support was negatively correlated with depression and anger/hostility and positively correlated with social and family well-being, 6 months post intervention * no sig effects of intervention on mood, QOL or healthcare utilisation * Most pts found writing valuable and did not report any long-term negative	and so no assumptions can be made about the suitability of the writing paradigm for pts with more advanced disease * no provision was made to offer pts an alternative means of disclosure, such as the use of audiotapes and so excluding women who were unable to write
			*Pts asked to write at same time each day *Pts provided with guidelines for each day; day 1- emotional disclosure, day 2- cognitive appraisal, day 3- benefit funding, day 4- looking to the future		

						effects	for whatever reason.
Sloan, D. M., Feinstein, B. A., & Marx, B. P. (2009). The durability of beneficial health effects associated with expressive writing. *Anxiety, Stress & Coping, 22*(5), 509-523.	* Depression, Anxiety and Stress Scale (DASS) * The Pennebaker inventory of limbic languidness (PILL) * Manipulation check	* Pts needed to be a first year undergraduate students	* No exclusion criteria	* 69 pts were randomised to either an expressive writing condition or a control condition using a computerised random number generator * Pts were given an envelope containing general instructions for writing and specific instructions for the first	* Control group were asked to write about how they spent each day without any emotion or opinions.	* Pts in the EW condition reported sig fewer depression symptoms compared with pts assigned to the control condition but this was not sustained at follow up assessments	* Larger sample size needed

writing
session
* Pts in EW
condition were
asked to write
about their
most stressful
or traumatic
experience of
their lives with
as
much emotion
and feeling as
possible.
* Pts in both
conditions
were asked to
write
continuously
for
20 mins on
three
consecutive
days
* After 20
mins the
experimenter

				entered the room and asked pts to stop writing			
Zakowski, S. G., Ramati, A., Morton, C., Johnson, P., & Flanigan, R. (2004). Written emotional disclosure buffers the effects of social constraints on distress among cancer patients. *Health Psychology, 23*(6), 555-563.	* Social constraints scale (SCS) * Brief symptoms inventory (BSI) * Impact of events scale (IES)	* First time diagnosis of prostate or gynaecological cancer * Completion of an active cancer treatment * No evidence of psychiatric problems * No life-threatening disease other than cancer	N/A	* 104 pts were randomised to either an emotional disclosure condition or the control condition * Pts wrote for 20 mins a day for 3 consecutive days * Pts were given detailed standardised instructions * Pts wrote in their own homes but experimenter rang pts after	* Pts in control group were asked to describe in detail their daily activities in a non-emotional manner	* Nonsignificant main effect of experimental condition on distress suggests that EW was not effective for all cancer patients in the study * EW buffered the effects of social constraints on stress at 6 month follow-up and that avoidance partly mediated these effects	* Small effect size

		* Ability to fluently read and write in English		they had finished their writing session to see if they had been interrupted * Pts in the EW condition were instructed to write about their thoughts and feelings regarding their cancer experience			
Lepore, S. J. (1997). Expressive writing moderates the relation between intrusive thoughts and depressive symptoms.	* Manipulation check * Depressive symptoms - 13-item depressive symptom subscale of the SCL-90R * Intrusive thoughts- Impact	* Pts must be taking an exam	N/A	* Pts wrote for 25 mins on one occasion	* Control group told specifically not to write about their feelings or emotions	* EW did not affect the frequency of intrusive thoughts but it moderated the impact of intrusive thoughts on depressive	* Stressor was not as grave as those typically associated with chronic and clinically sig levels of distress. * A single writing session

Journal of Personality and Social Psychology, 73(5), 1030-1037	of events scale (IES)					symptoms.	would not moderate the effects of intrusive thoughts on depressive symptoms under such severe distress * The effect of the manipulation on exam performance is unknown
Sloan, D. M., Marx, B. P., Epstein, E. M. & Dobbs, J. L. (2008). Expressive writing buffers against maladaptive rumination. *Emotion, 8*(2), 302-306.	* Ruminative response scale (RRS) * Depression and anxiety stress scale (DASS)	N/A	N/A	*Pts in the EW condition were asked to write about their most stressful or traumatic experience of their lives with as much emotion and feeling as possible	* Pts in the control group were asked to write about how they spent their time each day without and emotion	* A brooding ruminative style moderated the effects of expressive among those assigned to the EW condition * Pts with greater brooding	* Small sample size

				* Pts in both groups asked to write for 20mins a day for 3 consecutive days * Changes in depressive symptoms assessed at 2, 4, 6 months	scores reported sig fewer depressive symptoms at all follow-up assessments relative to individuals with lower brooding scores	
Klein, K., & Boals, A. (2001). Expressive writing can increase working memory capacity. *Journal of Experimental Psychology, 130*(3), 520-533.	* Arithmetic operation-word-memory span task (OSPAN) * College adjustment test	N/A	N/A	* EW condition instructed to write about their deepest thoughts and feelings about coming to college * Control condition	* Pts in EW showed greater working memory improvements and declines in intrusive thinking compared to those who	* Single measure of working memory

				instructed to write about everything they had done that day and describe how they may have done a better job		wrote about a positive experience or trivial topic * EW reduces intrusive and avoidant thinking about stressful experience, freeing up working resources	
Laccetti, M. (2007). Expressive writing in women with advanced breast cancer. *Oncology Nursing Forum, 34*(5), 1019-1024.	* Functional assessment of cancer therapy-breast (FACT-B) * The sociodemographic information survey	* Historical diagnosis of primary breast cancer * Clinical evidence of stage IV breast cancer * Life expectancy greater than 6 months	* Women with mental status precluding meaningful participation * Medical status precluding meaningful participation	* Pts wrote for 20-30 mins for 4 consecutive days *Pts were instructed to write about experiences with metastatic breast cancer, thoughts and	N/A	* Sig relationship found between positive-affect word use and emotional well-being * A positive relationship between affective language in disclosure and QOL was	* Small sample size * Lack of diversity reducing generalisability of findings *Writing may have been diff for individuals

		* Ability to read and write English		feelings related to not fully recovering from cancer and possibility of facing death		found, demonstrating a cognitive process occurring in EW	who struggle with writing or for those whose English is there 2nd language
Poon, A., & Danoff-Burg, S. (2011). Mindfulness as a moderator in expressive writing. *Journal of Clinical Psychology, 67*(9), 881-895.	* Freiburg mindfulness inventory (FMI) * Physical symptom checklist (PSC) * Pittsburg sleep quality index (PSQI) * Brief symptom inventory (BSI) * Positive and	* 18 years old * Ability to write continuously in English for 20 mins	N/A	* Pts in the EW writing group were instructed to write about a highly stressful or traumatic event and to let go and explore their deepest emotions and thoughts about their event. * Randomisation was through a	Not stated	* Main effects favouring EW were found and these were qualified by sig interactions with mindfulness * Individuals with higher mindfulness scores responded better to EW, experiencing greater physical and psychological	* Studies relied on self-report measures *Experimenter effects as the experimenter was not double blind

	negative affect schedule (PANAS)			random number generator		benefits	
Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., Sworowski, L.A., & Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 68*(5), 875-882.	* COPE * Emotional approach coping scales * Hope scale * FACT * Perceived social receptivity	* Not mentioned	Not mentioned		Not stated	* Expressive coping was related to improved QOL for those who perceived their social contexts as highly receptive * Coping through emotional processing was related to one index of greater distress over time	* Measures relied on self-reports

Low, C. A., Stanton, A. L., & Danoff-Burg, S. (2006). Expressive disclosure and benefit finding among breast cancer patients: Mechanisms for positive health effects. *Health Psychology, 25*(2), 181-189.	* Physical health benefits * HR- personal computer physiological monitoring system * Linguistic content analysis * Self report mood	* Stage I or II breast cancer *Completed primary medical treatment	* Diagnosed with recurrent or metastatic disease * Unable to read or write English	*Pts in the EMO condition were instructed to write about their deepest thoughts and feelings regarding their experience with breast cancer * Pts in the POS condition were instructed to write about positive thoughts and feelings regarding their experience with breast cancer * Pts in the control condition were	Facts relating to their experience of breast cancer	* Within session heart rate habituation mediated effects of expressive disclosure on physical symptoms * Post writing mood and use of positive emotion and cognitive mechanism words in essays were not sig mediators * Greater cognitive mechanism words were related to greater heart rate	* Small sample size * As sample was limited to women with early breast cancer, difficult to generalise findings to individuals with more advanced cancer * Reliance on pts self-report

				asked to write about facts regarding their experience with breast cancer		habituation and negative word use	
Low, C. A., Stanton, A. L., Bower, J. E., & Gyllenhammer, L. (2010). A randomized controlled trial of emotionally expressive writing for women with metastatic breast cancer. *Health Psychology, 29*(4), 460-466.	* The center for epidemiological studies-depression scale * The Pittsburgh Sleep Quality Index *Emotional support	* Pts diagnosed with stage IV breast cancer * Able to complete writing exercise and assessments in English *Any current medical treatments for cancer were allowed	Not mentioned	* Randomisation was through a computerised random number * Pts called research office to schedule four 20 min sessions within a 3 week interval * A trained research assistant telephoned pts at beginning of session to read instructions to	Not stated	* No main effect of experimental condition * A sig condition x social interaction emerged on intrusive thoughts * sig condition x time since metastatic diagnosis interactions were observed for somatic symptoms and sleep	* Sample predominantly white and well educated- diff to generalise findings * Physical health outcomes relied on self-report * Underpowered to detect main effects

				the pts, they then called again 20 mins later to instruct pts to stop writing.		disturbances * Expressive writing may be beneficial for a subset of metastatic patients and contraindicated for others	
Baum, E. S., & Rude, S. S. (2013). Acceptance-enhanced expressive writing prevents symptoms in participants with low initial depression. *Cognitive Therapy Research, 37,* 35-42.	* The center for epidemiologic studies depression scale (CES-D) * Linguistic inquiry and word count (LIWC)	* Students from a subject pool were eligible if they responded negatively at pre-screening to a question asking if they were currently feeling down or depressed, but endorsed	Not mentioned	* Pts in the EW condition were instructed to write about their deepest thoughts and feelings about an extremely difficult or emotional event that has affected their life * The EW plus	Not stated	* Writing condition interacted sig with initial depression such that at the 5 week post-test, EWEA was more beneficial than control writing for pts * EW was more beneficial than control writing	* 26% of students who began the study didn't complete post-test measures * High attrition rates * Lack of interaction with a researcher contributed to pts feeling less personally supported which may

		experiencing a period of time, 2 weeks or longer over the past 2 years in which they felt sad or down most days.		emotional acceptance group (EWEA) received the same instructions as the EW group plus additional directions adapted from mindfulness and self-compassion interventions and were designed to increase pts awareness of a broader context for their emotional experience		for pts with very low initial depression symptoms (CESD)	have led to poorer results for the traditional EW condition among pts with elevated depression symptoms
Lee, H. S., & Cohn, L. D. (2010). Assessing	* 60-item COPE * 66-item Ways of Coping-Revised * 33-item Coping	* not stated	* Not stated	* Pts were instructed to write about a stressful event	Not stated	* Depression scores were related to the use of words	* Lack of generalisability of findings

coping strategies by analysing expressive writing samples. *Stress and Health, 26*, 250-260	Strategies Indicator * 20-item Center for Epistemological Studies Depression * 8-item language proficiency test			related to college life * 20 mins was required to complete the single session writing Task		denoting negative emotion but were unrelated to the use of pronoun 'I' * Pts who used more words denoting negative emotions in their essays obtained lower problem-focused coping scores on the COPE * The use of insight-related words were associated with lower scores on measures of emotion-focused coping	
Gortner, E., Rude, S. S., &	* The Beck Depression	* Undergraduate	Not stated	* Pts in the EW condition	* Control group wrote	* Pts scoring above the	* Few pts in the study

Pennebaker, J. W. (2006). Benefits of expressive writing in lowering rumination and depressive symptoms. *Behavior Therapy, 37,* 292-303.	Inventory (BDI) * Inventory to Diagnose Depression-Lifetime Version (IDD-L) * Ruminative Response Scale (RRS) * Emotion Regulation Questionnaire (ERQ) * Follow-up Questionnaire on Participants' Subjective Experience (FQPSE)	students who reported elevated symptoms of depression in the past but whose present level of depressive symptoms was within normal levels		were instructed to write about their thoughts and feelings on current and past emotional upheavals * Half of the EW condition and half of the control individuals were randomly assigned to a 20-min booster session 5 weeks after their initial intervention	objectively about time management	median on the suppression scale of the Emotion Regulation Questionnaire showed sig lower depression symptoms at the 6-month assessment when they wrote in the EW versus the control condition * A booster writing session failed to have a sig effect	experienced large increases increases in depressive symptoms * Sample was neither selected or assessed by clinical interview
Knowles, E. D., Wearing, J. R., &Campos, B. (2011).	* Language proficiency and preference questions	Not stated	Not stated	* Pts were randomised to either a trivial or traumatic	* No control	* European Americans who wrote about trauma	* Not stated

Culture & the health benefits of expressive writing. *Social Psychological and Personality Science, 2*(4), 408-415	* Symptoms of illness	writing condition * Each morning for the following 3 days, pts were emailed a link to a website where they completed a 20-min writing exercise consistent with their condition * Trivial writing condition- pts wrote about topics such as the weather, routine and minor happenings;	increased their use of insight words over four sessions and reported fewer illness symptoms a month later * Neither effect obtained for Asian Americans

				while avoiding emotional commentary * Traumatic writing condition- pts were instructed to write about their deepest thoughts and feelings about the most traumatic experience in their life			
Arigo, D., & Smyth, J. M. (2012). The benefits of expressive writing on sleep difficulty and appearance concerns for college women. *Psychology & Health*, *27*(2), 210-226	* Eating disorder examination questionnaire- 29-item * Body image quality of life inventory- 19-item * Iowa-Netherlands comparison orientation measure * Perceived stress scale- 10-item * Pittsburgh sleep quality index	Not stated	Not stated	* Pts randomised into either an EW or control condition * Pts in the EW condition were instructed to write about related aspects of a stress full experience	* Control group asked to write about their plans for over the next week	* Pts in the EW condition reported less sleep difficulty and less body focused upward social comparison at 8 week follow up, relative to control participants. * For individuals	* Moderating effect of perceived stress on some outcome variables suggest that this intervention may be optimally effective for those experiencing

	* Pts asked to write for 15 mins * First two writing sessions were in the first day and then the third as week later * Follow up was 8 weeks after the pts third writing session * 1st session pts were asked to focus on their deepest thoughts and feelings about their body image and eating	who reported higher perceived stress at baseline, the EW condition resulted in less eating disturbance and less social comparison, relative to the control condition * EW about body image and appearance concerns may positively influence the trajectory of risk for or resilience against future complications as result of	high stress, this may have limited our ability to detect sig main effects
* Manipulation check			

				concerns * 2nd session pts were asked to evaluate their thoughts and feelings related to body image and eating * 3rd session pts asked to synthesise their thoughts and feelings about body image and eating concerns		sleep difficulty, eating disturbance and body dissatisfaction	
Danoff-Burg, S., Mosher, C. E., Seawell, A.	* Center for Epidemiological Studies Depression	* Able to write by hand, in English for up	Not stated	* Pts instructed to write	* Pts in control group were asked to	* The narrative and EW groups	* Use of college students

H., & Agee, J. D. (2010). Does narrative writing instruction enhance the benefits of expressive writing. *Anxiety, stress and coping: An international journal, 23*(3), 341-352	Scale (CES-D) * Perceived Stress Scale (PSS) * University Health Center visits	to 20 minutes		continuously for 20 mins in accordance to their assigned instructions and were asked to return two days later to complete another 20 min writing session * EW pts were asked to let go and express their deepest thoughts and feelings relating to a personally stressful or traumatic experience	write a detailed, factual, description of the inside of an apartment or house in which they had lived.	reported lower levels of perceived stress and depressive symptoms relative to controls but did not differ from each other regards to outcomes	
Creswell, J. D., Lam, S., Stanton, A. L.,	* Satisfaction with life scale (SWLS)	* Early stage breast cancer patients who	* Pts were excluded if they had a	* Pts wrote 4 essays about their breast	No control	* Self-affirmation writing was	* Rather than manipulating self-

Taylor, S. E., Bower, J. E., & Sherman, D. K. (2007). Does self-affirmation, cognitive processing or discovery of meaning explain cancer-related health benefits of expressive writing. *Pers Soc Psychol Bull, 33*, 238-250.	* Profile of Mood States (POMS)	were within 20 weeks of completing cancer treatment	diagnosis of recurrent or metastatic disease * Unable to write in English	cancer experiences during a 3 week period * Pts were randomly assigned to one of three conditions * Condition 1- deepest thoughts and feelings regarding their experience	associated with fewer physical symptoms at a 3 month follow up assessment * Self-affirmation writing fully mediated the effects of emotional expression and benefits finding writing conditions on reduced physical symptoms	affirmation, cognitive processing or discovery of meaning writing directly we assessed the naturalistic occurrence of these statements in the context of EW trial	

	with breast cancer * Condition 2 - positive thoughts and feelings regarding their experience with breast cancer * Condition 3- facts regarding their cancer and its treatment * for each condition pts were instructed to write conditionally for 20 mins	* Self - affirmation plays an important role in buffering stress * Self-affirmation as a viable mechanism underlying the health benefits of EW	* The study didn't define the potential mediators as mutually exclusive categories, making it difficult to interpret correlations among the mediators or assess their independent contributions as orthogonal constructs

Appendix 20. Dissemination of findings from the program of research

Peer-reviewed Publications

Pilkington, M. (2014). Expressive writing interventions for individuals with appearance concerns. *Journal of Aesthetic Nursing, 3*(8), 390-393.

Pilkington, M. (2013). Supporting patients who are affected by chemotherapy-induced hair loss. *Journal of Aesthetic Nursing, 2*(9), 456-457.

Conference Publications and Invited Presentations

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2012). *Psychosocial interventions to support breast cancer patients affected by treatment-related hair loss*. Presented at the British Psychosocial Oncology Society PhD event, Chester.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2012). *A systematic review of the effectiveness of interventions to improve psychological outcomes for individuals affected by hair loss*. Poster presented at the British Psychosocial Oncology Society Conference, 2012, Southampton.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2012). *A systematic review of the effectiveness of interventions to improve psychological outcomes for individuals affected by hair loss*. Presented at the Appearance Matters 5 Conference, 2012, Bristol.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2013). *Patients' experiences of cancer-related hair loss and a camouflage-based support service'*. 'Work in Action' poster presented at the Division of Health Psychology Conference, 2013, Brighton.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2013). *"This is a journey, this isn't just a quick fix": Breast cancer patients' experiences of treatment-related hair loss and a camouflage based support service*. Poster presented at the British Psychosocial Oncology Society Conference, Preston.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2013). Feasibility and Acceptability of an Expressive Writing Intervention for Breast Cancer Patients with Chemotherapy-Induced Hair Loss. Presented at the Bristol Haematology & Oncology, Research Forum.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2014). *"This is a journey, this isn't just a quick fix": Breast cancer patients' experiences of*

treatment-related hair loss and a camouflage based support service. Presented at the University of the West of England (UWE) Health and Applied Sciences faculty conference.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J (2014). *Breast cancer patients' experiences of a camouflage based support service for treatment-related hair loss.* Presented at the University of the West of England (UWE) Postgraduate conference.

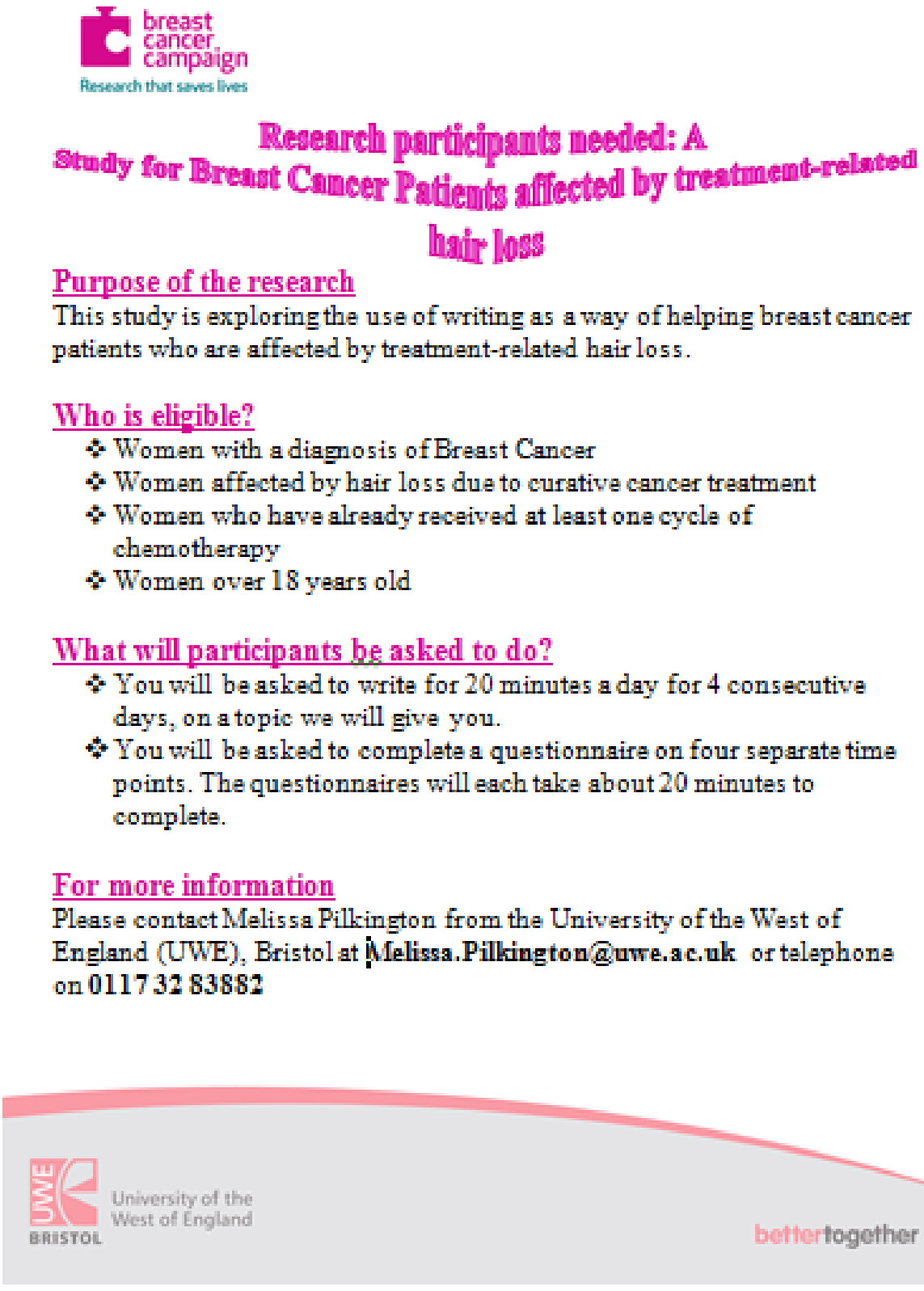
Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2014). *"This is a journey, this isn't just a quick fix": Breast cancer patients' experiences of treatment-related hair loss and a camouflage based support service.* Presented to Breast Cancer Care.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2014). *"This is a journey, this isn't just a quick fix": Breast cancer patients' experiences of treatment-related hair loss and a camouflage based support service.* Presented at the Appearance Matters 6 conference, Bristol.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2014). *"Your hair's your crowning glory": Breast cancer patients' experiences of treatment-related hair loss and a camouflage based support service*. Presented at the early career researcher event at International Psychosocial-Oncology Society conference, 2014, Lisbon.

Pilkington, M., Harcourt, D., Rumsey, N., O'Connor, D., & Brennan, J. (2015). *You're actually mourning a loss": Breast cancer patients' experiences of a camouflage based support service for treatment-related hair loss".* Poster presented at the British Psychosocial Oncology Society Conference, Leeds.

Appendix 21. Poster advertisement for the expressive writing study



Appendix 22. Press release for the expressive writing study

Women with breast cancer who are expecting to/experiencing treatment-related hair loss are wanted for study

A new study exploring the use of expressive writing as a psychosocial intervention for breast cancer patients who are affected by chemotherapy-induced hair loss has begun at UWE, Bristol.

There is a large body of research around the use of expressive writing with other populations, but to our knowledge it has not yet been looked at with breast cancer patients affected by hair loss.

Melissa Pilkington is a PhD researcher from the Centre for Appearance Research at the University of the West of England (UWE), Bristol. With the support of Breast Cancer Campaign, she is carrying out a study looking at the use of expressive writing to support women who have received a breast cancer diagnosis to see whether writing might help them manage their thoughts and feelings about hair loss.

She said "If found to be effective, expressive writing could (we think) be an easy and very cost-effective way of supporting breast cancer patients through this experience".

Taking part in this study would involve writing for a period of 20 minutes a day for 4 consecutive days on a topic that will be given to you and will involve completing 3 questionnaires. All participants who complete the study will receive a £20 Marks and Spencer's voucher.

To find out more about Melissa's research or to volunteer for this study, please follow this link: http://tinyurl.com/ExpressivewritingQ1 or contact Melissa directly: Melissa.Pilkington@uwe.ac.uk

Appendix 23. Confirmation of NRES ethical approval for the expressive writing study

NHS
Health Research Authority
NRES Committee South West - Frenchay
Bristol Research Ethics Committee Centre
Level 3, Block B
Whitefriars
Lewins Mead,
Bristol BS1 2NT
nrescommittee.southwest-frenchay@nhs.net

Telephone: 0117 342 1335
Facsimile: 0117 342 0445

04 February 2014

Miss Melissa Pilkington
PhD Researcher
University of the West of England
Centre for Appearance Research, Faculty of Health and Applied Sciences,
Frenchay Campus,
Bristol BS16 1QY

Dear Miss Pilkington

Study title:	**A pilot study of an expressive writing intervention for breast cancer patients affected by treatment-related hair loss.**
REC reference:	**14/SW/0007**
Protocol number:	**n/a**
IRAS project ID:	**136780**

Thank you for your letter of 27 January 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Advertisement	3. Poster	20 January 2014
Covering Letter		
Evidence of Insurance or Indemnity	Ins.docs.	
Investigator CV	M Pilkington	22 November 2013
Letter from Sponsor	letter	25 November 2013
Letter from Statistician	Letter	19 November 2013
Letter of invitation to participant	5	20 January 2014
Other: CV for D Harcourt		12 November 2013
Other: Debrief sheet	4	13 November 2013
Other: Cv for N Rumsey		12 November 2013
Other: CV for D O'Connor		22 November 2013
Other: CV for J Brennan		22 November 2013
Participant Consent Form	5	20 January 2014
Participant Information Sheet	5	20 January 2014
Protocol	6	
Questionnaire: Qn 1	4	20 January 2014
Questionnaire: Qn. 2	4	20 January 2014
Questionnaire: Qn. 3	4	20 January 2014
Questionnaire: Qn. 4	4	20 January 2014
REC application	3.5	25 November 2013
Referees or other scientific critique report	4	12 October 2013
Response to Request for Further Information	letter	27 January 2014
Summary/Synopsis	3. Flow chart	07 November 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Naazneen Nathoo, nrescommittee.southwest-frenchay@nhs.net.

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/SW/0007	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp. Mr PeterJones
Chair

Email:nrescommittee.southwest-frenchay@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *Ms Leigh Taylor*
Miss Diana Benton

A Research Ethics Committee established by the Health Research Authority

Appendix 24. Confirmation of UWE ethical approval for the expressive writing study

University of the West of England
BRISTOL

Faculty of Health & Applied Sciences
Glenside Campus

Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

Our ref: JW/lt

28th February 2014

Miss Melissa Pilkington
PhD Researcher
University of the West of England
Centre for Appearance Research, Faculty of Health and Applied Sciences,
Frenchay Campus,
Bristol BS16 1QY

Dear Melissa

Application number: HLS/14/02/38
Application title: A pilot study of an expressive writing intervention for breast cancer patients affected by treatment-related hair loss
REC reference: 14/SW/0007

Your NHS Ethics application and approval conditions have been considered by the Faculty Research Ethics Committee on behalf of the University. It has been given ethical approval to proceed with the following conditions:

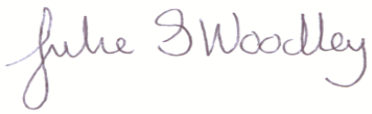
You comply with the conditions of the NHS Ethics approval.
You notify the Faculty Research Ethics Committee of any further correspondence with the NHS Ethics Committee.
You must notify the Faculty Research Ethics Committee in advance if you wish to make any significant amendments to the original application.
If you have to terminate your research before completion, please inform the Faculty Research Ethics Committee within 14 days, indicating the reasons.
Please notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.
Any changes to the study protocol, which have an ethical dimension, will need to be approved by the Faculty Research Ethics Committee. You should send details of any such amendments to the committee with an explanation of the reason for the proposed

changes. Any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
Please note that any information sheets and consent forms should have the UWE logo.
Further guidance is available on the web:
http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx
Please note that the University Research Ethics Committee (UREC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please note that your study should not commence at any NHS site until you have obtained final management approval from the R&D department for the relevant NHS care organisation. A copy of the approval letter(s) must be forwarded to Leigh Taylor in line with Research Governance requirements.

We wish you well with your research.

Yours sincerely



Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. *Diana Harcourt*

Appendix 25. Participant information sheet for the expressive writing study

Writing Study: Information Sheet

You are being invited to take part in a study. Please read this information carefully and do not hesitate to contact us with any questions that you may have. Thank you.

What is the purpose of the study?

This study is exploring the process of writing as a way of helping individuals who have received a breast cancer diagnosis and are experiencing/or are expected to experience, treatment-related hair loss. The study is being carried out by Melissa Pilkington, a PhD researcher from the Centre for Appearance Research (CAR) which is based at the University of the West of England (UWE), Bristol.

Why have I been chosen?

You are being invited to take part because you have been diagnosed with breast cancer and undergoing chemotherapy treatment at the Bristol Haematology & Oncology Centre. We are looking for a total of 120 people to take part.

Do I have to take part?

No, taking part is voluntary. You do not have to take part if you do not want to and, if you do take part, you can withdraw from the study up to a month after taking part. Whether or not you take part will not make any difference to your care, now or in the future.

What will I have to do if I take part?

You will be randomised into one of two writing groups. Both groups will be asked to write about a specific topic that we will give you – one group will be asked to write about their thoughts and feelings in relation to that topic (we refer to this as the expressive writing group) and the other group will be asked to write about their topic

in terms of facts, without their thoughts and feelings (we call this the neutral writing group). You will be asked to write either by hand or typing for 20 minutes a day for 4 consecutive days. We would like you to give us what you write, but this is completely optional and you can still take part without giving us what you have written. If you do decide to send your writing to us, it will be treated as confidential. Also, you will be asked to complete a questionnaire on four separate time points; one now, and then two weeks, one month and 3 months later. The questionnaires will each take about 20 minutes to complete. We will post them to you and send a stamped addressed envelope to return them to us. If you would prefer to complete the questionnaires online, please use the following link: http://tinyurl.com/or2ap6u

What are the possible benefits of taking part?

You might find it interesting to participate, although we cannot promise that this study with help you personally. However, the results of the study will inform future plans for ways we might support cancer patients affected by hair loss in the future.

Will my identity be protected?

Yes. Only a summary of this information will be reported during the write up of the study, and your name or any other identifying information will not be known to anyone other than the researcher.

What will happen with the results of the study?

The results of the study will be reported to Breast Cancer Campaign, who are funding this research. However, your individual questionnaires will not be passed on to Breast Cancer Campaign or anyone outside of the research team.

What will happen if any disturbing information comes to light?

Should any disturbing information come to light whilst reading participants' writing samples or questionnaires, the researcher will raise any concerns with her supervisory team.

How will the findings be shared with other people?

The overall findings will be published in a journal and presented at conferences for health professionals and written up as part of a PhD thesis. Also, a summary of the findings will be made available to participants and to Breast Cancer Campaign.

Who has reviewed the study?

The study has been approved by the NRES Committee South West- Frenchay REC, the Bristol Haematology & Oncology Centre local Research and Development office and the University of the West of England (UWE) Research Ethics Committee. Also, the study was reviewed by Breast Cancer Campaign before they agreed to fund the research.

Your right to withdraw from the study

You have the right to withdraw from the study up to a month after taking part. If you wish to withdraw from the study, please contact the researcher and all your information will be withdrawn from the study and destroyed.

What do I do now?

If you would like to take part in the study, please complete the questionnaire and return it to Melissa Pilkington, together with the consent form, in the envelope provided. You do not need to put a stamp onto the envelope. Alternatively, you can complete the questionnaire online, please use the following link: http://tinyurl.com/or2ap6u

More details about what we would like you to write about will be sent once you have returned your consent form

What if I have a complaint?

If you have a complaint about the research study, in the first instance please contact the researcher Melissa Pilkington at Melissa.Pilkington@uwe.ac.uk or telephone 0117 3283882. If you would like to speak to someone other than the researcher, please contact Melissa's supervisor Prof. Diana Harcourt at Diana2.Harcourt@uwe.ac.uk or telephone 0117 3283967.

If you would like to speak to someone at the Bristol Haematology and Oncology Centre, the Patient Support and Complaints Team have a drop in service, which you can access at the main entrance of the Bristol Royal Infirmary or you can contact the Patient Support and Complaints Team via the following methods - Telephone: 0117 342 3604 or Email: pals@uhbristol.nhs.uk

Further information about taking part in research

If you would like further information about taking part in research, please follow the link below:

http://www.nbt.nhs.uk/research-and-innovation/our-research/take-part-research

Contact for further information

If you have any further questions please contact, Melissa Pilkington at:-

Email:- Melissa.Pilkington@uwe.ac.uk

Telephone No:- (0117) 3283882

Work Mobile Telephone No:- 07972733919 (Monday – Friday 9-5pm)

Or you can contact Melissa's supervisor, Prof. Diana Harcourt at:

Diana2.Harcourt@uwe.ac.uk

Telephone No:- (0117) 3283967

If you would like any more information about cancer, or have any concerns that you would like to discuss, you might like to contact any of the following specialist organisations:-

Listening ear service at the Bristol Haematology & Oncology Centre:-

The Information and Support Centre on the Ground Floor of BHOC offers a 'listening ear' service for any patients that would benefit from having time to speak to someone about their current experience.
Telephone: 0117 3423369

Email: cancerinfoandsupport@uhbristol.nhs.uk

Penny Brohn Cancer Centre:-

Penny Brohn Cancer Centre offer a free counselling and psychotherapy service and patients can self-refer to this service.

Website: www.pennybrohncancercare.org

Telephone No: 08451232310 or 01275370100

Breast Cancer Care:-

Website: www.breastcancercare.org.uk

Peer Support Team Telephone No:- 0845 0771893

Peer Support Team Email:- ukpeersupportteam@breastcancercare.org.uk

Breast Cancer Care's Free Helpline for one-to-one support:- 0808 800 6000

Maggie's Centre:-

Website: http://www.maggiescentres.org/

To arrange face-to-face support with a support specialist:-

Email:- enquiriesatmaggiescentres.org

Telephone No:- 0300 123 1801

Macmillan:-

Website: www.macmillan.org.uk

If you have any questions, would like support or someone to talk to:-

Cancer Support Specialist Telephone No:- 0808 808 00 00

Appendix 26. Participant invitation letter for the expressive writing study

University Hospitals Bristol NHS
NHS Foundation Trust

Bristol Haematology and Oncology Centre
Horfield Road
Bristol, BS2 8ED

Tel: 0117 3423113
Fax: 0117 3423273

Dear patient,

Invitation to take part in a Research Study

I am writing to patients receiving treatment at the Bristol Haematology & Oncology Centre who are eligible to take part in a new research study. Women who have received a diagnosis of breast cancer and may be affected by treatment-related hair loss, now or in the future, are eligible to participate.

You are being invited to take part in a study which is exploring a new way of helping patients manage the emotional impact of chemotherapy in particular any distress associated with losing their hair. The research is being carried out by Melissa Pilkington, a PhD researcher from the Centre for Appearance Research (CAR) which is based at the University of the West of England (UWE), Bristol.

Please read the information sheet which has been sent to you with this letter and decide if you would like to take part. If you have any questions about the research, please do not hesitate to contact Melissa, whose contact details are on the information sheet.

It is up to you whether or not you take part in this research. If you do decide to take part, any information that you give to Melissa will be treated as confidential and will only be seen by Melissa and her supervisors. You are free to withdraw from the research up to a month after taking part and you do not have to give a reason for withdrawing. Whether or not you take part will not make any difference to the care you receive now, or in the future.

P.T.O

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

University Hospitals Bristol NHS Foundation Trust
0117 923 0000 | 0117 934 9869 www.uhbristol.nhs.uk

University Hospitals Bristol NHS
NHS Foundation Trust

Bristol Haematology and Oncology Centre
Horfield Road
Bristol, BS2 8ED

Tel: 0117 3423115
Fax: 0117 3423073

If you wish to take part in the study, please read the enclosed information and sign the consent form and return it to Melissa Pilkington by using the pre-paid envelope enclosed.

Yours faithfully,

Dr. Amit Bahl
Dr. Jeremy Braybrooke
Dr. Charles Comins

Appendix 27. Participant consent form for the expressive writing study

University of the West of England
BRISTOL

Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
Telephone +44 (0)117 965 6261
www.uwe.ac.uk

Writing Study: Consent Form

This study is exploring the use of a writing study as a way of helping individuals who have received a breast cancer diagnosis and are having chemotherapy treatment. Taking part in this study will involve a writing task for 20 minutes a day, over the course of 4 consecutive days. Also, you will be asked to complete a questionnaire on 4 different occasions, either on paper or online.

In order to protect your identity only a summary of the information you provide will be reported during the write up of the study. Your completed questionnaires will be stored securely and only accessible to the research team. You do not have to take part and you have the right to withdraw from the study up to a month after taking part.

Please tick the relevant box

	Yes	**No**
I Confirm that I have read and understood the information sheet relating to the above study and have had the opportunity to ask questions.	☐	☐
I understand that my participation is voluntary and that I am free to withdraw from the study up to a month after taking part, without giving any reason and without my health care being affected.	☐	☐
I agree to take part in the above study.	☐	☐
We would like you to give us what you write, however, this is completely optional and you can still take part without giving us what you have written. I consent to the researcher reading what I write during the study.	☐	☐

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of the West of England, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐ ☐

Name of Participant	Signature	Date
Researcher	Signature	Date

Please indicate below how you would prefer to receive the instructions about the writing task and later questionnaires.

☐ Post

☐ Email

Address.....

.....

.....

Email address.....

Telephone Number.....

If you give your consent to take part in the study please return this form along with the completed questionnaire in the pre-paid envelope provided.

Return Address:-

FAO Melissa Pilkington
Centre for Appearance Research
Room 2L13
University of the West of England, Bristol
Frenchay Campus
Coldharbour Lane
BRISTOL
BS16 1QY

Thank you for your time.

Appendix 28. Baseline expressive writing questionnaire

Questionnaire 1

Create Your Own ID Code

You have the right to withdraw from the study up to one month after you have completed the study. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code please enter the first three letters of your first name and the date of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

Please write below the date on which you completed this questionnaire:

_____

Demographic Information

The following information will be used to understand the sample of data collected and will be used for statistical purposes only, not to identify you. Please remember that all responses are treated as confidential.

A: About you (*please tick the relevant box or write your answer in the space provided*):

1. Please state your age _____

2. How would you describe your ethnic group? (*please tick one box*)

White

☐ English/Welsh/Scottish/Northern Irish/British

☐ Irish

☐ Gypsy or Irish Traveller

☐ Any other white background

Please write in _____

Mixed/multiple ethnic groups

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other Mixed/multiple ethnic background

Please write in _____

Asian/Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

please write in _____

Black/African/Caribbean/Black British

☐ African

☐ Caribbean

☐ Any other Black/African/Caribbean background

please write in _____

Other ethnic group

☐ Arab

☐ Any other ethnic group

please write in

Or

☐ Prefer not to answer

3. Are you currently in education or employed? (*please tick one box*)

☐ School

☐ College

☐ University

☐ Working Full time

☐ Working Part time

☐ Unemployed

☐ Other (please state) _____

4. What is your marital status? (*please tick one box*)

☐ Married

☐ Divorced

☐ Separated

☐ Widowed

☐ Single

☐ In a same-sex civil relationship

☐ Other (please state) _____

B: About your cancer and hair loss

1. Which type of cancer were you diagnosed as having? (*please tick one box*)

☐ Breast Cancer

☐ Other (*Please specify*) _____

2. How long ago were you given your cancer diagnosis? _____ years _____ months

3. What type of treatment, if any, have you received? (*Please tick all that apply*)

☐ Chemotherapy ☐ None ☐ Other (*Please specify*)

☐ Radiotherapy ☐ Not sure _____

☐ Surgery (*Please specify*) _____

_____

4. What type of treatment, if any, are you currently undergoing? (*Please tick all that apply*)

☐ Chemotherapy ☐ None ☐ Other (*Please specify*)

☐ Radiotherapy ☐ Not sure _____

☐ Surgery (*Please specify*) _____

5. Until now have you experienced any hair loss due to cancer treatment? (*please tick one box*)

☐ Yes

☐

No

If you answered yes to the above question, approximately how long after your first chemotherapy treatment did your hair start to fall out?

_____ Days Or _____ Weeks

6. If you have experienced/are experiencing hair loss, how much of your hair have you lost? *(please tick one box)*

☐ All of it ☐ Some

☐ A lot ☐ None

7. How upset or distressed are you by your hair loss? *(please tick one box)*

☐ Not at all ☐ A little

☐ Quite a lot ☐ Extremely

8. Are you currently receiving any practical or emotional support regarding your cancer? (*please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, please state below what type of support you are receiving? _____

9. Since receiving you cancer diagnosis, have you been keeping a diary?

☐ Yes ☐ No

If yes, what are your reasons for keeping a diary?

_____

C: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					
When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					
When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the first time, I wonder what they think about how I look.					

In my everyday life, lots of things happen that make me think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasize about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to find out if you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

From now on, we will refer to this aspect of your appearance as your 'feature'

(c) The thing I don't like about my feature is

.....

(d) If you are sensitive or concerned about any other features of your body or your appearance, please say what they are

.....

.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my feature:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine/masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my feature:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How normal do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your feature?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My feature causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always ....

My feature limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ...

D: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				

I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

E: Your Health and Wellbeing

Below is a list of statements that other people with your cancer have said are important. By ticking one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					
I feel ill.					
I am forced to spend time in bed.					
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next item.* I am satisfied with my sex life.					

I feel sad.					
	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					
I worry that my condition will get worse.					
I am able to work (include work at home).					
My work (include work at home) is fulfilling.					
I am able to enjoy life.					
I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

F: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how characteristic it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable					

impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I am making on someone.					
I am afraid that others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's opinions of me do not bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too					

concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate by ticking the box that matches what you think.

	Yes Definitely	Yes Sometimes	No, Not Much	No, Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				
I get palpitations, or sensations of 'butterflies' in my stomach or chest.				
I have a good appetite.				
I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am often confused about what emotion I am feeling					
I have physical sensations that even doctors do not understand					
When I am upset, I do not know if I am sad, frightened or angry					
I am often puzzled by sensations in my body					
I have feelings that I cannot quite identify					
I do not know what is going on inside me					
I often do not know why I am angry					
It is difficult for me to find the right words for my feelings					
I am able to describe my feelings easily					
I find it hard to describe how I feel about people					
People tell me to describe my feelings more					
It is difficult for me to reveal my innermost feelings, even to close friends					
Being in touch with emotions is essential					
I prefer talking to people about their daily activities rather than their feelings					
I prefer to watch “light” entertainment shows rather than psychological dramas					
I can feel close to someone, even in moments of silence					
I find examination of my feelings useful in solving personal problems					
I prefer to analyse problems rather than just describe them					
I prefer to just let things happen rather than to understand why they turned out that way					
Looking for hidden meanings in movies or plays distracts from their enjoyment					

Please place any further comments you would like to make in the box below.

Thank you for taking part

Please return the questionnaire in the pre-paid envelope provided.

Return Address:-

FAO Melissa Pilkington
Centre for Appearance Research
Room 2L13
University of the West of England, Bristol
Frenchay Campus
Coldharbour Lane
BRISTOL
BS16 1QY

Appendix 29. Two week follow-up expressive writing questionnaire

Questionnaire 2

Create Your Own ID Code

You have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code please enter the first three letters of your first name and the date of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

Please write below the date on which you complete this questionnaire

All questions are optional

A:About your hair loss and use of health resources

1. Until now, have you lost any hair due to cancer treatment?

☐ Yes

☐ No

If you answered yes to the above question, approximately how long after your first chemotherapy treatment did your hair start to fall out?

_____ Days Or _____ Weeks

2. If you have experienced/are experiencing hair loss, how much of your hair have you lost? *(please tick one box)*

☐ All of it ☐ Some

☐ A lot ☐ None

3. How upset or distressed are you by your hair loss? *(please tick one box)*

☐ Not at all ☐ A little

☐ Quite a lot ☐ Extremely

4. Are you currently receiving any practical or emotional support regarding your cancer? (*please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, please state below what type of support you are receiving? _____

5. For the following questions please tick the answer that applies to you.

	Not at all	A little	A lot	Extremely
Are you happy with the level of information and support you have received from your GP?				
Are you happy with the level of information and support you have received from your Consultant?				
Are you happy with the level of information and support you have received from your Breast Care Nurse?				
Are you happy with the level of information and support you have received from your Support Organisations?				

B: About your writing experience

1. During the writing task, where in terms of location were you when you did the writing task on each of the four days? i.e home, hospital, cafe etc

Day one _____ Day three _____

Day two _____ Day four _____

2. What did you think of the writing task?

_____

_____

3. Did you find the writing task useful?

☐ Yes ☐ No

If yes, please state why below

_____

_____

If no, please state why below

_____

_____

4. Since receiving you cancer diagnosis, have you been keeping a diary?

☐ Yes ☐ No

If yes, what are your reasons for keeping a diary? _____

C: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					
When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					
When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the					

first time, I wonder what they think about how I look.					
In my everyday life, lots of things happen that make me think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasize about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to find out if you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

From now on, we will refer to this aspect of your appearance as your 'feature'

(c) The thing I don't like about my feature is

.....

(d) If you are sensitive or concerned about any other features of your body or your appearance, please say what they are

.....
.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my feature:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine/masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my feature:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my

mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How normal do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your feature?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My feature causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always ....

My feature limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ...

D: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

E: Your Health and Wellbeing

Below is a list of statements that other people with your cancer have said are important. By ticking one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					
I feel ill.					
I am forced to spend time in bed.					
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next item.* I am satisfied with my sex life.					
I feel sad.					
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					

I worry that my condition will get worse.					
I am able to work (include work at home).					
My work (include work at home) is fulfilling.					
I am able to enjoy life.					
I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

F: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how characteristic it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I					

am making on someone.					
I am afraid that others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's opinions of me do not bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate by ticking the box that matches what you think.

	Yes Definitely	Yes Sometimes	No, Not Much	No, Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				
I get palpitations, or sensations of 'butterflies' in my stomach or chest.				
I have a good appetite.				
I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am often confused about what emotion I am feeling					
I have physical sensations that even doctors do not understand					
When I am upset, I do not know if I am sad, frightened or angry					
I am often puzzled by sensations in my body					
I have feelings that I cannot quite identify					
I do not know what is going on inside me					
I often do not know why I am angry					
It is difficult for me to find the right words for my feelings					
I am able to describe my feelings easily					
I find it hard to describe how I feel about people					
People tell me to describe my feelings more					
It is difficult for me to reveal my innermost feelings, even to close friends					
Being in touch with emotions is essential					
I prefer talking to people about their daily activities rather than their feelings					
I prefer to watch “light” entertainment shows rather than psychological dramas					
I can feel close to someone, even in moments of silence					
I find examination of my feelings useful in solving personal problems					
I prefer to analyse problems rather than just describe them					
I prefer to just let things happen rather than to understand why they turned out that way					
Looking for hidden meanings in movies or plays distracts from their enjoyment					

Please place any further comments you would like to make in the box below.

Thank you for taking part

Please return the questionnaire in the pre-paid envelope provided.

Return Address:-

FAO Melissa Pilkington
Centre for Appearance Research
Room 2L13
University of the West of England, Bristol
Frenchay Campus
Coldharbour Lane
BRISTOL
BS16 1QY

Appendix 30. One month follow-up expressive writing questionnaire

Questionnaire 3

Create Your Own ID Code

You have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code please enter the first three letters of your first name and the date of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

Please write below the date on which you complete this questionnaire

All questions are optional

A:About your hair loss

1. Until now, have you lost any hair due to cancer treatment?

☐ Yes

☐ No

If you answered yes to the above question, approximately how long after your first chemotherapy treatment did your hair start to fall out?

_____ Days Or _____ Weeks

2. If you have experienced/are experiencing hair loss, how much of your hair have you lost? *(please tick one box)*

☐ All of it ☐ Some

☐ A lot ☐ None

3. How upset or distressed are you by your hair loss? *(please tick one box)*

☐ Not at all ☐ A little

☐ Quite a lot ☐ Extremely

4. Are you currently receiving any practical or emotional support regarding your cancer? (*please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, please state below what type of support you are receiving? _____

5. For the following questions please tick the answer that applies to you.

	Not at all	A little	A lot	Extremely
Are you happy with the level of information and support you have received from your GP?				
Are you happy with the level of information and support you have received from your Consultant?				
Are you happy with the level of information and support you have received from your Breast Care Nurse?				
Are you happy with the level of information and support you have received from your Support Organisations?				

B: About your writing experience

1. Did you find the writing task useful?

☐ Yes ☐ No

If yes, please state why below

_____

_____

If no, please state why below

_____

_____

2. Have you done any writing since you completed the writing task?

_____

3. Since receiving you cancer diagnosis, have you been keeping a diary?

☐ Yes ☐ No

If yes, what are your reasons for keeping a diary?

_____

C: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					
When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					
When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the first time, I wonder what they think about how I look.					

In my everyday life, lots of things happen that make me think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasize about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to find out if you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

From now on, we will refer to this aspect of your appearance as your 'feature'

(c) The thing I don't like about my feature is

.....

(d) If you are sensitive or concerned about any other features of your body or your appearance, please say what they are

.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my feature:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine/masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my feature:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my
mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How normal do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your feature?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My feature causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always ....

My feature limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ...

D: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

E: Your Health and Wellbeing

Below is a list of statements that other people with your cancer have said are important. By ticking one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					
I feel ill.					
I am forced to spend time in bed.					
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next item.* I am satisfied with my sex life.					
I feel sad.					
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					
I worry that my condition will get worse.					
I am able to work (include work at home).					

My work (include work at home) is fulfilling.					
I am able to enjoy life.					
I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

F: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how characteristic it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I am making on someone.					

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I am afraid that others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's opinions of me do not bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate by ticking the box that matches what you think.

	Yes Definitely	Yes Sometimes	No, Not Much	No, Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				
I get palpitations, or sensations of 'butterflies' in my stomach or chest.				
I have a good appetite.				
I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am often confused about what emotion I am feeling					
I have physical sensations that even doctors do not understand					
When I am upset, I do not know if I am sad, frightened or angry					
I am often puzzled by sensations in my body					
I have feelings that I cannot quite identify					
I do not know what is going on inside me					
I often do not know why I am angry					
It is difficult for me to find the right words for my feelings					
I am able to describe my feelings easily					
I find it hard to describe how I feel about people					
People tell me to describe my feelings more					
It is difficult for me to reveal my innermost feelings, even to close friends					
Being in touch with emotions is essential					
I prefer talking to people about their daily activities rather than their feelings					
I prefer to watch “light” entertainment shows rather than psychological dramas					
I can feel close to someone, even in moments of silence					
I find examination of my feelings useful in solving personal problems					
I prefer to analyse problems rather than just describe them					
I prefer to just let things happen rather than to understand why they turned out that way					
Looking for hidden meanings in movies or plays distracts from their enjoyment					

Please place any further comments you would like to make in the box below.

Thank you for taking part

Please return the questionnaire in the pre-paid envelope provided.

Return Address:-

FAO Melissa Pilkington
Centre for Appearance Research
Room 2L13
University of the West of England, Bristol
Frenchay Campus
Coldharbour Lane
BRISTOL
BS16 1QY

Appendix 31. Three month follow-up questionnaire

Questionnaire 4

Create Your Own ID Code

You have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw, you will need to inform us by email at Melissa.Pilkington@uwe.ac.uk, quoting your unique ID code.

To create your ID code please enter the first three letters of your first name and the date of the month you were born.

For example, if your first name is Lucy and you were born on 12 August you would enter **LUC12**

Please enter your code in the box below.

Please write below the date on which you complete this questionnaire

All questions are optional

A:About your hair loss

1. Until now, have you lost any hair due to cancer treatment?

☐ Yes

☐ No

If you answered yes to the above question, approximately how long after your first chemotherapy treatment did your hair start to fall out?

_____ Days Or _____ Weeks

2. If you have experienced/are experiencing hair loss, how much of your hair have you lost? *(please tick one box)*

☐ All of it ☐ Some

☐ A lot ☐ None

3. How upset or distressed are you by your hair loss? *(please tick one box)*

☐ Not at all ☐ A little

☐ Quite a lot ☐ Extremely

4. Are you currently receiving any practical or emotional support regarding your cancer? (*please tick one box*)

☐ Yes

☐ No

If you answered yes to the above question, please state below what type of support you are receiving? _____

5. For the following questions please tick the answer that applies to you.

	Not at all	A little	A lot	Extremely
Are you happy with the level of information and support you have received from your GP?				
Are you happy with the level of information and support you have received from your Consultant?				
Are you happy with the level of information and support you have received from your Breast Care Nurse?				
Are you happy with the level of information and support you have received from your Support Organisations?				

B: About your writing experience

1. Did you find the writing task useful?

☐ Yes ☐ No

If yes, please state why below

_____

_____

If no, please state why below

_____

_____

2. Have you done any writing since you completed the writing task?

_____

3. Since receiving you cancer diagnosis, have you been keeping a diary?

☐ Yes ☐ No

If yes, what are your reasons for keeping a diary?

_____

C: Your Appearance

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and indicate by ticking the box that matches what you think. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
I spend little time on my physical appearance.					
When I see good-looking people, I wonder about how my own looks measure up.					
I try to be as physically attractive as I can be.					
I have never paid much attention to what I look like.					
I seldom compare my appearance to that of other people.					
I often check my appearance in a mirror just to make sure I look okay.					
When something makes me feel good or bad about my looks, I tend to dwell on it.					
If I like how I look on a given day, it's easy to feel happy about other things.					
If somebody had a negative reaction to what I look like, it wouldn't bother me.					
When it comes to my physical appearance, I have high standards.					
My physical appearance has had little influence on my life.					
Dressing well is not a priority for me.					
When I meet people for the first time, I wonder what they think about how I look.					
In my everyday life, lots of things happen that make me					

think about what I look like.					
If I dislike how I look on a given day, it's hard to feel happy about other things.					
I fantasize about what it would be like to be better looking than I am.					
Before going out, I make sure that I look as good as I possibly can.					
What I look like is an important part of who I am.					
By controlling my appearance, I can control many of the social and emotional events in my life.					
My appearance is responsible for much of what's happened to me in my life.					

The first part of the scale is designed to find out if you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

(a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

(b) **If No,** please go to the next page

If Yes, please continue:

The aspect of my appearance about which I am most sensitive or self-conscious is

.....

From now on, we will refer to this aspect of your appearance as your 'feature'

(c) The thing I don't like about my feature is

.....

(d) If you are sensitive or concerned about any other features of your body or your appearance, please say what they are

.....

The following questions are concerned with the way you feel or act. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

How confident do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

How distressed do you get when you see yourself in the mirror/window?

Extremely .... Moderately.... A Little .... Not at all Distressed ....

My self-consciousness makes me irritable at home:

N/A .... Never/Almost never .... Sometimes .... Often .... Almost always ....

How hurt do you feel?

Extremely .... Moderately .... Slightly .... Not at all ....

At present my self-consciousness has an adverse effect on my work:

Almost always .... Often .... Sometimes .... Never/almost never .... N/A .....

How distressed do you get when you go to the beach?

N/A .... Not at all .... A little .... Moderately .... Extremely ....

Other people mis-judge me because of my feature:

Almost always .... Often .... Sometimes .... Never/almost never ..... N/A .....

How feminine/masculine do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I am self -conscious of my feature:

N/A .... Never/ Almost never .... Sometimes .... Often .... Almost always ....

How irritable do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I adopt certain gestures (e.g. folding my arms in front of other people, covering my
mouth with my hand):

Never/almost never .... Sometimes .... Often .... Almost always ...

I avoid communal changing rooms:

Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

How distressed do you get by shopping in department stores/supermarkets?

N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

How rejected do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

I avoid undressing in front of my partner:

N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

How distressed do you get while playing sports/games?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

I close into my shell:

Almost always .... Often .... Sometimes.... Never/Almost never ....

How distressed are you by being unable to wear your favourite clothes?

Extremely .... Moderately .... Slightly .... Not at all .... N/A .....

How distressed do you get when going to social events?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

How normal do you feel?

Not at all .... Slightly .... Moderately .... Extremely ....

At present my self-consciousness has an adverse effect on my sex life:

Almost always .... Often .... Sometimes.... Never/almost never .... N/A .....

I avoid going out of the house:

Almost always .... Often .... Sometimes.... Never/almost never ....

How distressed do you get when other people make remarks about your feature?

N/A .... Not at all .... Moderately .... A fair amount .... Extremely ....

I avoid going to pubs/restaurants:

Almost always .... Often .... Sometimes....Never/almost never .... N/A .....

My feature causes me physical pain/discomfort: :

Never/almost never .... Sometimes .... Often .... Almost always ....

My feature limits my physical ability to do the things I want to do:

Almost always .... Often .... Sometimes....Never/ almost never ...

D: Your Feelings and Emotions

For the following statements, please indicate by ticking the box that matches what you think.

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

E: Your Health and Wellbeing

Below is a list of statements that other people with your cancer have said are important. By ticking one box per line to indicate your response as it applies to the **past 7 days.**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I have a lack of energy.					
I have nausea.					
Because of my physical condition, I have trouble meeting the needs of my family.					
I have pain.					
I am bothered by the side effects of treatment.					
I feel ill.					
I am forced to spend time in bed.					
I feel close to my friends.					
I get emotional support from my family.					
I get support from my friends.					
My family has accepted my illness.					
I am satisfied with family communication about my illness.					
I feel close to my partner (or the person who is my main support).					
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ *and go to the next item.* I am satisfied with my sex life.					
I feel sad.					
I am satisfied with how I am coping with my illness.					
I am losing hope in the fight against my illness.					
I feel nervous.					
I worry about dying.					
I worry that my condition will get worse.					
I am able to work (include work at home).					
My work (include work at home) is fulfilling.					
I am able to enjoy life.					

I have accepted my illness.					
I am sleeping well.					
I am enjoying the things I usually do for fun.					
I am content with the quality of my life right now.					

F: Your Thoughts and Concerns

Please read each of the following statements carefully and indicate how characteristic it is of you by ticking the appropriate box.

	Not at all characteristic of me	Slightly characteristic of me	Moderately characteristic of me	Very characteristic of me	Extremely characteristic of me
I worry about what other people will think of me even when I know it doesn't make any difference.					
I am unconcerned even if I know people are forming an unfavourable impression of me.					
I am frequently afraid of other people noticing my shortcomings.					
I rarely worry about what kind of impression I am making on someone.					
I am afraid					

that others will not approve of me.					
I am afraid that people will find fault with me.					
Other people's opinions of me do not bother me.					
When I am talking to someone, I worry about what they may be thinking about me.					
I am usually worried about what kind of impression I make.					
If I know someone is judging me, it has little effect on me.					
Sometimes I think I am too concerned with what other people think of me.					
I often worry that I will say or do the wrong things.					

For the following statements, please indicate by ticking the box that matches what you think.

	Yes Definitely	Yes Sometimes	No, Not Much	No, Not At All
I wake early and then sleep badly for the rest of the evening.				
I get very frightened or have panic feelings for apparently no reason at all.				
I feel miserable and sad.				
I feel anxious when I go out of the house on my own.				
I have lost interest in things.				
I get palpitations, or sensations of 'butterflies' in my stomach or chest.				
I have a good appetite.				
I feel scared or frightened.				
I feel life is not worth living.				
I still enjoy things I used to.				
I am restless and can't keep still.				
I am more irritable than usual.				
I feel as if I have slowed down.				
Worrying thoughts constantly go through my mind.				

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am often confused about what emotion I am feeling					
I have physical sensations that even doctors do not understand					
When I am upset, I do not know if I am sad, frightened or angry					
I am often puzzled by sensations in my body					
I have feelings that I cannot quite identify					
I do not know what is going on inside me					
I often do not know why I am angry					
It is difficult for me to find the right words for my feelings					
I am able to describe my feelings easily					
I find it hard to describe how I feel about people					
People tell me to describe my feelings more					
It is difficult for me to reveal my innermost feelings, even to close friends					
Being in touch with emotions is essential					
I prefer talking to people about their daily activities rather than their feelings					
I prefer to watch “light” entertainment shows rather than psychological dramas					
I can feel close to someone, even in moments of silence					
I find examination of my feelings useful in solving personal problems					
I prefer to analyse problems rather than just describe them					
I prefer to just let things happen rather than to understand why they turned out that way					
Looking for hidden meanings in movies or plays distracts from their enjoyment					

Please place any further comments you would like to make in the box below.

Thank you for taking part

Please return the questionnaire in the pre-paid envelope provided.

Return Address:-

FAO Melissa Pilkington
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Frenchay Campus
Coldharbour Lane
BRISTOL
BS16 1QY

Appendix 32. Writing instructions for the expressive writing group

Writing instructions 1

Over the next **four days**, I would like you to write about your **very deepest thoughts and feelings in relation to your treatment-related hair loss**. It is advised that you write from somewhere comfortable, where you won't be disturbed, with plenty of paper to hand or alternatively, you can use a computer if you prefer.

In your writing, I'd like you to really let go and explore your very deepest emotions and thoughts. Ideally, I would like you to write about any parts of your experience of hair loss which you may have found hard to share with others. Perhaps this will provide an opportunity to really examine those thoughts and emotions. You might want to write about your hair loss in relation to other parts of your life. For example, how is it related to your family life, relationship with your spouse, your children, parents, friends, daily activities, hobbies, or your work? These are just some examples.

For each of the four days of writing, we would like you to write about a slightly different topic:-

- **Day one-** your deepest thoughts and feelings in relation to hair loss
- **Day two-** your deepest thoughts and feelings around hair loss specifically in relation to your appearance
- **Day three-** your deepest thoughts and feelings around treatment-related hair loss in relation to your life in general
- **Day four-** your deepest thoughts and feelings around managing hair loss.

All of your writing will be completely confidential. Don't worry about spelling, sentence structure, or grammar. Don't worry about erasing things or crossing things out, just write freely. Once you begin writing, please continue to do so for a period of **20 minutes**.

Appendix 33. Writing Instructions for the Control Group

Writing instructions 2

Over the next **four days**, I would like for you to write about the following topics:-

- **Day one –** please describe your home
- **Day two –** please describe your neighbourhood or the area that you live in
- **Day three –** please describe the town, village or city that you live in
- **Day four –** please describe a place which you have recently visited

In your writing, I'd like you to write about each of the above topics **without including emotions, feelings or opinions.** Just describe them – for example, where they are, what they look like or what's there. It is advised that you write from somewhere comfortable, where you won't be disturbed, with plenty of paper to hand or alternatively, you can use a computer if you prefer.

All of your writing will be completely confidential. Your descriptions should be as detailed and objective as possible. Don't worry about spelling, sentence structure, or grammar. Don't worry about erasing things or crossing things out, just write freely. Once you begin writing, please continue to do so for a period of **20 minutes**.

Appendix 34. Debrief sheet for the expressive writing study

University of the West of England
BRISTOL

Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
Telephone +44 (0)117 965 6261
www.uwe.ac.uk

Writing Study: Debrief Sheet

The aim of the study was to explore the use of expressive writing as a way to help individuals who have received a breast cancer diagnosis are having chemotherapy treatment. Previous research has demonstrated that the process of making sense of an event, of gaining insight about a trauma, and organise and interpret an upsetting experience through expressive writing can be helpful. We wanted to see if an expressive writing task would help breast cancer patients' with treatment-related hair loss.

We did this by randomly allocating participants into one of two groups; an expressive writing or control group. Participants in the expressive writing group were asked to write for 20 minutes a day for 4 consecutive days about their thoughts and feelings in relation to their treatment-related hair loss, whereas those in the control group were asked to write for the same period of time but to write about a neutral topic without an emotional expression. Also, all participants regardless of whether they were in the expressive writing or control group were asked to complete a questionnaire at four separate time points. The purpose of the questionnaires were to see whether any changes in hair loss distress, self-esteem and quality of life reported soon after expressive writing are maintained in the longer term.

Our analysis will compare the questionnaire data from the two groups. Once the study is complete, I will send you a summary of the findings.

If you have any further questions about the study, please do not hesitate to contact Melissa Pilkington at Melissa.Pilkington@uwe.ac.uk.

Thank you again for taking part in the study.

Appendix 35. Executive summary report presented to Breast Cancer Care

Executive summary of preliminary findings

Prepared by:

Melissa Pilkington
Centre for Appearance Research, University of the West of England (UWE)

Supervised by:

Prof. Diana Harcourt (Centre for Appearance Research, UWE)
Prof. Nichola Rumsey (Centre for Appearance Research, UWE)
Prof. Daryl O'Connor (University of Leeds)
Dr. James Brennan (Consulting Clinical Psychologist)

Prepared for:

Breast Cancer Care

15th September, 2014

Preliminary findings not for distribution until they have been published

Background

The psychosocial impact of cancer treatment is wide-ranging, including changes to appearance, such as hair loss. Hair loss (including loss of eyelashes, eyebrows and all body hair) can be a very distressing side-effect of cancer treatment and some women find it harder to cope with this than with the loss of a breast (Benjamin et al, 2002). The visible nature of hair loss can affect individuals' body image, self-esteem and quality of life (Williams et al, 1999). Even though chemotherapy-induced alopecia is often temporary, the negative emotional repercussions can continue after hair has re-grown.

Aims:

- To explore, breast cancer patients' experiences of treatment-related hair loss and their experiences of Breast Cancer Care's HeadStrong service.
- To examine the short and longer-term impact of the HeadStrong service on appearance-related distress, self-esteem, quality of life, confidence in managing hair loss and psychosocial distress.

Qualitative study

Design

A semi-structured interview schedule was developed to explore participants' motivation for accessing HeadStrong, their expectations of it, whether it helped them in managing their hair loss and whether they had any recommendations for the HeadStrong service in the future.

Demographic details

- 25 women elected to participate
- Mean age of participants was 51 (range = 34-68 years)
- All partcipants described themselves as White
- Mean time since diagnosis was 8 months at the time of the interview
- Participants were from a variety of geographical locations across the country

Data analysis

The interviews were transcribed verbatim and subjected to thematic analysis (TA).

Findings

Three main themes emerged: challenges of hair loss, support for treatment-related hair loss and unmet needs.

Theme 1: Challenges of hair loss

- Hair loss-related distress began when individuals first anticipated their hair loss.

- Participants were surprised by the extent of the impact that hair loss had had on their lives and their sense of self

Theme 2: Experiences of receiving support for treatment-related hair loss

- Participants found HeadStrong to be very helpful in providing practical advice and information
- HeadStrong was found to help increase confidence
- Some participants knew little about HeadStrong prior to attending their session
- Some participants were pleased that HeadStrong had been provided on a one-to-one, however, some participants felt alone within the hair loss journey and would have liked HeadStrong to have been a group session

Theme 3: Unmet needs

- Some participants felt that they would have liked to receive more emotional support
- A few of participants spoken about how they would have like the room to have been bigger where the HeadStrong session was held
- Many participants would have preferred the HeadStrong setting to have been separate from the hospital or at least separate from the Oncology department

Quantitative study

Design

A pre, 2 week and 3 month follow-up questionnaire design was utilised. Participants were recruited from the HeadStrong centres in Chester and Southend.

Demographic details

- N = 16 women treated for breast cancer
- Mean age = 52.9 yrs (SD= 7.29; range 41- 64yrs)
- Mean time since diagnosis 2.3yrs
- 10 participants completed the 2 week follow-up HeadStrong questionnaire (38% dropout rate)
- 9 participants completed the 3 month follow-up questionnaire (44% dropout rate from baseline, 10% dropout rate from post)

Reasons for attending HeadStrong

- Seeking advice for scalp care (9)
- To prepare for hair loss (7)
- To learn how to use scarves (7)
- To find out about where to purchase head scarves (5)
- To increase confidence (4)
- To meet others in the same situation (2)
- Seeking psychological support (2)

Using Visual Analogue Scales (VAS), this study found that, after attending a HeadStrong session, respondents reported:

- A significant increase in confidence in managing the consequences of hair loss
- A significant increase in confidence in managing other people's reactions to their hair loss
- Significantly increased confidence in using headwear to camouflage hair loss

Using standardised measures of value placed on appearance, self-esteem, fear of negative evaluation, quality of life, appearance-related distress, anxiety and depression, this study found that, after attending a HeadStrong session, respondents reported:

- A significant decrease in quality of life scores following from 2 week to 3 month follow-up
- A significant decrease in fear of negative evaluation from pre-intervention to 3 month follow-up
- No significant differences were found for measures of value placed on appearance, self-esteem, appearance-related distress, anxiety or depression

Conclusions

- Participants described a number of challenges regarding their hair loss, which had led them to attend the HeadStrong service
- Participants said they would recommend HeadStrong to others
- Participants not always clear what HeadStrong involves
- Quantitative date shows improvements in confidence and fear of negative evaluation
- HeadStrong was found to be a helpful, however, it did not meet all participants needs, therefore suggesting additional interventions and sources of emotional support are required

Limitations

- Small sample size for quantitative study
- Drop-out rates
- Recruitment for quantitative study from 2 HeadStrong centres only
- Findings can't be generalised for all breast cancer patients who attend a HeadStrong session

Recommendations for HeadStrong in the future

- Beneficial to build into the service an ongoing larger scale evaluation of HeadStrong