Exploring the subjectivities of people with alopecia areata: A critical qualitative study to inform applied psychology practice

Louise Davey

February 2020

A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Professional Doctorate in Counselling Psychology

Word Count

38,372

Abstract

Alopecia areata (AA) is an unpredictable appearance-changing hair loss condition that biomedicine is currently powerless to cure. The physical symptoms are not painful or life-threatening but people living with AA report high levels of distress and appear to struggle to develop effective coping strategies (Hunt & McHale, 2004). Little qualitative research exists to provide insight into what it is like to live with AA or what support may help to ameliorate the distress associated with it. This study contributes to the predominantly mainstream visible difference literature by exploring experiences of living with AA from a critical perspective. A poststructuralist feminist approach was used that attends to discourse, embodiment and agency in the constitution of subjectivity in order to explore meanings, distress and resistance in the accounts of women and men living with this condition. Data were collected via an online qualitative survey and face-to-face interviews. They were analysed using reflexive thematic analysis (Braun & Clarke, 2006; 2013; 2019).

Three themes were identified 1) Transgressing appearance norms: Restricted and shameful subjectivities 2) Submitting and resisting: Performances and performativity in the management of hair loss, and 3) Changing subjects? Acceptance, relationships and growth. Together, these capture the discursive constitution of subjectivity, the oppressive subjective power of normative discourses, and the processes through which agency is performed and change becomes possible. Consideration was given throughout the research process to the relevance of this study to applied psychology practice. This shaped the development of the data collection, analysis, discussion and conclusions which emphasise the power of relational encounters to both reinforce distressing meanings, and provide validating recognition that can create new subjective possibilities. The congruence between critical qualitative research and the discipline of counselling psychology is explored and the case is put for greater emphasis on this in the identity of the profession.

Acknowledgements

To all the loving, inspiring and supportive people in my life, you made this possible in so many ways. Thank you.

Special thanks to all the people who shared their experiences for this study and to Alopecia UK for promoting it. I hope that together we have produced some knowledge that can help to improve care for people with alopecia areata, totalis and universalis. To the person who inspired this research, please know that I am in awe of your courage.

Victoria and Liz, thank you for your guidance, insights and encouragement throughout the long process of bringing this research to fruition. Also, to the counselling psychology team at UWE, and to all my clinical supervisors. You challenged and stretched me into the dialogue that I understand to make me a counselling psychologist – I will always be grateful for these new subjective possibilities.

My enormous (extended) family – yes every one of you – thank you for all the relating, the story-telling and the setting the world to rights. How could I not be this curious about people and the world. Mum and Dad, thank you for love, and for showing me the value of each and every life.

And finally, my dear husband and my precious children, thank you for all the joy and meaning you give my life, and for putting up with the “T” word for so long – it’s done now.

Contents

Appendices

Introduction

A critical qualitative approach to applied research on visible difference

In the 24-hour media world of contemporary western societies we are continuously bombarded with visual messages about how we should look and the products and services we need to buy in order to become our idealised selves (Craddock, Ramsey, Spotswood, Halliwell & Diedrichs, 2019; Dittmar, 2007; Grogan, 2016). Unsurprisingly, levels of preoccupation with appearance are high, as are levels of dissatisfaction with our "imperfect" faces and bodies (Rumsey & Harcourt, 2012). For people with a visible difference, the social value placed on normative appearance and physical beauty can present complex psychological challenges, yet individuals appear to vary in the degree to which their identity and emotional wellbeing are influenced, regardless of the nature or extent of difference (Clarke, Thompson, Jenkinson, Rumsey & Newell, 2014; Rumsey & Harcourt, 2012). Such variation in the psychological impact of non-normative bodily appearance raises questions relating to the discursive constitution of subjectivity and the possibilities for subjective resistance to the distressing effects of dominant appearance-related discourses (see Appendix A for a glossary of terms). This study aims to contribute to the predominantly mainstream literature on visible difference by using a critical perspective to explore the subjectivities of people living with alopecia areata, an unpredictable appearance changing hair loss condition for which there is no effective medical treatment.

Appearance and embodiment have been prominent themes in critical and feminist theory (e.g. Bordo, 2003; Grosz, 1994; Jagger and Bordo, 1989; Ussher, 1997), yet there is little research that undertakes the challenge of translating this approach and the insights it offers into applied psychological practice. Counselling psychology positions itself as an applied discipline with a "critical edge" (Strawbridge & Woolfe, 2010, p.3), but has been challenged for failing to develop this into a meaningful professional identity due to the limitations created by an emphasis on its humanistic roots (Moller, 2011). Social constructionist and poststructuralist approaches operate at the critical edge of contemporary thought by exploring dynamics of power and deconstructing dominant ways of understanding people and the world (e.g. Burr, 2015; Gergen, 2015; Henriques, Hollway, Urwin, Venn, & Walkerdine, 1984). A tendency to become overly abstract (Bordo, 2003) has led to claims that this kind of theorising is of little value to the understanding of “human pain, suffering and misery” (Turner, 2012, p.10). However, as a practitioner working in the emotionally and ethically fraught field of post sexual violence support, I have found poststructuralist and feminist ideas and research (e.g. Foucault, 1975; 1976; Gavey, 2005; Hollway, 1984; Shah-Beckley, 2017) to be essential tools in helping me to understand the particular meanings that operate to produce distress in each of my clients. In turn, I believe this understanding supports my capacity to offer a therapeutic relationship that can scaffold access to less shameful and dislocated subjectivities. Critical psychology research has demonstrated that appearance related distress is also discursively produced (e.g. Malson & Burns, 2009; Tischner, 2013), suggesting that a poststructuralist analysis may generate knowledge that can helpfully inform the practice of health care professionals, including psychological therapists, working with people who have an appearance-altering condition.

A focus on distress and resistance in relation to socially dominant meanings of bodies, calls for a strand of poststructuralist theory that both recognises the subject as embodied, and allows for exploration of agency alongside power and subjection (Blackman, Cromby, Hook, Papdopoulos & Walkerdine, 2008; Hanna, 2013; Willig, 2000). The feminist philosopher Judith Butler has extensively explored the relationship between power, agency and the body in the constitution of subjectivities, drawing upon Foucauldian and psychoanalytic theory in order to do so (e.g. Butler, 1990; 1993; 1997). Complex, continually evolving and not entirely successful in its attempts to integrate Foucauldian and psychoanalytic concepts (Campbell, 2001; McNay, 1999), Butler’s work embraces the challenges and value of remaining open to diverse theoretical positions. It has been argued that such willingness to engage with potentially contradictory perspectives should be “carefully nurtured” by counselling psychologists, not least for the resistance it offers to reductionist, more easily evidenced, and thus dominant, models of psychological practice (Draghi-Lorenz, 2010).

This study is, therefore, particularly informed by Butler’s ideas, but also draws upon the broader social constructionist, poststructuralist and feminist literature (e.g. Bordo, 2003; Burman, 1998; Foucault, 1975; 1976; Gergen, 2015; Parker & Shotter, 2015; Weedon, 1987). This includes thinking around how to acknowledge the ways in which social science analyses are located within the researcher’s own subjectivities as well as those of study participants

(Ellis, Adams & Bochner, 2011; Gough & Madill, 2012). I therefore use a poststructuralist feminist approach in which I deploy my perspective as a counselling psychology practitioner to explore distress and resistance in the subjectivities of people living with alopecia areata. The critical lens that I bring to the topic is also shaped by my personal relationship with someone who lives with alopecia areata and whose distress I have seen, heard and been affected by. Through this theoretically framed, critical and reflexive analysis of the data, I hope to identify sources and processes of coping and agency that can be translated into recommendations for clinical practice by psychological and other health care professionals.

In this introductory chapter I will outline the biomedical understanding of alopecia areata before critically appraising the limited research literatures on experiences of living with the condition, and the use of psychological interventions to ameliorate the distress associated with it. The meaning of hair loss will then be theorised with reference to cultural and symbolic associations, and studies that demonstrate how these meanings operate in people's lives and identities. The case will be put for the value of exploring alopecia areata through a feminist poststructuralist lens and the study will be located within the broad feminist and poststructuralist literatures. Particular emphasis will be placed on the potential of this approach to generate understanding of embodied, socially produced distress, subjective possibilities for resistance and agency, and the wider relevance of poststructuralist and critical thinking to counselling psychology practice.

Alopecia areata (AA): A biomedical definition

Alopecia is the medical term for baldness or "the partial or complete absence of hair from areas of the body where it normally grows" (Oxford English Dictionaries online). Alopecia areata is a condition in which patchy hair loss occurs on the head, face or body; it is relatively common, with lifetime risk estimated at 1.7%-2.1% (Mirzoyev, Schrum, Davis & Torgeson, 2014; Safavi, Muller, Suman, Moshell & Melton, 1995). Its trajectory is unpredictable; some people experience complete, permanent hair regrowth, others, periods of remission interspersed with further episodes of hair loss (Strazzulla et al., 2018). Between 7% and 30% of people diagnosed with alopecia areata subsequently lose all scalp hair (alopecia totalis) or all head, face and body hair (alopecia universalis) (Muller & Winkelman, 1963; Safavi et al., 1995). From a biomedical perspective the only difference between the three presentations is extent and location of hair loss (Islam, Leung, Huntley & Gershwin, 2015). Although the condition can cause physical discomfort such as dry eyes or increased vulnerability to extremes of heat and cold, it is not painful or life-threatening and hair follicles remain intact meaning that remission is possible and, in the case of alopecia areata, likely (Alfani et al., 2012; Messenger, McKillop, Farrant, MacDonagh & Sladden (2012). However, studies have found that it is accompanied by psychosocial difficulties and psychological distress (Rencz et al., 2016; Tucker, 2009), the levels of which do not appear to be correlated with extent of hair loss (Hunt & McHale, 2004). The term alopecia areata, abbreviated to AA, will therefore be used throughout this report to refer to all three presentations.

Current biomedicine understands AA to be a chronic inflammatory disease (Islam et al., 2015; Messenger et al., 2012), in which the immune system's ability to discriminate between self and non-self becomes defective, leading it to attack the hair follicles in the skin (Lleo, Invernizzi, Gao, Podda & Gershwin, 2010). Diagnosis and treatment of AA therefore lie within the medical field of dermatology. In common with other dermatological conditions, genetic and environmental factors, including trauma and stress, are thought to be triggers for AA (Simakou, Butcher, Reid, Fiona & Henriquez, 2019), but ultimately, causation "remains an enigma" (Islam et al., 2015, p.81). Effective treatment is also lacking; a Cochrane Review found no evidence that any available pharmacological interventions offer long-term benefits, and documented side-effects from treatments range from itching to cancer risk (Delamere, Sladden, Dobbins & Leonardi-Bee, 2008). Consequently, the British Association of Dermatologists (BAD) concluded in their Guidelines for the Management of Alopecia Areata that "not treating is the best option in many cases" (Messenger et al., 2012, p.922). Alongside this, they recognised that AA can cause "considerable psychological and social disability" and suggested that psychological intervention may be appropriate. This was welcomed by the charity Changing Faces, which provides training for health professionals and support for people living with visible difference. However, concern has been expressed at lack of implementation (Changing Faces, 2014).

The most recent National Institute for Health and Care Excellence (NICE) Clinical Knowledge Summary (CKS) for AA suggests that treatment should generally be within general practice and that "advice should be given" on "the provision of psychological support if needed and appropriate" (NICE.org, 2018). This recommendation is vague, positioned after recommendations relating to pharmacological treatments and camouflage tools, and fails to highlight the psychological impact of the condition. Furthermore, it lacks guidance on how to identify distress, what forms of support may be helpful, or how they should be delivered. This failure to acknowledge and provide support for the psychological impact of AA is found in relation to dermatological conditions more generally; despite evidence that specialist multi-disciplinary psychodermatology services are in demand, improve patient outcomes and deliver a cost benefit to the NHS, few such clinics exist (Aguilar-Duran, Ahmed, Taylor & Bewley, 2014; Bewley, Affleck, Bundy, Higgins & McBride, 2013; Shah, 2018). Consequently, assessments for AA and its treatment are undertaken by general practitioners (GPs) or dermatologists alone and are likely to focus on extent and visibility of the condition rather than subjective meaning of hair loss. This can result in differences between clinician and patient understandings of severity and a failure to recognise and offer support for psychological distress (Endo, Miyachi & Arakawa., 2012; Reid et al., 2012).

Such privileging of a medical understanding of AA over a psychological one reflects the ongoing dominance of biomedical discourses in defining illness, and in determining what constitutes, and should be funded, as "treatment" (Wade & Halligan, 2017). Where potential psychological and psychosocial distress are recognised by doctors treating dermatological conditions, the absence of specialist psychological provision or effective pathways to community talking therapies services can inhibit the accessing of support (Shah, 2018). A need for research to develop specialist interventions and clear referral pathways has also been identified in the provision of psychological support for people experiencing appearance related distress more generally (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014; Guest et al., 2019; Rumsey & Harcourt, 2005; Williamson et al., 2018; Williamson & Rumsey, 2017). Qualitative and critical studies such as the one presented in this thesis have an important contribution to make in such service development by providing detailed analysis of the experiences of people with appearance related distress. This can inform development of a theoretical framework for understanding such distress and indicate what health care changes and therapeutic interventions might ameliorate it.

Thinking holistically or pathologizing distress? Psychiatric and psychological perspectives on AA

The relationship between skin conditions and psychological distress is understood to be complex. Alongside recognition that visible difference and appearance change can affect psychological wellbeing, it has been hypothesised that stress and trauma may operate as triggering and exacerbating factors in the trajectory of dermatological conditions including psoriasis (Moon, Mizara & McBride, 2013), eczema (Ehlers, Stangier & Gieler, 1995) and AA (Garcia-Hernandez, Ruiz-Doblado, Rodriguez-Pichardo & Camacho, 1999; Muller & Winkelmann, 1963). Studies have found high levels of levels of post-traumatic stress symptoms in dermatology patients (Gupta, Jarosz & Gupta, 2017), and a skin-brain axis has been suggested in which neurobiological responses to traumatic experiences are thought to produce immunosuppressant effects that lead to skin inflammation (Moon et al., 2013). Within this framework, a multi-factorial model has been proposed for the aetiology of AA in which genetic and environmental variables interact to produce an autoimmune response (Randall, 2001). Elsewhere, it has been suggested that the negative psychological impact of living with AA may affect the course of the condition via psycho-neuro-immunological pathways which produce a vicious cycle of psychological distress and further hair loss (Fabbrocini et al., 2013).

This perspective and studies that support it indicate a need to provide holistic treatment for AA through multi-disciplinary teams with specialist psychological intervention available to all patients. Furthermore, although the evidence around the role of trauma and stress in the causation and trajectory of AA remains inconclusive (Wang & McElwee, 2011), qualitative research has found that people often refer to stressful events when talking about first onset (Hunt & McHale, 2004; Matzer, Egger & Kopera, 2011). This suggests that the idea of stress or trauma as a trigger for AA not only forms one theoretical framework for investigating the condition, but also contributes to people's sense-making in living with an unpredictable disease of unclear aetiology. Health care practitioners should be mindful of this when providing diagnosis and treatment, regardless of their own professional position on the stress/trauma theoretical perspective.

Despite calls for improved access to psychodermatology services (Bewley et al., 2012; Bewley, Affleck, Bundy, Higgins & McBride, 2013) and increased policy recognition of the social, economic and mental health benefits delivered by integrated psychological support for people with long term physical health conditions (NHS England, 2016), few dermatology clinics offer this approach. Furthermore, the sub-discipline of psychodermatology is strongly influenced by a psychiatric perspective (see psychodermatology.co.uk), reflecting the ongoing dominance of biomedical models, even where attention is paid to mental wellbeing alongside physical health (Wade & Halligan, 2017). This is evident in a strand of research that has attempted to establish a relationship between specific psychiatric diagnoses or personality traits and AA. Such studies have described high levels of co-morbidity between AA and a range of psychiatric diagnoses including depression, anxiety disorder, social phobia and paranoid disorder (Koo, Shellow, Hallman & Edwards,1994; Okhovat et al., 2019). Elsewhere, constructs such as avoidant attachment style and alexithymia (Matzer et al., 2011) have been correlated with diagnosis of AA, leading to suggestions that susceptibility is related to personality characteristics (Garcia-Hernandez et al., 1999; Picardi et al., 2003; Willemsen, Vanderlinden, Roseeuw, & Haentjens, 2009). However, other studies have failed to find a correlation with alexithymia (Sellami et al., 2014) and debate continues among researchers working from this perspective as to whether AA should be understood as a dermatological condition with psychiatric comorbidities, or a psychiatric disorder that has dermatologic effects (Ghanizadeh & Ayoobzadehshirazi, 2014).

Elsewhere, research has focused on the subjective psychological impact of AA and the implications of this for treatment. A review of 19 studies with 1271 male and female participants found that AA is associated with low self-esteem, poor quality of life, poor body image, and high levels of anxiety and depression (Tucker, 2009). Studies, in the UK, and internationally, have attempted to measure and quantify the impact of AA on individual patients using general dermatology and AA specific Health Related Quality of Life (HRQOL) assessment tools (Cartwright, Endean & Porter, 2009; Rencz et al., 2016). A systematic review and meta-analysis of HRQOL studies among people diagnosed with AA found significantly reduced quality of life for these patients, particularly in relation to mental health (Rencz et. al., 2016). The few existing qualitative and mixed-methods studies on AA support these findings (Hunt &McHale, 2004; 2005; Matzer et al., 2011; Rafique & Hunt, 2015; Welsh & Guy, 2009; Wiggins, Moore-Miller & Thomson, 2014). They additionally provide insight into lived experience of the condition (Willig,1999) and authors have highlighted feelings of ugliness, shame, loneliness and the sense that nobody understands what it is like to lose hair (Hunt & McHale, 2005; Rafique & Hunt, 2015; Welsh & Guy, 2009). This sense of alienation can affect relationships with friends, family and intimate partners, and even extend to feelings of no longer being oneself (Hunt & McHale, 2004; 2005; Rafique & Hunt, 2015). Existing research therefore indicates a need for psychologically informed care for people with AA, whether this is provided in primary care settings or in dermatology departments.

The development of psychologically informed care calls for further qualitative research to provide practitioners, including GPs, dermatologists and psychological therapists, with insight what it is like to live with AA, particularly its effect on identity (Hunt & McHale, 2005), and what can help to ameliorate subjective distress. Existing studies indicate that people often struggle to develop effective coping strategies (Hunt & McHale, 2004; 2005; Matzer et al., 2011), although strong social support and the passage of time may lead to acceptance and renewed optimism (Hunt & McHale, 2005; Welsh & Guy, 2009). High levels of distress have been reported by both men and women with AA, but studies have identified gender differences in its impact. For example, it has been suggested that women may find it harder than men to develop coping strategies, and this has been attributed to differences in the social value placed on appearance for men and women (Hunt & McHale, 2009; Matzer et al.,2011; Rafique & Hunt, 2015; Welsh & Guy, 2009). However, these studies all appear to be underpinned by a realist epistemology, and comments about gender and appearance seem to be offered as common-sense interpretations, rather than empirically or theoretically grounded analysis of the role of cultural context in generating meaning or experience (Braun & Clarke, 2013).

Given that AA is not painful or life-threatening but is accompanied by high levels of distress, an understanding of its subjective impact requires research that explores the social construction (see Appendix A) of meaning and experience (Willig, 2000). There currently appears to be only one such study relating to living with AA (Wiggins et al., 2014). This used discursive psychology to analyse accounts of wig use among people with alopecia; it identified a complicated relationship between desire to hide hair loss in order to appear normal, and concern that the wig should both look like hair and not be noticeable as a wig. The authors concluded that medical professionals need to be aware of the complex and burdensome work involved in managing social interaction in relation to wig use in order to provide informed guidance and support around their use as a coping strategy for people with AA (Wiggins et al., 2014). A critical approach can therefore generate important insights for the development of psychologically informed care for people with AA.

Psychological support for people with AA

Although both BAD and NICE indicate that psychological support should be considered for people with AA, few studies have explored what can help people with this form of hair loss, or whether psychological and psychosocial interventions may be useful. This reflects the limited research into the benefits of psychological interventions for appearance related distress more generally (Bessell & Moss, 2007; Jenkinson, Williamson, Byron-Daniel & Moss, 2015), including distress resulting from dermatological conditions (Lavda, Webb & Thompson, 2012). The lack of research in this field may be partly due to methodological challenges such as the diffuse geographical spread of relatively small numbers of people with any given condition, and variability in the extent to which psychological treatment is offered or accessed (Persson, 2012). Two systematic reviews to evaluate the evidence for the effectiveness of interventions for adults (Bessell & Moss, 2007) and children (Jenkinson et al., 2015) with visible difference found a limited number of studies and an inconclusive evidence base. However, the authors of both reviews concluded that there was promising support for the effectiveness of cognitive behavioural therapy (CBT) and social skills training (SIST) for people with visible differences. A CBT based psychosocial approach for appearance anxiety has therefore been developed as part of a stepped care model (Clarke et al., 2014), which advocates multiple access points to meet varying needs in a resource limited NHS (Lovell & Richards, 2000). However, there are challenges in ensuring that primary care practitioners access the knowledge and training necessary for this to work effectively (Bower & Gilbody, 2005; Charlton, Rumsey, Partridge, Barlow, & Saul, 2003). Additionally, access to specialist level 3 and 4 interventions such as face to face CBT appears to be limited, with most specialist clinics located in urban centres (Bessell & Moss, 2007).

A stepped care approach has also been proposed for the development of psychodermatology services, although guidance is currently limited to minimum standards and detailed, evidence-based recommendations are yet to be produced (Atkar et.al., 2012). For AA, based on currently available services, a stepped care approach could include access to Level 1 and 2 interventions through specialist charities such as Changing Faces and Alopecia UK (AUK). Changing Faces offers a helpline, online resources and face to face support for people with a visible difference, and AUK provides information, online forums and access to local support groups. Level 3 and 4 interventions such as face to face CBT and other forms of psychotherapy are likely to be harder to access, particularly given the lack of specialist psychodermatology clinics or psychological services for people with a visible difference more generally (Bessell & Moss, 2007; Bewley et al., 2013). Moreover, the development of such provision requires better understanding around the lived experience of AA and the value of different psychological therapies in people's accounts of living with the condition.

The few studies that have looked at psychological and psychosocial interventions specifically for people with AA suggest that a variety of approaches may offer benefits. Two papers report on a study into the impact of hypnosis on the evolution of anxiety, depression and health related quality of life (HRQOL) in people with the condition. Participants were 21 patients who were being treated for hair loss in a dermatology department in Belgium (Willemsen, Haentjens, Roseeuw & Vanderlinden., 2010; 2011). The study found positive effects after treatment and at 6-month follow-up. A pilot study into the use of a Mindfulness Based Stress Reduction course also yielded positive results (Gallo et al., 2017), and recently the therapeutic value of group interaction for children with AA and their families has been demonstrated (Aschenbeck, McFarland, Hordinsky, Lindgren, & Farah, 2017). Dermatology nurses have also highlighted the benefits of patient support groups for people with AA (Prickitt, McMichael, Gallagher, Kalabokes, & Boeck, 2004). Offering a different perspective, a clinical paper presented the outcomes of psychodynamically orientated therapy for patients with dermatological conditions; this included the case of a 6-year old girl with AA who experienced both hair regrowth and resolution of emotional and behavioural difficulties during therapy (Koblenzer, 1995).

These diverse studies indicate that psychological and psychosocial interventions may be beneficial for people with AA. However, given how few they are in number, and the variety of methodologies used, there is clearly a need for more high quality research to investigate the potential of psychosocial and psychotherapeutic support for people with AA. In addition to studies investigating outcomes from specific forms of intervention, there is a need to research how therapy is seen by people with AA, to explore what it is about this condition that produces distress and to identify what processes might be involved in finding alternative ways of living with it. The need for such an evidence base to inform development of referral pathways and therapeutic practices was highlighted by a recent Priority Setting Partnership of people with AA, their relatives and health care professionals which. This ranked the question “Are psychological interventions helpful in alopecia areata?” fourth out of ten research priorities (Macbeth et al., 2017).

Theorising hair loss

Although hair loss is not physically painful or life-threatening, people with AA often undergo pharmacological treatments to stimulate regrowth despite poor efficacy and potentially serious side-effects (Delamere et al., 2008). Wigs, semi-permanent make-up and other camouflage products are used by many with AA to manage the visibility of hair loss alongside, or instead of, pharmacological interventions, but can themselves challenge sense of identity and impact negatively on daily life and social interactions (Montgomery, White & Thompson, 2017; Wiggins et al., 2014). Additionally, these forms of appearance management can involve significant financial cost to the individual since they are understood by the NHS to be cosmetic and are therefore rarely funded (Johnson & Montgomery, 2017). Acrylic wigs cost between £72.80 and £282 but “can be itchy and hot” and only last for about 9 months (www.nhs.uk). Human hair wigs may last up to 4 years and tend to be more comfortable but cost up to £3,000 (Alopecia UK). Micro-bladed eyebrows cost around £300-£500 and need retouching every 1-3 years to maintain an authentic hair appearance. More broadly, the annual global market for hair loss treatments is worth an estimated $4 billion and the total hair product market is worth over $43 billion (MarketWatch.com). Such availability of products, and people’s willingness to spend their money on them, suggest that hair and hair loss carry significant social and cultural meanings which generate an imperative to engage in practices to ensure hair is groomed, present or absent at specific, culturally mandated, bodily sites. An understanding of the experiences of people with AA, the distress they report and how best to offer care to them, calls for exploration of these social and cultural meanings.

The need to recognise cultural influences on experiences of appearance related distress was highlighted by the Appearance Research Collaboration (ARC) which developed a biopsychosociocultural framework to guide the study of appearance and visible difference (Clarke et al., 2014; Rumsey & Harcourt, 2005; Thompson, 2012). This involves a pluralistic approach to appearance research that expands the evidence base to include social and cultural influences on body image, distress, adjustment and coping, both in people who have a visible difference and those who do not (Thompson, 2012). The biopsychosocial perspective (Engel, 1977) is familiar to medical and psychological practitioners, albeit that biomedical discourses remain dominant in current understandings of injury and disease, and are privileged over psychosocial factors in determining what treatments are funded or offered (Wade & Halligan, 2017). The incorporation of culture into this framework therefore usefully focuses researcher and practitioner attention on the significance of cultural context in producing peoples' experiences of living with appearance altering conditions such as AA. However, this theoretical model retains the multi-factorial perspective of mainstream psychological approaches so that biological, social, psychological and cultural factors become fixed as separate, if intersecting, objects of analysis. Although this can generate valuable knowledge that is readily communicable to health practitioners and policy makers, the rich complexities of human subjectivity are lost (Henriques et al., 1984). Insight into the subjective challenges and sources of resistance bound up with the meanings of hair and hair loss calls for a critical approach that understands subjectivity as embodied and dynamically constituted within fluid sociocultural processes that cannot be reduced to separate measurable parts (Blackman et al., 2008; Nightingale & Cromby, 1999; Willig, 1999; 2000).

Poststructuralist analyses explore the construction of meaning in terms of power dynamics by attending to the role of both language, and material and social structures in constituting the discourses that produce our lived worlds (Burman, 1998; Henriques et al., 1984; Parker & Shotter, 2015; Weedon, 1987). Such Foucauldian-informed perspectives contrast with more micro social constructionist approaches to discourse and meaning where analysis is focused on the deployment of specific linguistic devices in social interaction (Burr, 2015; Willig, 2000). Given the materiality of hair, the role of economic and systemic factors in the production of distress associated with AA, and the ongoing dominance of biomedicine in health care, this study calls for a Foucauldian approach to discourse. However, while this conceptual position can usefully identify social, economic and other material forces in the constitution of subjectivities, it risks reducing people to texts, “signifiers without context” (Bordo, 2003, p.294). In a culture that promotes endless appearance possibilities (for a price), an appearance-changing condition that defies biomedical management cannot be understood without recognition that the physical body operates as more than a text (Bordo, 2003; Braun, 2000; Gillies et al., 2004; Ussher, 1997). AA challenges people who live with it because it is defined by unpredictable, uncontrollable, appearance changing biochemical processes. An exploration of subjectivities in people living with it must therefore also account for the embodied dimension of existence (Blackman et al., 2008; Willig, 2000; 2016).

The body and embodiment in the constitution of subjectivity have been a focus of much feminist and critical research (e.g. Bordo, 2003; Malson & Burns, 2009; Ussher, 1997). The feminist postmodern discourse that encourages us to “imagine the possibilities” (Bordo, 2003, p.39) in how we conceive of, and experience our bodies, closing our eyes to limits and consequences, can be particularly salient for people living with an appearance altering condition. However, quite aside from limitations relating to financial resources, and therefore access to cosmetic and biomedical technologies, possibilities are limited by the uncontrollable and unpredictable course of a “disease” such as AA. An understanding of subjectivity in this study therefore calls for attention to the material body within and alongside discourse (Willig, 2000; 2016). The varied, at times contradictory, theories that have come to be located within the term poststructuralist feminism share a focus on subjectivity, the role of gendered discourse in its constitution, the operation of power relations, and an agenda around identifying possibilities for agency and change (Burman, 1998; Weedon, 1987). This concern with power and subjectivity, although provoked by the cultural and material subjugation that has been the experience of women (Burman, 1998; Weedon, 1987), means that a feminist poststructuralist approach allows for exploration of distress and resistance in all people, not only those categorised as female.

The power of hair: Symbolic and discursive meanings

Visual and written texts across cultures and epochs are littered with examples of hair operating as a signifier of meaning (Sherrow, 2006; Toerien & Wilkinson, 2003). From the biblical Samson's disempowering hair shearing to elaborate hairstyles on wealthy Japanese "beauties" in Edo era prints and the quirky red-headed Weasleys in the Harry Potter stories, the presence, absence, texture, colour, quantity, length and styling of hair operate as symbolic communicators of gendered, racial and classed meanings. Sociological, psychoanalytic and anthropological studies have variously described cultural, unconscious (see Appendix A) and religious symbolic meanings of hair (e.g. Hallpike, 1969; Leach, 1958; Obeyesekere, 1981; Synnott, 1987; Weitz, 2004), demonstrating the communicative power of this growing, shedding and malleable bodily fibre (Stenn, 2016). Judith Butler describes the body as a "variable boundary" (1990, p.189) through which gender and other subjectivities are reiteratively performed in practices of submission and resistance (Butler, 1990; 1993). Studies have demonstrated how head, body and facial hair are groomed and removed by women and men in gendered acts that both reflect accepted social norms and contribute to the production of new discourses (e.g. Barber, 2008; Basow, 1991; Clarke & Braun, 2019; Fahs, 2011; Frank, 2014; Terry & Braun, 2016). Hair can therefore be understood as one of the "surfaces" on which gendered meanings are performed and become changed through re-articulations across time and cultural context.

Critical research has shown how body hair grooming and removal practices can be understood in terms of gender role and identity negotiation (e.g. Braun, Tricklebank & Clarke, 2013; Clarke & Braun, 2019; Fahs, 2011; 2013; 2014). Body hairlessness has become established as a Western feminine norm, exercising regulatory power that constructs women with body hair as less social, intelligent, happy and positive (Basow, 1991; Basow & Braman, 1998; Tiggeman & Hodgeson, 2008). A study in which female students grew leg and underarm hair for 10 weeks found that they experienced hostile, heterosexist and homophobic assumptions both socially, and in their own personal response to their hairy bodies (Fahs, 2011). Additional analysis suggested that these gendered meanings were especially punishing when they intersected with marginalised class and race identities (Fahs & Delgado, 2011). A parallel study where male participants were asked to remove body hair and record their responses found that men experienced hair removal as emasculating (Fahs, 2013). However, elsewhere there are indications that hair management norms for men may be in a transitional period, with body hair removal increasingly common in practice and in media representations of desirable masculinity (Braun et al., 2013; Frank, 2014; Terry & Braun, 2016).

The literature examining discourses and practices around head hair appears to be more limited than that investigating body hair meanings. A study that analysed interviews with people about their hair found that men feared balding, whereas women feared uncontrollable hair growth anywhere other than the scalp (Lewis, 1987). It has also been suggested that bald men are considered less attractive (Cash, 1990) and that an absence of head hair on women is perceived as “repulsive” (Lewis 1987). As with body hair, meanings associated with head hair may change over time; an exploration of men’s use of salon hair care found that professional men reconstructed this traditionally feminine “beauty work” in terms of a white, heterosexual professional masculinity - the “progressive man” (Barber, 2008).

The culturally located nature of hair related meanings is further highlighted by the existence of a greater body of research into the meanings of head hair for two specific groups - Black Women (Randle, 2015; Robinson-Moore, 2008; Robinson, 2011) and people with chemotherapy-induced alopecia (Harcourt & Frith, 2008; Trusson & Pilnick, 2017). For Black Women, studies have shown that intersecting race and gender discourses produce pressure to conform to Eurocentric beauty paradigms, whereby straight hair is valued as “good hair” and kinky hair is judged as “bad hair” (Robinson-Moore, 2008; Robinson, 2011). This generates pressure to engage in hair management practices involving use of potentially harmful chemicals (Randle, 2015). Research has also found that Black Women feel compelled to strive for a straight hair “western (White) beauty standard” in order to be seen as heterosexual, attractive to men, employable and professional (Randle, 2015; Robinson, 2011; Thompson, 2009).

For people with chemotherapy-induced alopecia the meanings of hair are particularly salient due to the operation of hair loss as a visual and public signifier of a cancer identity (Harcourt & Frith, 2008; Hilton, Hunt, Emslie, Salinas & Ziebland, 2008; Trusson & Pilnick, 2017). For female patients, the consequent challenges to their sense of self extend to gendered identity due to the role of hair as a signifier of femininity (Harcourt & Frith, 2008). This gendered signification may be further complicated by cultural associations between baldness and madness in women (Trusson & Pilnick, 2017) as exemplified by media speculation around the mental health of celebrity women who appear with bald heads (Guardian, 2007). Hair loss has consequently been described as the most distressing part of cancer treatment for women (Frith, Harcourt & Fussell, 2007). The experience of hair loss for chemotherapy patients does therefore seem to be shaped by gendered meanings. However, a study that specifically compared the experiences of young male and female patients found that both reported similarly negative feelings about their alopecia, although a notable difference in the accounts was that men mentioned concerns about body hair loss and women did not (Hilton et al., 2008).

The literature therefore suggests that presence of head and body hair may symbolise masculine virility for men (Synnott,1987), while presence of body hair and absence of head hair are both perceived as unfeminine for women (Lewis, 1987). Additionally, absence of hair operates as a signifier of illness in men and women, while texture and colour of head hair operate to reflect and shape classed and raced femininities. Given these meanings and the constant gaze of traditional and social media, operating to discipline us with messages about how we should look in order to have personal value (Dittmar, 2007), it is unsurprising that people with AA experience distress and struggle to find ways to cope. Capitalism and its socio-economic, cultural and biomedical discourses operate to produce subjectivities in which hair loss results in acts of concealment or social withdrawal, producing a docile, self-punishing body (Foucault, 1975). Yet acts of resistance can also be observed as in the case of former model, actress and television presenter Gail Porter who developed AA in 2005; she frequently appears on television “defiantly wigless”' (Guardian Newspaper, 2008) and has used the media to speak about both her hair loss and her mental health difficulties (Enable.org, 2018), thereby claiming agency within the disciplining discourses of hair loss and madness.

Poststructuralism and counselling psychology practice

Counselling psychology positions itself as a discipline in which reflective-scientist-practitioners (BPS, Division of Counselling Psychology, 2005), equipped with knowledge, skills and theories produced within diverse epistemological and ontological frameworks, engage in a dialectical process to generate ways of working that help individuals and organisations in all their complexity (McAteer, 2010; Woolfe, 2016). Critical and constructionist approaches, including poststructuralist research, produce forms of knowledge that practitioners can draw upon in their work with clients and organisations (Gergen, 2015; Larsson, Loewenthal & Brooks, 2012; Milton, Craven & Coyle, 2010; McNamee & Gergen, 1992; Parker, 1999; Shah-Beckley, 2017; Willig, 2019). By locating difficulties within the social context in which they arise rather than within the individual, a constructionist perspective depathologises the client, provides insight into the operation of power in the constitution of subjectivity and offers alternative ways of understanding suffering (Milton et al., 2010; Parker, Georgaca, Harper, McLaughlin, Stowell-Smith , 1995). This has produced increasing identification among counselling psychologists with a social justice agenda whereby the inequalities and vulnerabilities that the work reveals, demand action to challenge the causes (Kagan, Tindall & Robinson, 2010; Moller, 2011). However, understanding of the interplay between subject and social context requires that the therapist is equipped to hear and work with the client's meanings rather than imposing their own (Willig, 2019). The teaching of discursive and humanistic approaches alongside each other in training has been found to increase flexibility, tolerance and awareness of difference in therapists, enabling them to take up new positions in relation to taken for granted assumptions (Cornforth, 2010). Critical constructionist research can therefore provide knowledge that helps the therapist enter into the client's "vocabularies of meaning" and then to collaborate with them in accessing alternative constructions in their process of meaning-making (Gergen, 2015, p.176).

Of equal significance, however, is the role of poststructuralism in constituting a framework that allows for the dialectical process in which the therapist can move between forms of knowledge and practice to respond meaningfully to people's difficulties (Parker, 1999). This includes cultivation of the epistemological and ontological reflexivity necessary to hear how a client conceptualises themselves and the world, an understanding that is essential to the formation of an effective therapeutic relationship (Willig, 2019). While it is important to recognise that a constructionist position in the applied field presents a challenge in that it posits a socially constructed subject while seeking to work with an agentic person (Lyddon, 1998), it also involves rejection of the claim that there is a single knowable truth. This approach therefore abandons the modernist belief in grand narratives (Lyotard, 1979) and adopts instead a focus on small-scale theories and accounts (Milton et al., 2010). In so doing, it enables a postmodern epistemology of practice in which it becomes possible to move between contradictory forms of knowledge, thinking flexibly and creatively to select the most helpful theoretical and therapeutic resources to meet each client's need (Polkinghorne,1992). If a truly poststructuralist approach is embraced, then the therapist is empowered to reject a binary either/or position in favour of a both/and one in which the knowledges about suffering, its causes and its alleviation are all available to the practitioner in their therapeutic relationship with each unique client (Milton et al., 2010). A poststructuralist sensibility therefore has the potential to produce insights that can help the therapist enter into dialogue with the client in ways that can scaffold resistance to dominant discourses and the subjective distress these can create (Blackman et al., 2008; Willig, 2000).

Research objectives and questions

This study aimed to investigate how meanings associated with hair and its loss operate in the subjectivities of people with AA, an unpredictable, appearance-altering hair loss condition that biomedicine is currently powerless to cure or control. As a critical study designed to inform applied psychology practice, the objective was to explore the subjectifying power of discourses associated with hair loss, and to identify any ways in which participants demonstrate agency to resist distressing meanings and access alternatives. A key purpose of the study was to generate knowledge that could inform the practice of a range of professionals, including the GPs and dermatologists who diagnose AA, and the nurses, therapists and others offering psychosocial or psychological support. Additionally, it was hoped that a focus on subjectivity and resistance would provide insights relevant to therapists working with subjective distress at relational depth (Clarke, Hahn & Hoggett, 2008; Clarkson, 2003; Kahn, 1997; Loewenthal & Samuels, 2014). This called for attention to be paid to any resources, actions or processes in the accounts that seem to support resistance to oppressive meanings around hair and hair loss and the distress that these can produce.

The questions that drove this study were therefore:

- How do discourses of hair and hair loss operate in the subjectivities of people with AA?
- What possibilities do people with AA find for resisting distressing discourses?
- What resources can help people with AA to cope with the condition?

Methods

Research design overview

The aims and objectives of this study called for methods of data collection and analysis that allowed for: breadth and depth of information; exploration of nuance and complexity, and communicability to health care practitioners operating from diverse perspectives. In order to achieve this, data were collected using an online qualitative survey and a small number of face-to-face, loosely structured interviews. Thematic analysis (TA) was chosen to analyse the data due to its theoretical flexibility (Braun and Clarke, 2006; 2013; Willig, 2013), combined with its relatively unusual position as a qualitative analytic method that is accessible and familiar to practitioners working in diverse fields. These characteristics mean that TA allows for analysis of the same data from a variety of positions on the realist-critical continuum (Braun and Clarke, 2013). This can enable the researcher to find ways to speak across theoretically diverse professional boundaries, while maintaining epistemological and analytical coherence.

To achieve this coherence, the study must be clearly located within a qualitative research paradigm (Terry, Hayfield, Clarke & Braun, 2017) whereby subjectivity, reflexivity and meaning are valued, regardless of the epistemology underlying the analytical technique. This has been called “Big Q” qualitative research (Kidder & Fine, 1987) and contrasts with “small q” studies in which data collected using qualitative methods are analysed within a quantitative, hypothetico-deductive framework (Braun & Clarke, 2013; Willig, 2013). Use of TA therefore allowed me to undertake the in-depth, complex and nuanced feminist poststructuralist analysis that my own subjectivities, shaped by my practice and training as a counselling psychologist, drew me to. However, it was also relatively straightforward for me to generate more readily communicable knowledge from the data. This felt ethically important in order for me to honour the generosity and motivations of participants in sharing their personal experiences. Among the many ethical concerns to navigate in the process of research is the potential for a study to generate beneficial outcomes (Brinkman & Kvale, 2017). For practitioner-researchers I believe this includes production of analyses with potential to influence service provision.

In the case of this research project, the flexibility of TA allowed me to produce a broadly critical realist paper (Davey, Clarke & Jenkinson, 2019; see Appendix B) that has been published in the *British Journal of Dermatology* (BJD) and was therefore considered by the journal editors to be relevant to their medical readership – practitioners with the power to effect change in the experiences of people with AA. These health care professionals were a key target audience for the research and the journal's explicit commitment to publishing more qualitative studies (Anstey & Reynolds, 2015; Nelson, Magin & Thompson, 2017; 2019) indicates that its readership may be increasingly open to Big Q qualitative research as productive of knowledge that is of value to their practice. However, as medical doctors, they might perceive the kind of analysis presented in this thesis to be an example of the abstract theorising for which poststructuralism has been criticised (Bordo, 2003; Cromby & Nightingale, 1999). By presenting a critical realist TA of the data, the paper was able to provide a rich, clinically meaningful account, demonstrating how the experiences of people with AA are shaped by the social and cultural meanings associated with hair loss, and highlighting the psychological distress and social avoidance that these can lead to. It also showed that many people with AA experience health care professionals as dismissive and unhelpful. Since medical professionals form part of the "real world" context in which meanings are negotiated (Willig, 2016), it was important to communicate this finding to a medical audience. Alongside this, it was possible to outline the potential benefits of providing people who have AA with care that is sensitive to the cultural meanings of hair and hair loss, and that includes the offer of psychological and psychosocial support.

The use of multiple methods of data collection and data analysis within the same study has been described as qualitative pluralism (Chamberlain, Cain, Sheridan & Dupuis, 2011; Frost & Nolas, 2011). The case for this approach is based on the principle that our experiences are multi-dimensional and multi-ontological, and therefore cannot be adequately captured by any single method (Frost & Nolas, 2011). The term pluralism has also been used to describe the discipline of counselling psychology due to the requirement for practitioners to be trained in multiple therapeutic orientations, allowing for therapy that is tailored to individual clients (Josselin & Willig, 2015; Rafalin, 2010). I deeply value the therapeutic flexibility that this has cultivated in me as a practitioner and when I attended to the literature on methodological pluralism while writing up this thesis, it felt like a useful way of describing the mindset through which I developed the research.

Over the course of the project, the process of engaging with different sources of information, together with different epistemological and ontological ideas, mirrored and complemented my reflexive and theoretical development as a practitioner. Both frequently felt messy and confusing, and both also called for sustained focus on the purpose of the work through dialectical engagement with potentially contradictory ideas rather than rigid adherence to pre-defined methods (McAteer, 2010; Stainton-Rogers & Willig, 2017). Post-qualitative and new-materialist writing also offer helpful reflections on the purpose, possibilities and challenges presented by embracing a fluid, open approach to research (Feely, 2019; Lather & St Pierre, 2013; Lather, 2016; Rosiek, 2013; St Pierre, 2019). This developing theoretical field provides an important reminder that the focus on language generated by postmodernism's critiques of positivist science can only offer a partial, limited understanding and, indeed, risks perpetuating the very binarism it emerged to challenge. An open, pragmatic methodological approach that embraces ontology as well as epistemology is therefore vital to ensuring that qualitative research continues to generate meaningful insights without falling into the modernist trap to "privilege knowing over being" (Lather & St Pierre, 2013, p.630). In developing this research I have attempted to remain open and connected to the interrelatedness of knowing and being; I have (inevitably perhaps) not fully realised this aspiration, but I have engaged reflexively in the process, challenging myself along the way to tolerate the messy uncertainty that such an approach (also inevitably) generates.

Data Collection – Methods and Participants

Online qualitative surveys

Unusually amongst qualitative methods, online qualitative surveys allow for collection of data from lots of people (Terry & Braun, 2013; Toerien & Wilkinson, 2004) across a geographically dispersed area (Peel, 2009), quickly and cost-effectively (Braun & Clarke, 2013). The textual nature of the data produced means there is no need for transcription, and the online survey software collates the responses. This results in time savings that offset some of the challenges produced by the potentially large volume of data (Braun & Clarke, 2013). They are therefore an ideal tool for investigating under-researched topics (Toerien & Wilkinson, 2004) from within a big Q qualitative paradigm (Kidder & Fine, 1987), particularly when researcher resources are limited (Braun & Clarke, 2013). From a participant perspective, they offer greater flexibility than many qualitative data collection methods in that people can choose when and where they respond (Terry & Braun, 2017). This potentially increases diversity in the sample, allowing for participation by people whose work, caring or other constraints and commitments would otherwise make it difficult for them to share their experiences for qualitative research. Qualitative surveys, both in paper and online form, also offer a high level of felt anonymity. This makes them suitable for researching sensitive topics, as shown by their successful use in studies on issues including: pregnancy loss in gay and bisexual women (Peel, 2009); pubic hair removal (Braun et al., 2013), and experiences of orgasm (Opperman, Braun, Clarke & Rogers, 2014).

Purely qualitative surveys are an under-used and under-theorised research method (Terry & Braun, 2017). Although qualitative questions are often included in quantitative or mixed methods surveys, the data tend to be analysed within a quantitative paradigm (Braun & Clarke, 2013; Terry & Braun, 2017). However, when designed and analysed within a purely qualitative orientation, the method allows for collection of rich, detailed data from within participants' "own sense making frameworks" (Braun & Clarke, 2013; Terry & Braun, 2017, p.19). They can therefore allow for production of knowledge that offers insight into people's subjective worlds and meanings (Braun & Clarke, 2013) and have been successfully used for studies within constructionist (Beale, Malson & Tischner, 2016; Clarke, 2016), critical realist (Jowett & Peel, 2009; Opperman et al, 2014) and realist (Moller, Timms & Alilovic, 2009) epistemological perspectives. The method therefore presented an ideal fit with the objectives of this study, offering a flexible wide-angle lens (Toerien and Wilkinson, 2004) on the sensitive and under-researched topic of what it is like to live with AA.

The survey was designed to encourage participants to write subjective accounts of their experiences of living with AA, including their experiences of help-seeking. This involved drafting open questions, with the most general questions positioned before more specific ones in order to prompt reflections on day-to-day life and identity without pre-empting answers. The number of questions was kept to a minimum to reduce the risk of participant attrition or submission of incomplete surveys. Short questions designed to collect demographic data, were positioned before the main qualitative questions on the basis that this can ease participants into a qualitative survey (Terry & Braun, 2017). I first circulated a pilot survey via my email and social media contacts, which generated 5 responses from 4 women and 1 man with AA. I reviewed these data with my supervisors, and we found that they provided rich, detailed accounts of participants’ experiences of living with AA, including its effects over time, and gendered dimensions of hair loss and identity. However, no participants had been offered counselling or psychological therapy by the doctors responsible for diagnosing and treating their AA, and consequently, there was little data on experiences of therapy. Given that a key research objective was to generate knowledge that could be of relevance to applied psychology practice, questions were added to the survey about interest in, and perceived value of, counselling and psychological therapy. An additional minor change was made to prompt further detail about the gendered aspects of living with AA, due to its prominence as a feature in the pilot data. (See Appendix C for the final version of the main survey questions). The study design aimed for collection of around 100 survey responses, a number considered sufficient to provide breadth of data in a smaller project (Terry & Braun, 2017).

Interviews

Among the limitations of qualitative surveys are their inflexibility and the absence of opportunities for the researcher to probe individual participants’ answers (Frith & Gleeson, 2008; Peel, 2009). To allow for further exploration of key points of interest generated by the survey’s wide-angle lens, the study design therefore included collection of further data through a small number of semi-structured, face-to-face interviews. Semi-structured, responsive interviews each cover the same broad topics, offering some comparability of data, while allowing participants to speak about what is important to them (Rubin & Rubin, 2012). Importantly, they also enable the researcher to probe meanings, complexities and ambiguities in participant responses (Opperman et al., 2014).

In this study, initial analysis of the survey data revealed them to be even richer and more detailed than anticipated, but few participants reported being offered counselling or other psychological interventions. Consequently, the data around experiences of therapy were very limited, despite the amendments made to the survey after it was piloted. However, many participants said they would have liked to have been offered therapy and those who reported positive experiences strongly valued what they had gained. As a practitioner-researcher investigating subjectivity and sources of resistance to distressing discourses, I was interested to know more about how therapy might operate as one such resource and whether accounts of relevant experiences could offer insights into what else might (or might not) be helpful to people with AA. To provide additional depth in a data corpus for a TA study, 6-10 interviews is considered sufficient (Braun & Clarke, 2013). Given the large volume of data collected through the survey, I therefore recruited 6 participants who had accessed some form of counselling or psychological intervention in relation to their AA. I then completed loosely structured, face-to-face, audio-recorded interviews with them. These took place at locations of their choice to help them to feel as comfortable as possible given that they were sharing sensitive experiences.

Before the interviews I developed a guide (Appendix D) to ensure that I covered the same broad topics with each participant and that these included experiences of living with AA generally, and of seeking and receiving information and support in relation to it. However, the guide was used as a loose prompt to allow space and flexibility for participants to describe the aspects of their experience that they deemed important, within a conversational flow that was driven primarily by them rather than me. They had volunteered to participate in the study so I anticipated that they would each have a sense of what they wanted to share. Given that my interest was in subjective experience, I wanted to minimise the impact of my own assumptions on the accounts produced in the interviews. I made reflexive notes before and after the interviews, and during transcription which I completed in the couple of weeks following each interview. Although my interest in language created a temptation to transcribe in detail, I considered orthographic transcription to be sufficient and appropriate for the TA I was undertaking in this study (Braun & Clarke, 2013), particularly given the relatively large volume of data generated by the combined survey and interview data collection methods. See Appendix E for the transcription notation system that was used.

Recruitment and participant demographics

Convenience/volunteer purposive samples were generated for both the online qualitative survey and the interviews. Survey participants were recruited primarily online using email, social media, and the charity Alopecia UK’s (AUK) online newsletter. Inclusion criteria were that participants should be aged over 18, UK resident and identify as having alopecia areata, totalis or universalis, with first hair loss at least 1 year previously. This was so that the data could provide a sense of impact over time, particularly on people's sense of self, rather than capturing their initial responses to their hair loss. Participants were not required to have a formal diagnosis because existing research indicates that many people with the condition do not seek one, not least due to the lack of effective treatments. Furthermore, qualitative research's focus on subjective experience means that self-disclosure is both acceptable and common in qualitative studies (Braun & Clarke, 2013). Data were collected and collated using the *Qualtrics* online survey software and participants were instructed to answer the questions in their own words in as much depth as they chose. At the end of the survey an email address was given for participants to reply to if they wanted to express interest in being interviewed. The 6 interview participants were recruited via a mixture of these contacts, and emails sent to AUK support groups. Eligibility criteria were the same as for the survey, with the additional requirement that participants had engaged in some form of counselling or psychological intervention in relation to their AA.

The final number of participants who met the eligibility criteria for the survey was 98. Participants overwhelmingly identified as female (n= 86), white (n = 78) and heterosexual (n = 91). Most were married, civil-partnered or partnered (n=65). Of the 6 interview participants, 5 were female, 4 identified as White British, all identified as heterosexual, 5 were married and 1 was single. (See Appendices F and G for the full survey and interview demographic data). The lack of diversity in the sample may reflect AUK's membership and the online contacts that I and my supervisors reached as white women. After an initial review of the survey data, I attempted to recruit a more diverse sample, including through distribution of business cards that briefly detailed the study and how to access it. I particularly focused on circulating these through barbers and hairdressers in areas with large non-white populations. Staff in these businesses were enthusiastic about the study and shared stories of customers with AA. One business owner even told me about personal experience of living with the condition. However, this did not translate into more survey responses. This suggests that a limitation of the survey method is the requirement to write responses; English was not the first language for many of these proprietors and their customers, and it is possible that writing in English presented challenges in terms of skill and/or effort. It is also possible that people are more willing to participate in online studies if they are presented with a link electronically. Attempts to reach men via online forums did produce some limited results so future studies should investigate online groups with more diverse memberships.

The survey was left open for as long as possible to allow for further submissions following these additional recruitment efforts. Consequently, the sample in the analysis presented in this thesis differs slightly from the sample in the BJD paper. However, the sample remains lacking in diversity and the research predominantly captures the experiences of people who are white and heterosexual. The greater number of responses from female participants also means that there is more data on the experiences of women than of men. Gendered meanings featured prominently in both the survey and interview data which is consistent with findings in the wider visible difference literature (Clarke et al, 2014). I therefore analysed the data from male and female participants as separate data corpuses in addition to analysing them as a single data set. While developing the themes, I also paid particular attention to similarities and differences in accounts from men and women and was mindful to reflect upon my own subjectivities as a woman and how these might be influencing my reading of the data.

Data Analysis – Reflexive Thematic Analysis

TA is a theoretically flexible method of data analysis (Braun & Clarke, 2006; 2013; Willig, 2013) in which meaningful and salient patterns across a data set are systematically identified and organised by the researcher (Braun & Clarke, 2006; Joffe, 2012). There are a variety of approaches to TA; the one applied here is the reflexive form developed by Braun and Clarke (Braun & Clarke, 2006; 2013; 2019) and firmly located within a Big Q qualitative research paradigm (Kidder & Fine, 1987). Reflexive TA eschews quantitative research notions of accuracy or reliability and rejects the essentialist idea that there is a single knowable truth to be uncovered. Instead, it values researcher subjectivity as an analytical resource and promotes in-depth engagement with data (Terry et al., 2017). It is an approach that has been used effectively in studies undertaken from diverse theoretical perspectives, including essentialist/realist (e.g. Douglas et al., 2009; Harcourt & Frith, 2008; Moller et al., 2009), critical realist (e.g. Jowett, Peel & Shaw, 2012) and constructionist perspectives (e.g. Clarke, 2019; Frith, 2015). This flexibility allows the researcher to pragmatically explore a topic from the theoretical position or positions that “fit” with their epistemological and ontological commitments and that they deem appropriate, useful and meaningful to the topic of study (Dewe & Coyle, 2014). This offers scope for rich qualitative inquiry, avoids the traps of methodolatry (Chamberlain, 2000), and permits the spirit of adventure that is a hallmark of good qualitative research (Willig, 2013).

The flexibility of TA requires theoretical clarity and transparency on the part of the researcher, positions that can only be realised through personal and epistemological reflexivity (Terry et. al., 2017; Willig, 2013). Reflexivity is a core quality for counselling psychology practice and training is designed to nurture this through personal therapy and clinical supervision (James, 2017). Additionally, counselling psychologists are required to train in two major therapeutic orientations which calls for a capacity to understand and practice from within different, potentially contradictory epistemological frameworks (Hadjiosif, 2015). This reflexive and flexible engagement with the constitution of knowledge and meaning, potentially equips trainee and qualified counselling psychologists to utilise the creative possibilities offered by TA in theoretically informed and coherent ways. Counselling psychologists may also be experienced in working within multi-disciplinary teams where there is a need to develop skills in communicating across theoretical perspectives (Fairfax, 2016). The insights and skills developed in these ways can cultivate a pluralistic approach to psychological research in which different analyses are applied to the same data, building “rich, multi-layered, multi-perspective readings”, an approach to which TA is ideally suited (Dewe & Coyle, 2014, p.23). As already outlined, the benefits of such an approach in this project enabled the communication of salient issues to a medical readership that is unlikely to be familiar with the methods or language of critical constructionist qualitative research, but to whom the concept of themes was accessible.

Theoretical positioning: Subjectivities and objects of analysis

In their ground-breaking work *Changing the Subject*, Henriques et al. (1984) challenged the discipline of psychology to recognise the problems inherent in the positivist, unitary individual that it claims to reveal yet, in the process, actively constitutes. However, they also critiqued the poststructuralist perspective that prompted their challenge, recognising that although deconstruction of the unitary individual allows for multiplicity and contradiction in sense of self, it fails to account for subjective motivation, agency and change. It therefore fails to address “the specificity of the construction of actual subjectivities in the domain of discursive practices” (Henriques et al., 1984, p. 204). The authors proposed that in order to meaningfully theorise subjectivity, there is a need to integrate the social with the subjective processes accounted for within psychoanalytic theory. The difficulties and potential value of this task are exemplified in the work of Judith Butler who, in *The Psychic Life of Power,* asks the question “What is the psychic form that power takes?” (Butler, 1997, p.2). Like Henriques et. al., (1984) she argues that power and the psyche need to be thought together rather than constituting the split objects (See Appendix A) of separate and conflicting Foucauldian and psychoanalytic perspectives.

This theoretical approach resonated with the epistemological and ontological ideas to which I am drawn. As therapeutic practitioner, mother, wife, friend, sister and daughter I am interested in people, how we come to be who we are, how we interact, relate and produce the world we live in. I see and experience the power of discourses in constituting my own subjectivities and those of the people in my life, including my clients. In my years of work within post sexual assault support services, I have seen just how powerful dominant discourses can be in constituting subjectivities. However, this work has also allowed me to witness and reflect upon courageous resistance and capacity for subjective change (see Appendix A), often involving the operation of unconscious and intersubjective processes in the therapy room. Consequently, I am interested in the complex and subtle relationship between subjectivities and discourse, the processes through which discourses operate as power in the individual psyche, and the possibilities for agency and change in the embodied and gendered subject over time.

The feminist poststructuralist theoretical perspective adopted for this study acknowledges the gendered, embodied nature of these complex processes while avoiding the essentialist binarism of more oppositional feminisms. Research from within these forms of feminism focuses, importantly, on redressing the absences and silences produced by patriarchal structures and scholarship, but tends to reduce subjectivities to identities or natures based on pre-determined sex-categories (Weedon, 1987). In contrast, the approach used here offers theoretical possibilities for exploring the multiple and complex meanings that operate to produce the positions available to gendered subjects. My use of thematic analysis in this thesis is particularly influenced by feminist poststructuralist thinkers who have grappled with the challenges of accounting for embodiment and the dynamics of agency alongside (and bound up with) the discursive operation of power (e.g. Butler, 1990; 1993; 1997; Flax, 1990; Ussher, 1997). Their attempts at integration or at least a putting "into conversation with one another" (Flax, 1990 p.4) of psychoanalytic and discursive ideas at the theoretical level (e.g. Butler, 1997; Flax, 1990; Grosz, 1994) and in critical psychology and psychosocial research (e.g. Hollway, 1984; Josselin & Willig, 2015; Walkerdine, 2015; Young & Frosh, 2010), are fraught with challenges, contradictions and shortcomings. However, they also enrich the analytic possibilities for the study of embodied subjectivity by acknowledging unconscious processes and avoiding reductionist splitting of subjectivities into biological, social, and psychological objects of analysis.

The analytic process

A six phase TA (see Table 1) was undertaken to explore patterns across both data sets (Braun and Clarke, 2006; 2013; Terry et. al., 2017). These phases are distinct yet recursive, the reflexive nature of this approach to TA calling for repeated movements between them in a spirit of inquiry and interpretation (Braun & Clarke, 2013).

Table 1 - Thematic analysis process based on the procedures outlined by Braun and Clarke (2006), table adapted from Davey, Clarke and Jenkinson (2019)

Phase	Process
Phase 1: Data familiarisation	The researcher reads and re-reads the data making a note of any initial impressions or insights. Familiarisation facilitates a rich and complex account of the data.
Phase 2: Coding	The researcher systematically codes the data. Coding is not fixed, but an organic and evolving process. Coding can be at both the semantic (data surface) and latent (underlying assumptions) level.
Phase 3: Generating initial themes	The researcher generates initial themes from the codes and coded data. This typically involves clustering together similar or related codes.
Phase 4: Reviewing and refining theme	The researcher reviews the initial themes, first in relation to the coded data and second in relation to the entire data set. Themes are reworked or even discarded until there is a final set of themes that provide a good 'fit' with the data.
Phase 5: Defining and naming themes	The 'story' of each theme is refined and developed through finalising theme names and writing theme definitions.
Phase 6: Producing the report	Producing the report constitutes the final analytic stage, with further opportunities for refinement of themes.

I used both electronic and hard copies of the data over the course of my analysis and found that the movement between different media prompted in me new reflections, insights and interpretations. I also moved between different physical environments; sitting on the grass in quiet rural spaces, at my desk, in busy cafes and in the university library, among others. I was conscious that these changing physical environments brought shifts in my mood and energy, shaping and colouring my analytic sensibility and interpretative responses to the data.

Most of the survey data were generated very quickly over the space of a couple of weeks following promotion of the study in the AUK online newsletter. With excitement and some trepidation, I immediately entered the familiarisation process that constitutes the first phase of analysis (Braun & Clarke, 2006). Because I had designed the project as a constructionist study, my initial analytic observations and interpretations were primarily deductive, shaped by discursive ideas so that I identified latent meanings underlying participants' words (Braun & Clarke, 2006; 2013). I noticed multiple discourses of hair and hair loss in the data, yet alongside these intellectual or cognitive interpretations, I experienced strong emotional responses. I am conscious that that the identities I occupy are multiple, overlapping and fluid, performed dynamically in relation with the material world, the subjects I encounter and the body I occupy. I was therefore aware that some of what I was reading resonated with things I had heard from, or noticed in, the person in my life who lives with AA, and was mindful of the influence of my own subjectivities in my reading.

However, as I moved into the more systematic and rigorous second stage of analysis in which I began coding the data (see Appendix H for examples of coded data), I could see that strong emotion was a pervasive feature of the accounts. I realised that the analysis needed to be able to capture both this semantic, affective quality, while allowing me to identify discourses and their operation in the constitution of subjectivity. By the time I had completed an initial coding of the survey data and started to undertake the interviews, it was clear to me that discourses and emotions were intertwined in the data, meeting, shaping and changing subjectivities in conscious and unconscious processes in which the visibility of hair loss and its signifying meanings were managed through a variety of strategies, including decisions about whether or not to camouflage. This prompted me to seek ways to capture all this complexity in a sufficiently coherent analytical frame. Butler's (1990; 1993; 1997) explorations of subjectivity through discursive and psychoanalytic concepts, accounting for the body through her theory of performativity proved a helpful guide.

Just when I was ready to engage in systematic deductive coding of the full data corpus of interviews and surveys, shaped by the theoretical framework I have outlined, the BJD announced a qualitative special edition and issued a call for papers for qualitative research relevant to dermatology. Given the ethical responsibility I felt to fulfil my research objective of producing a study that was of relevance to diverse practitioners, this felt like too important an opportunity to miss. However, I was also aware that the Butler framed analysis of subjectivity that I intended to undertake for my thesis was unlikely to speak to the BJD audience. My first supervisor and I independently coded the data from a broadly critical realist perspective (Madill, Jordan & Shirley, 2000; Willig, 1999), identifying semantic and latent meanings and focusing on the lived experience of AA. We each then developed candidate themes, attending to socially produced meanings while staying close to the lived experiences described by the participants. We then met with my second supervisor to review and agree the final themes before producing the paper which presented a critical exploration of meaning, while giving voice to the participants (Willig, 2013).

Having completed the paper, I returned to coding of the data from a feminist poststructuralist position; both at this stage and as I developed the themes presented in the analysis section of this thesis, I was aware that the coding I had undertaken for the BJD paper was helping me to retain an empathic awareness of the experiences described by the participants. This helped me to engage in theoretical analysis of discourse and subjectivity without losing connection to the affective quality of their accounts. The process felt akin to working at relational depth with therapy clients; the theoretical and analytical tools operated alongside the empathic sensibility that is core to relational approaches to therapy (Clarkson, 2003; Kahn, 1997). As I worked through the coding of all the data, I moved into phase three of the analysis, identifying candidate themes and then collating relevant data extracts (Braun & Clarke, 2013). Phase four involved reviewing, revising, recoding and lots of finding ways to "let things go" (Braun & Clarke, 2013, p.234), a process that continued into and overlapped with phases five and six, where I defined and named themes and began writing up the analysis presented in this report.

I subjected data from male and female participants to separate analyses at various points in the process of coding and theme development to ensure that I continued to identify and reflect upon differences and similarities as my analysis evolved. The overarching patterns presented in the themes apply to both male and female participants, but gendered discourses are a feature of the data and significant differences are noted and discussed as the themes are presented.

Ethics

The many ethical issues involved in designing and conducting psychological research become yet more complex when considered within a reflexive, postmodern paradigm (Parker, 2005). By acknowledging that meanings are multiple, contextually produced and involve the operation of unequal power dynamics, critical qualitative research raises multiple ethical questions (Harper, 2003). These acquire particular significance in studies such as this where there is an aspiration to produce knowledge that can inform applied psychology practice (Burman, 1998). There is insufficient space here to explore all these issues. However, by holding in mind the principle of transparency, I have sought to engage in ethical research practice (Parker, 2005), sharing my motivations and assumptions throughout the study and the writing of this thesis, insofar as I am aware of them and they are mine to share.

The study was approved by the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England (see Appendix I) and adheres to the British Psychological Society's Code of Human Research Ethics (BPS, 2014).

Analysis

In my analysis I identified three themes, each consisting of several subthemes (Braun & Clarke, 2006; 2013), as detailed below (see Appendix J for a visual map of the themes). Supporting quotations in the analysis are tagged with participant numbers, with survey participant abbreviated to SP and interview participant abbreviated to IP. The data extracts from the survey are not corrected with regard to spelling and grammar but presented exactly as written by the participants.

Theme 1 - Transgressing appearance norms: Restricted and shameful subjectivities

- Abnormal freaks – defeminised women and restricted masculinities
- Sex, intimacy and the heterosexual matrix
- It’s (not) just hair – subjects in dis-ease
- Hiding transgression - work, socialising and exercise

Theme 2 - Submitting and resisting: Performances and performativity in the management of hair loss

- The “real me”, the “mask” and the “fraud”
- Out and bald – (in)authentically brave
- Playful identities

Theme 3 - Changing subjects? Acceptance, relationships and growth

- Accepting ambivalently – “why fight a battle I can’t win?”
- Loving relationships and validating encounters – (re)constituting a subjectivity of worth
- Mourning and growth – “it’s a highly personal journey”

Theme 1: Transgressing appearance norms: Restricted and shameful subjectivities

Throughout the data, multiple discourses of hair and hair loss operate in layered, overlapping and contradictory ways to restrict who participants can be and how they are able to live. AA produces transgression of normative constructions, particularly relating to gender and illness, with restrictive implications for all aspects of life, including intimate relationships, work and socialising. These transgressions and restrictions are bound up in shame, operating at times to constitute the subject as shameful, trapped within a sense of utter hopelessness. Assertions such as "it doesn't affect who I am" (SP15, male, heterosexual) are often immediately contradicted - "it has made me more self-conscious", while for others, any adjustment to life with AA is a challenging and ongoing "personal journey" (SP34, female, heterosexual):

> *I made a promise to myself when it started that I wasn't going to let it affect the things I did, and I've stuck to that even when it's been tough* (SP28, female, heterosexual).

The juxtaposition of subjective restriction and resistance, apparent in this statement from SP28, is frequently discernible in the data. This ambivalence is attended to throughout the analysis, however, while resistance and subjective change are the focus of the second two themes, the first theme primarily explores key hair-related discourses and their power in constituting subjectivities. Four sub-themes have been identified which together capture the restricting and shaming operation of dominant discourses when appearance norms are transgressed: 1) Abnormal freaks - restricted masculinities and defeminised women, 2) Sex, intimacy and the heterosexual matrix, 3) It's (not) just hair – subjects in dis-ease, and 4) Hiding transgression: Work, socialising and exercise.

Abnormal freaks – restricted masculinities and defeminised women

In the data, hair is seen to structure normative appearance, and hair loss is understood as an indicator of abnormality. Many suffer intense distress at these "abnormal" positionings, with participants describing themselves as "strange" (SP80, male, heterosexual), "alien" (SP75, female, heterosexual) or "freakish" (SP45, female, heterosexual) and expressing a sense of disconnection from other people due to their alopecia:

> *A freak I try to avoid conversation with people and never make eye contact* (SP65, male, gay).

> *I feel like I dont fit in & not normal. I feel the need to fit in & not draw attention to myself.* (SP35, female, heterosexual).
>
> *Just don't feel or look normal. Can't bear the looks I get from people* (SP45, female, heterosexual).

AA is believed to produce transgression of a social imperative to “fit in” through conformity to culturally specified appearance norms. This draws unbearable “looks” from others, constituting the person as “a freak” and rendering them unable to be “normal”. Strategies to manage the shame of this stigma (Goffman, 1963) can lead to self-exclusion through attempts to “not draw attention” or “make eye-contact”. This further reinforces an outsider position, demonstrating the regulatory power of normative discourses. A restricted, shameful subjectivity is thus constituted and re-iterated in self-disciplining, discursively shaped performances (Butler, 1990).

Throughout the data, subjective restriction and shame are shaped by gendered discourses. For men, AA restricts the masculinities available, while for women hair has such signifying power that the subject is often wholly or partly defeminised:

> *Hair is always used to exemplify femininity and good looks. It is almost revered. In literature it is often the hair of a female character which is described and it is that which defines her.* (SP66, female, heterosexual)
>
> *I feel excluded from so many conversations - women seem to talk about hair a lot! They are even categorised and objectified by hair colour. Some dating websites have no option for no hair. It makes you feel like you do not belong in the category of female sometimes.* (SP20, female, heterosexual)

Not only is hair equated here with “good looks” for women, characteristics such as “hair colour” operate as cultural signifiers that categorise women into types – for example, the dumb, fun, blonde (Burton, 2012; Shifman & Lemish, 2010; Synnott, 1987) or the capable brunette (Kyle & Mahler, 1996). The power of such symbolic meanings to construct gendered identity is manifested in the frequent conversations between women about their hair. Those with AA are excluded from this cultural language, isolating them not only from dialogue and connection with other women, but placing them outside the “category of female" - the bald woman does not exist. The pain of this threat to female identity is emphasised through references to bereavement and amputation:

> *it's a deeply personal feeling, and at times akin to women who have had a mastectomy and feel that something that made them a woman has been taken away from them.* (SP49, female, heterosexual).
>
> *it must be treated like grief. The psychological impact is all encompassing and never seems to diminish. It is extremely lonely and isolating.* (SP73, female, heterosexual).

Mastectomy due to cancer treatment is widely understood to affect women's sense of gendered identity (Emilee, Ussher & Perz, 2010; Frith et al., 2007; Millsted & Frith, 2003). Such references therefore communicate how the "deeply personal" loss of hair brings "grief" that contributes to a sense of disconnection from gendered self and others, a "lonely and isolating" process that is "all-encompassing" and may never "diminish".

Some made sense of the defeminising or denial of the bald woman through binary gender discourses:

> *For many years I felt very masculine, losing my hair, eyebrows and eyelashes. I used to have the most fantastic brown naturally curly hair and was remembered for it. Suddenly it was gone and I didn't feel the same person and don't really feel the same even now* (SP42, female, heterosexual).

Without her femininity structuring "brown, naturally curly hair", SP42 conceptualises herself as "masculine" and consequently not "the same person". Yet this change seems limited, hair loss and its meanings creating only a surface inscription (Butler, 1990) that confuses her sense of self but under which she sustains identification as female. Thus, she indicates that she has worked towards a sense of reconciliation with her gender transgressive appearance; unable to "really feel the same even now", her very words suggest some partial, incomplete reconnection with the (feminine) person she was. Simultaneously, her existence as a gendered subject remains troubled, not clearly located within femininity or masculinity (Butler, 1990).

Others conceptualised these gender troubling effects of AA through reference to androgyny:

> *Not viewed as womanly but as androgynous by many* (SP64, female, heterosexual).

> *I feel unfeminine and do not feel like a woman at all more androgynous.* (SP77, female, heterosexual).
> *I try not to think about how others perceive me but I believe I look androgynous.* (SP73, female, heterosexual).

Unable to feel feminine, these women stop short of identifying as masculine, instead locating themselves somewhere in between. Yet more radically, two participants both used the term, “blank canvass” to make sense of the effects of hair loss:

> *having no eyebrows or eye lashes makes me feel like I'm no longer a woman as I don't have the womanly face anymore, it's just a blank canvas with no features at all now.* (SP55, female, heterosexual)

> *Before it fell out, my hair used to be a big part of my identity, not just as a woman but who I am. Now I feel like a blank canvass, with no personal qualities anymore.* (SP39, female, heterosexual)

Here, not only is hair loss understood to deconstruct “the womanly face”, the consequent loss of female identity is seen to be accompanied by erasure of subjectivity constituting “qualities” and “features”. If the bald woman does not exist in cultural discourse, then blank space is left where the subject was. Yet the term “blank canvass” suggests something waiting to be painted; creative possibilities are signified and the potential is recognised for new subjectivities to form in the vacuum left by the loss of the feminine. The same desubjectification produced by AA as a disease that alters appearance in gender norm transgressive ways, also produces conditions for agency and change, a body that can become a site of “critical agency” (Butler, 1993, p.x).

Gendered meanings also shape male participants’ accounts, although references are often less explicit or symbolic than in the female data. The impression produced by analysis of these data is of restrictions to the masculinities available rather than the degendering identifiable in the women’s accounts. One explanation for this is that head baldness can be understood within normative constructions of masculinity due, for example, to associations between aging and male loss of head hair (Cash, 1990; Ricciardelli et al., 2010):

> *Looking older than I really am.* (SP94, male, heterosexual).

> *I lost my hair at the top of my head when I was 25. I was clubbing dating girls and loving life. Alopecia knocked the wind out of my sails at the time. Men tend to say the worst things to one another, no man wants to go grey let alone lose their hair so I had to bare a lot of verbal abuse which really bothered me inside although I never let it show personally.* (SP87, male, heterosexual).
>
> *Inadequacy. Stigmatism. Increased social difficulty.* (SP96, male, heterosexual).

These participants developed AA in their early twenties. Their accounts show how head hair loss, like going "grey", is understood to make young men look older, potentially signalling loss of virility (Synnott, 1987) and producing a sense of "inadequacy" and "increased social difficulty". SP87 constructs youthful heterosexual masculinity as care-free and sociable; the onset of AA interrupted this for him, and the meanings associated with hair loss are understood to be disempowering, positioning him as oppressed victim of "verbal abuse". Yet he also describes resisting the disempowering (emasculating) effect of the "worst things" that his abusers, as men, "tend to say" by not showing how it bothered him. He thus seeks to reposition himself within a re-constituted, re-empowered masculine subjectivity (Wetherell & Edley, 1999).

Elsewhere in the data, the association between aging and hair loss offers access to less distressing positions for men:

> *Hard to disentangle this from just ageing, during which a more rounded and mature approach to life means that younger feelings of some baldness embarrassment have disappeared. (*SP81, male, heterosexual).
>
> *During my second experience the alopecia does not affect my life the way it did the first time. People do mix it with normal baldnes which is more comfortable for me. It bothers me a lot when people ask about it, but I always try to explain all about it.* (SP6, male, heterosexual).

Baldness is less embarrassing for these older men whose hair loss is more likely to be seen by others as "normal", a perception which they themselves can accept as congruent with an older sense of self. Alongside this, the idea is expressed that the mature man is "more rounded" and therefore less concerned with how his appearance is judged by others, or more equipped to speak about it when people ask.

Sex, intimacy and the heterosexual matrix

Intricately layered through the gendered subjective challenges produced by hair-related discourses, are their power to restrict possibilities in and for intimate relationships. This subtheme is only explicit in data from female participants, but is pervasive, emotional and indicates preoccupation with the impact of AA on present and future partner relationships. Such preoccupation is notably absent in the male accounts, although references to social anxiety, avoidance of social situations, and feeling unattractive, suggest the condition may also create difficulties for men in meeting partners.

Concerns around intimacy and sex in women's accounts can be seen as operating within, and constitutive of, a heterosexual matrix (Butler, 1990); running through the data is the question, how can a man be attracted to a subject who, due to the absence of femininity signifying hair, is not truly female? This difference between male and female accounts suggests dominance for women of a "have/hold heterosexual discourse" (Hollway, 1984) in which they can only be whole if they have a partner – who should be a man - meaning that full or partial loss of gendered subjectivity is bound up with desexualisation and restricted possibilities for intimate relationships:

> *I feel rather ugly when I'm not wearing my wig and it makes it difficult for me to feel that men would find me attractive (even with my wig on*). (SP17, female, heterosexual).
>
> *I cannot date as feel I am a joke as a female as I have no eyelashes or eyebrows which is everything feminine* (SP35, female, heterosexual).
>
> *The only problem is meeting members of the opposite sex. I don't have a problem telling people I have alopecia however, having to tell someone who you potentially want a relationship with can knock your confidence.* (SP24, female, heterosexual).

Female heterosexual attractiveness is determined in these accounts by femininity signifying head, eyelash and eyebrow hair. Due to their hair loss, these participants position themselves as "a joke" or "ugly" as women and consequently understand their possibilities for intimacy with men to be restricted. Even successful concealment cannot resolve this; either the concealment itself creates the need for disclosure to potential partners, or subjective feeling of being “ugly” under the wig disrupts possibilities for feeling physically attractive to men.

Sexual and emotional intimacy are understood to be intertwined, and both are therefore understood to be restricted by AA:

> *I believe I have lost my 'attractive' ness in all aspects. Not just in a base sexual way. At 37 I believe I have said goodbye to that part of my life. I find it quite difficult to live with, as in I do not know how to live with it, I just do.* (SP73, female, heterosexual).

SP73’s words are emotionally restrained, yet the pain produced by ideas about appearance, hair and gender is tangible. She positions herself as alone, restricted to this for the rest of her life because the impact of her appearance-transgressing hair loss extends beyond her “base” sexual attractiveness into her deepest sense of self. She cannot believe that a man will ever want to be with her and is left struggling “at 37” with having “said goodbye” to a life in which intimacy is possible.

Women with current intimate partners also construct their relationships as emotionally and sexually restricted due to AA:

> *My husband took a little bit of time to get used to it. I used to cover it up for him to and even do my hair for bed. I don't anymore.* (SP91, female, heterosexual)
>
> *Lack of eyelashes make me feel the least feminine and my husband doesn't find me as attractive when I don't have hair on. But I'm quite a practical person and enjoy doing diy etc and I can still dress up for nights out so it's not the end of world. I would like to wake up with my husband with hair and eyelashes thou* (SP1, female, heterosexual).

The gendered meanings associated with hair and hair loss position these women unusually, as desexualised objects within the dominant male sex drive discourse (Hollway, 1984). Partners often reinforce this position, unsurprisingly since they are subject to the same socially-produced meanings. These participants describe working to maintain a position as object of sexual desire by camouflaging the absence of hair that they and their partner are both aware of. This can involve a sense of negotiation with both self and partner; subjective power is claimed – SP91's defiant "I don't any more" about covering up for her husband suggests she sees her own accommodation with her hairlessness as challenging him to "get used to it" too. SP1 constructs a more complex negotiation, weaving connections between hair loss, feeling "less feminine", her husband not finding her "as attractive" and her enjoyment of "DIY". She seems to imply that DIY is a masculine activity, consistent with her defeminised appearance, but that she can re-construct her feminine subjectivity through dressing up for nights out. In bed with her husband, hairless once more, this subjectivity is again lost, operates as a barrier to the heterosexual relationship and therefore remains longed for.

Some participants described the operation of the heterosexual matrix in public situations:

> *some people shout that your a lesbein this happened to me in Lidls.* (SP60, female, heterosexual)
>
> *Sometimes I get homophobic comments. Sometimes I have been mistaken from afar as a man and been threatened for kissing another man. Sometimes I feel they just see someone strange/other/unattractive/offensive in some way.* (SP20, female, heterosexual)

Such experiences of homophobic abuse highlight the power of hair as a signifier of femininity, but also show how gender and heterosexuality remain bound together in normative discourses, a cultural heterosexism operating alongside ontological homophobia (Clarke, 2019). Transgression of one norm indicates transgression of both, a perceived challenge to dominant social structures that some deem to justify shaming abuse.

Heteronormative assumptions also operate in encounters with health care professionals, albeit more subtly:

> *Going to the nurse for a smear test was humiliating as she said she assumed the headgear meant I was undergoing some form of chemo and when I said 'no' she said 'oh just a fashion statement then'. When I then told her I'd lost my hair she said she didn't know what she'd do if she lost her hair and then went on to ask me what my husband thought. I was so distressed when I left as I hadn't even thought that my*

> *husband would have been anything other than upset for me. She had just introduced yet another fear* (P45, female, heterosexual).

The nurse in this account reinforced multiple distressing discourses relating to the presence and absence of hair. However, most damaging was the assumption that SP45's husband would be "upset", not empathically for her, but because AA renders her unable to conform to the normative female appearance assumed by the nurse to be necessary for a woman to occupy a position as object of the male sex drive. The nurse's lack of knowledge that hair loss can have a variety of causes, her insensitivity to the impact it can have, and her normative assumptions about heterosex, made this routine health care appointment both "humiliating" and the source of "yet another fear".

It's (not) just hair – subjects in dis-ease

The data contain numerous references to AA as a "disease", "illness" or "autoimmune condition" that can be "shocking", "traumatic" and "devastating". Yet these feelings are often shrouded in a subjective dis-ease, produced in multiple and intersecting ways as contradictory discourses clash. One such clash involves the operation of two "just hair" discourses, the first of which constructs concern with appearance, including hair, as "vain":

> *I sometimes feel that my condition is a punishment for being so vain.* (SP66, female, heterosexual).

> *I feel people who don't know I have alopecia must think I'm high maintenance or vain as they won't understand why I must wear make up every day* (SP14, female, heterosexual).

These participants express discomfort at preoccupation with their appearance, understanding this to signal vanity which they view as shameful and warranting "punishment". However, elsewhere, this "just hair" discourse is seen as unjust:

> *People often say 'it is only hair', 'it is not a life-threatening condition' but personally I do not think that anyone can appreciate just how massive losing your hair is unless or until it happens to you. They need to understand how massive it is and how the condition often brings feelings of huge depression and suicidal thoughts.* (SP56, female, heterosexual).

> *Most people make the initial assumption that you have cancer. I feel that when they realise you don't they are relieved and then think it's easily solved by wearing a wig* (SP45, female, heterosexual).

SP56 describes how the impact of hair loss is so “massive” that suicide becomes considered as a means of escape. She expresses frustration that the emotionally devastating meanings associated with AA are unacknowledged because it is “only hair” (implying vanity at concern about its loss), while its loss also signifies “life-threatening” illness. In this second discourse, AA becomes constructed as a harmless condition of “just hair”, “easily solved by wearing a wig” unlike the potentially terminal cancer that others frequently assume to explain hairlessness. Yet the minimisation in these two “just hair” discourses is contradicted by the gendered normative appearance discourses already discussed. The confusion produced in this clash exacerbates distress and, paradoxically, can result in a depression through which the condition does indeed become “life-threatening”.

The association between cancer and hair loss was frequently mentioned in the data and was associated with feelings ranging from mild discomfort to guilt and anger:

> *Often they think I am on Chemo. so are ultra kind. I am careful to tell people that I am physically fine it is just hair loss.* (SP61, female, heterosexual).
>
> *It took me a long time to not feel self consciouse and embarrassed. It makes you feel lonley very different and isloated no one I knew had Alopecia so I was left to deal with how it made me feel on my own. I would then feel guilty for feeling so sorry for myself as I had not lost my hair due to cancer.* (SP60, female, heterosexual).
>
> *Also, it's cosmetic so wear a wig and get on with it. When I was 12 I used to wish I had cancer so there would be a greater understanding towards my hair loss. How rubbish is that!* (SP67, female, heterosexual).

People with AA can feel compelled to manage meanings in social interactions to ensure that others know their condition is one of “just” hair loss rather than cancer. However, the clash between “just hair” discourses and distressing feelings of loneliness constitutes a guilty subjectivity caught up in a struggle to make sense of conflicting feelings and meanings. This can lead to resentment, anger, and a confusing and painful twisting back of discourses as expressed in SP67s “wish” to have the life-threatening cancer assumed by others so that her emotional distress can become both justifiable and understood by other people.

Many participants reported distressing encounters with health care professionals in which the significance of hair loss was simultaneously reinforced and dismissed:

> *I get a lot of pity- even a GP I saw for the first time straight away asked how far into chemo I was without looking at my records which would have stated I had the all clear. Even after I told her I had Alopecia she persisted in asking 'how far into your chemo are you?' This made me very cross. If even a GP won't listen and continues making upsetting assumptions what on earth must other people think?!* (SP9, female, bisexual).
>
> *Some GP's weren't particularly helpful, had the "It's not life threatening just cosmetic" another one offered treatments which I tried with no response.* (SP10, female, heterosexual).

The GPs from whom help is sought respond with the same “upsetting assumptions” as others, reinforcing the conflicted sense of self produced by a condition that is not “life-threatening” but is also not experienced as “just cosmetic”. Such failed attempts to access help show the problematic dominance of a biomedical framework within the practice of medicine. The GPs “won’t listen”, they are not “helpful” because they work within a model that constructs disease as a physical dysfunction to be fixed through medical technology. Lacking a psychological perspective, the doctors fail to comprehend the complex, socially produced meanings associated with AA, so fail to hear their patients in ways that might help to free them from the shame of this condition.

The problematic doctor-patient dynamic may be related to the lack of effective pharmaceutical treatments for AA:

> *Dermatologists see us as a waste of time because there is no treatment or else guinea pigs for trials. some of which have horrible side effects or give false hope because as soon as the treatment stops the hair falls out again* (SP86, female, heterosexual).

GPs and Dermatologists refer to NICE and BAD Guidelines which recommend “not treating in most instances”, since treatments are largely ineffective and can cause “horrible side effects”. The biomedical model thus fails to offer a solution, disempowering doctors who, subject to the dominant “just hair” discourses, are experienced by these patients as dismissive. Guidelines do recognise that psychological treatment may be helpful, but few participants were offered this, indicating a lack of psychological mindedness among medical practitioners. As a result of this failure to recognise that the suffering involved in living with AA is produced by social and cultural meanings, medical practitioners not only fail to offer relief, but reinforce those problematic meanings.

Hiding transgression - work, socialising and exercise

In the data, the restricted sense of self produced by meanings of hair and hair loss, is often reinforced by attempts to cope:

> *It has driven most of my life choices, e.g. relationships, friendships, career etc. I find it very stressful and isolating however have used strategies over the years to keep focusing on healthy behavioural choices etc.* (SP67, female, heterosexual).
>
> *My alopecia now is a lot worse I seldom leave my home and if I have to go shopping I leave early as less people about.* (SP65, male, gay).

AA can drive “life choices” in far-ranging ways; from the intimate relationships already discussed to careers and essential tasks like shopping, participants describe feeling restricted by the need to hide or manage exposure of their AA. These “stressful and isolating” processes extend for some to avoidance of all social contact as with SP65 whose AA has led him to “seldom leave” his home.

Elsewhere, accounts show how these avoidance strategies further contribute to a more restricted sense of self:

> *I live in fear of someone discovering I wear a wig. There are jobs I would never do eg being a teacher as I could not bear students to know about my condition. Ditto any on camera role. I would have loved to learn to scuba dive but you can't really do that wearing a wig. Ditto fairground rides that spin you fast or make you go upside down.*

> *I used to be a keen diver as a child but have not dived since losing my hair.* (SP57, female, heterosexual).
>
> *I have very low self esteem, I don't like to go to social events and when I do I find a corner to sit in so no one can stand behind me and then can see my attempt to cover my baldness. I'm not me. Some one who was very bubbly inside, fun loving, out going. I'm now boring, unsociable and scared.* (SP74, female, heterosexual).

The powerful imperative to hide hair loss is accompanied by fear of exposure, which drives these participants to impose restrictions on themselves in their choices around work, socialising and exercise. This leads to a less energetic or "fun loving" sense of self, a shrinking into a "boring, unsociable and scared" subject. Yet the longed for freedom, to "scuba dive", or "spin fast" on a fairground ride implies other subjectivities, ones that continue to exist in some form but are hidden from the world, creating a sense of intra-subjective disconnection and inauthenticity as captured in SP74's words "I'm not me".

Theme 1 summary

The analysis in this theme shows how hair loss results in transgression of normative gendered appearance with restrictive implications for social interaction, personal relationships, work, and even basic life-tasks such as shopping. Men with AA retain a sense of themselves as recognisably male, but the masculinities available to them are limited by the meanings associated with hair loss. For women with AA, the failure of their bodies to cite gendered norms produces a defeminised subjectivity. These restrictions are accompanied by punishing constructions of appearance concern as vain, and denial that "just hair" loss warrants recognition as painfully distressing, particularly given the cultural association between hair loss and life-threatening cancer. Interactions with health care professionals not only fail to ameliorate these distressing and contradictory discourses but reinforce them. Subjection in shame is thus further re-iterated. The sense of disconnection and inauthenticity produced when this shameful, restricted subjectivity clashes with awareness of other, happier, facets of the self, can be profoundly disturbing. Yet it is in the contradictions and ambivalence that accompany these processes that the conditions for resistance and change appear to be generated.

Theme 2: Submitting and resisting: Performances and performativity in the management of hair loss

> *How precisely are we to understand the ritualised repetition by which such norms produce and stabilise not only the effects of gender but the materiality of sex? And can this repetition, this rearticulation, also constitute the occasion for a critical reworking of apparently constitutive gender norms? (Judith Butler, 1993, Bodies that Matter, p.ix).*

Participant accounts show a preoccupation with how to manage the effects of AA on appearance, including whether to conceal or expose hairlessness. An imperative to disguise hair loss is evident, and the meanings bound up with the resulting practices are complex and layered, involving repetition and ritual to manufacture and sustain the gendered bodies that are understood to be the “natural” manifestation of gendered identity (Butler, 1999, p.xv). Yet despite the perceived necessity of these practices, anxiety is frequently expressed about risk of exposure, not only of AA itself, but of the manufactured nature of the presented identity. Choice is asserted by some, and practices are described that demonstrate resistance to the imperative to disguise. Both defiance and playfulness are displayed as strategies through which the participants’ bodies become “sites of critical agency” (Butler, 1993, p.ix.). That both gender and sex are regulatory cultural constructions is laid bare by the data presented in this theme. The disciplinary power of these constructs and the imperative to maintain the essentialist fiction of naturally sexed bodies is demonstrated; the performativity of gender through strategies to conceal hair loss, simultaneously creates risk of discovery, of exposure as abnormal and therefore shameful.

The varied strategies for managing the visibility of hair loss, and the complex and layered meanings attached to these are captured in the subthemes: 1) The “real me”, the “mask” and the “fraud”; 2) Out and bald – (in)authentically brave; and 3) Playful identities.

The "mask", the "fraud" and the "real me"

In the data, strategies for managing AA differed for men and women. Most female participants referenced use of camouflage products, whereas men described practices involving further hair removal to disguise their AA:

> *I am self conscious about it, even though I try not to be! I have as a consequence shaved my hair really short to try and blend in the bald patches with the rest of my head* (SP15, male, heterosexual).
>
> *I shave every day to minimise questions/embarrassment. Previously I often grew a beard and I was much more comfortable with my appearance when I had stubble/beard.* (SP82, male, heterosexual).

Patchy hair loss on the head or face causes "embarrassment" but can be managed by shaving, which produces an appearance construed as "normal balldnes" (SP6, male, heterosexual). Absent head and facial hair can thus be accounted for within normative constructions of masculinity, although risks can be associated with these:

> *I did not do much with my hair, until recently, where I have begun to trim my hair into a buzz cut. As a result, my family has begun to give me a very hard time. The silver lining: I always thought that I should become less dependent on my family. There is not better way to gain respect, than to become self-sufficient.* (SP94, male, heterosexual).

The "buzz cut" has been described as a "code for masculinity" in the context of the military (Vojdik, 2002) and associated with marginalised subcultural masculinities including gay masculinity and racist/nationalist masculinity (Valeri, Sweazy and Borgeson, 2017). Such associations may explain the "hard time" SP94's family are giving him in response to this strategy for disguising his AA. Notably, he then asserts other features of dominant masculinities, including self-reliance (Wetherell and Edley, 1999). For men, the loss of head hair and its impact on subjectivity can therefore be managed within restricted but normative ideas and practices. It is not emasculating or desubjectifying, but strategies to disguise unusual hair loss can be risky due to associated masculinities and the potential impact of these on relationships with self and others.

Loss of eyelashes and eyebrows is shown in the men's data to be undisguisable and therefore especially distressing:

> *Starting to lose my eyebrow has led to anxiety around looking strange - I could handle the beard, as shaving every day helped mask this - but I do not want to look strange* (SP82, male, heterosexual).

> *Then my eyebrows went one by one, losing my eyebrows was the most distressing part of Alopecia for me.* (SP87, male, heterosexual).

Unusual or absent facial hair can be managed through shaving; removal of remaining hair effectively masks the potentially emasculating hair loss. However, loss of eyebrows or eyelashes is understood to create a "strange" appearance for which there is no solution. Given the rise of metrosexual masculinities, with grooming increasingly construed as normal in men's self-care (Barber, 2008; Braun et al., 2013), and evidence that male cosmetic products are a growth industry (Hall, Gough & Seymour-Smith, 2012), it is striking that permanent make-up is not utilised by male participants to disguise eyelash and eyebrow loss. This absence may simply reflect the small sample of male participants. However, a *Google* search for "micro-blading", "semi-permanent make-up" and "alopecia" showed these products are marketed only to women, unlike head hair loss products which are extensively marketed to men (Harvey, 2013). This suggests the picture in the data may be indicative of the practices of men with AA more broadly. The literature around male use of cosmetics demonstrates a concern to construct these practices as manly within normative constructions of masculinity (Hall et al, 2012; Gough, Hall & Seymour-Smith, 2014) and it may be that marketeers and consumers have yet to embark on constructing these particular products in this way.

In women's accounts, substantial space is given to hair loss camouflage products, albeit at times to explain decisions not to use them. This contrast with the men's data suggests both that women have more appearance management strategies available to them, and that a stronger imperative exists to use them. Such appearance work to disguise AA was presented by many female participants as a necessity, despite the time and financial cost involved:

> *used to being bald but have to put face on otherwise i look like death (my words) had eyebrows tattooed to look "normal" again my words. people have not noticed the*

> *alopecia - but often comment of how good hair & make up looks - just my mask - if they see me with nothing - i sure would be shocked* (SP36, female, heterosexual).
>
> *At first I wore acrylic wigs but since I've started wearing vacuum ones it's been much easier to cope. They are very expensive (£1,900) and o need a new one every 3 or so years so it's a significant financial burden but since I wear it every day it's one I save for. I've also had temporary tattoos regularly for my eyebrows and eyeliner. The latter I gave up because it didn't last very long and it was really unpleasant as well as expensive.* (SP50, female, heterosexual).

Here, make-up and wigs “mask” alopecia to produce “normal” appearance; while masking for men is accomplished through further hair removal, for women a new face must be put on, a bald head covered with artificial hair that nonetheless must look natural. The time and financial costs of achieving this presentation of self as naturally female are significant. However, the investment is seen as worthwhile because the products normalise appearance “every day”, precluding the need to deal with “shocked” responses to a hairless woman. Instead, an ideal woman is performed, reiterated through the act of making-up, and the acknowledgement of this in social encounters where “good hair and make-up” are complimented, in citational processes that reaffirm the performer in their gendered subjectivity (Butler, 1990).

Many of the female participants showed ambivalent consciousness of the performative nature of camouflage practices by describing conflict between an idealised, socially prescribed self and a “real self”:

> *I hated my appearance without a wig. With the wig on although I was much more confident in my appearance, I felt it wasn't the 'real' me.* (SP64, female, heterosexual).

SP64 recognises how the wig enabled her to cope by producing a normative appearance acceptable to herself and others. By wearing the wig, she re-produced an intelligible identity, enabling her to confidently face the world. Yet her very awareness of her actions produces a sense of disconnection; the psychological cost of reiterating normative identity is a sense of inauthenticity. The disguise may fool others, but the subject remains unchanged. For many participants this sense of disconnection between the performed identity and the “real me” produces destabilising anxiety:

> *I went out to the pub for a drink with my husband and some friends. I was convinced that a young lad was talking about my wig and so I confronted him. He said he wasn't but I had convinced myself he was. I feel that people immediately recognise the fact that I am wearing a wig but they are so natural that people often say they never even realised.* (SP42, female, heterosexual).

For SP42, desire to trust that the wig effectively masks her AA, constructing her as a normal subject engaged in normal social interaction, clashes with her knowledge that the wig is worn and her appearance is therefore not "natural". This signals the unacceptability of wig-wearing; the practice is undertaken to maintain gendered appearance norms, but the hairless woman transgresses nonetheless – and so lives in fear that her shameful secret will be exposed. In unconscious enactment (see Appendix A), conscious assertion of agency, or both, she pre-empts exposure, foreclosing the possibility that her disguise might be maintained and her womanhood sustained.

In some accounts, camouflage is explicitly described as deceit, and concerns are shared about the implications of this for relationships, yet these too can be tied up with ambivalent expressions of agency:

> *I find it a tricky one because erm in a sense er covering it up is is a bit like living er a lie and you know presenting one face to the world when the reality at the end of the day it all comes off and it the reality is very different ((laughs)) so erm er yeah I think I think it's quite tough really being single and you know er in your forties and trying to meet anyone (.) so well a lot of peop- women in their forties would say it's difficult anyway 'cause it's a case of who's who's available who's left who's out there and who's single so erm ha- I think having something that different well it's just something else to add add to the mix really so I suppose the other way of looking at it is it's er a a way of testing out whether someone's genuine and whether they are just you know going on looks or whether there's more to them than just how you look* (IP3, female, heterosexual).

Here, anxiety about the "lie" being revealed to a potential partner is balanced by a sense that subjectivity is more than gender and that the transgression produced by AA has potential to "add to the mix" in relation to self and others. Although continuing to reiterate gendered discourses through appearance-management practices that disguise her hair loss, IP3 also subverts their power to oppress by critically reworking her AA as a resource through which to test potential partners' authenticity. This complex mix of concern about her own and others' authenticity, and exercise of agentic power through critical deployment (see Appendix A) of her "lie" (the wig), was given added potency by the face-to-face context in which she gave her account. She chose to meet me, a stranger, to share this information so that her very personal experiences could contribute to research about what it is like to live with AA. Furthermore, her choice of venue for our meeting was a busy public space where our conversation could easily be overheard, and she wore a wig that, to my eye, was indistinguishable from "real" hair. It therefore seemed to me that many of the complex, ambivalent and layered meanings in her account were simultaneously performed in the social interaction that was our interview.

The complexities around wig use to disguise hair loss are heightened by symbolic meanings, particularly the cultural association between wigs and comedy:

> *I felt humiliated by the experience initially, I refused to wear a wig as I felt that they were seen as a comedy item although I have started to now.* (SP93, female, heterosexual).
>
> *Also I have to be constantly aware of the wig. I must not wear it when it is windy - the wig flying down the road would probably end up on you tube* (SP61, female, heterosexual).

Here, wigs represent "comedy items", potentially rendering the wearer laughable through failed attempts to deploy them to reiterate normative gender. Fear is expressed that such failure may be repeated again and again on Y*ouTube,* a 21st century technology that regulates and disciplines transgressive bodies, exposing and re-iterating shameful subjects. Such complexities in wig use have been found in other studies (Montgomery et al., 2017; Wiggins et al, 2014), yet many consider the risks, effort and financial cost of using them preferable to going "out and bald":

> *I still wear wigs however I would like to ditch them and embrace the real me. I struggle with headscarves tho and actually find wigs more comfortable! And I would never go out bald as I would hate being stated at constantly and don't want my children getting picked on at school.* (SP14, female, heterosexual).

Again, the belief is expressed that a “real me” exists somewhere beneath performative acts. Yet ultimately what is demonstrated is the constitutive power of gendered discourse; constructed as a woman, subject to discourses of the self-sacrificing mother (Hollway, 1984) and regulated by the stares of others, SP14 continues to discipline herself to conform, despite the sense of disconnection and inauthenticity that prompts psychic resistance, as expressed in the idea of a “ real me” waiting to be embraced.

For others, it is in the performance that the “real me” is to be found:

> *I feel it lets me down - I am otherwise quite fit and happy, but feel I dont look presentable, or even "me", unless I have done my hair and pencilled in the missing eyebrows* (SP76, female, heterosexual).
>
> *For a very long time I felt like I had no idea who I was. I struggled with the idea that I felt like I would have been a completely different person had I not lost my hair. It was only when I started wearing wigs (8 years ago now) that I started regaining my sense of self.* (SP17, female, heterosexual).

Meanings associated with appearance and hair are understood in these accounts to wield constitutive power in the availability of subjectivities, yet also to be limited in that power; other, pre-existing selves are claimed, despite the discursively imposed restrictions. The contradictions that shape life with AA are therefore highlighted here; these other subjectivities can only become manifest through submission to dominant discourses, as performed by engaging in practices that produce a normative appearance.

“Out and bald”: (In)authentically brave

Some female participants chose not to camouflage or cover up their hair loss and their accounts suggest a complex, vulnerable sense of agency. Their reasons varied but included defiance, liberation, and anxiety that concealment of hair loss equates to inauthenticity as a person. For these participants, the inauthenticity of “hiding behind a wig” (SP30, female, heterosexual) is somehow more unbearable than the degendering produced by other people’s culturally located perceptions. Many other participants expressed admiration for those who choose not to camouflage and aspired to do the same. Running through this subtheme are threads of both resistance and submission to gendered discourses that are sometimes explicit but more often opaque and possibly less conscious.

Allowing other people to see their baldness is often described as uncomfortable and stressful by those who choose not to camouflage their hair loss:

> *As someone with alopecia who has chosen not to wear a wig, I imagine there are some who perceive me to not have much pride in my appearance (I have a patchy head which I am comfortable with others seeing). I know that some people perceive me to be someone who wishes to be the centre of attention (not true) and that is why I choose not to wear a wig. The truth is, I just want to be comfortable to be me and I don't really care how others perceive me.* (SP3, female, heterosexual).

This account is filled with tensions and contradictions as SP3 strives to defy the imperative to cover up. She claims agency by stating twice that not wearing a wig is a choice and that she is "comfortable" with people seeing her patchy hair loss. Yet she simultaneously expresses anxiety that attempts "be me" constitute her, for others, as a different subject from the one she claims to be. By not reiterating the normative, appearance-proud woman, she fears that she draws attention to herself and so reveals, not only her AA, but herself as a contradictory subject who seeks attention, yet takes no pride in her appearance. The claim that this is "not true" feels authentic, but her defiant claim not to care about others' perceptions feels more desired than realised.

Unsurprisingly given the complexity involved, decisions not to camouflage are described as "brave":

> *I don't and have only wore a wig on two occasions ever as felt a fraud and fake wanted people to accept the real me not a facade/or fake. Many say I am very strong person viewed as beign very brave* (SP64, female, heterosexual).
>
> *Most people think that I am brave. Brave for facing the world as I am and not hiding behind a wig.* (SP30, female, heterosexual).

In these examples, a brave identity is constructed through ideas of authenticity and agency. Again, wigs are understood to mask not only hair loss but the true self; in contrast, the action of “not hiding behind a wig” constitutes an agentic self, brave for suffering the degendering that is a consequence of this choice. Here, the participants’ own subjectivity is absent; they are brave because others perceive them to be brave for revealing their abnormality. Elsewhere, the bravery imputed by others is explicitly rejected:

> *When people find out I'm 'just' bald, they tell me how brave I am, but I don't think that at all.* (SP11, female, heterosexual).

Despite the emotional distress and cost to sense of self involved in revealing hair loss, SP11 feels unable to claim a brave identity because it is “just hair”, shameful but not as shameful as positioning oneself as brave when hair loss is so often assumed to be caused by chemotherapy, a signifier of life-threatening illness. In this context, to position oneself as courageous would be to undermine the authenticity of the “real me” position that is so frequently mentioned as a reason for choosing not to camouflage.

Others do position themselves as brave for choosing not to wear a wig, but give physical discomfort as the primary reason for the decision, and often also appear ambivalent about the experience and implications of being wigless:

> *I try not to let it affect me day to day. I wear a wig when I go out but recently as it's been so hot I've decided to be brave and not wear one. I wear a lot of make up and have to draw my eyebrows on every day because I feel very unfeminine otherwise.* (SP21, female, heterosexual).

> *I'm out and proud with my baldness. I do have wigs, but they're too hot to wear. I wear a hat if it's cold but otherwise I go au naturel. I don't like being bald and I hate looking in the mirror. When I lost my eyelashes and eyebrows I looked like Voldermort out of Harry Potter. I do feel a bit of a freak sometimes, especially with no make up. But it is what it is, so I try to not to let it affect me too much, certainly when I'm in public I try and stay as positive as I can.* (SP11, female, heterosexual).

Although physical discomfort is given as the reason for not wearing a wig, these participants also claim bravery for revealing themselves to the world as bald women. Threaded through these assertions are contradictions and ambivalence; they labour to convince (themselves) that their baldness does not “affect” them too much or too often. Yet SP11, while “out and proud” with her baldness still hates to see herself in the mirror, and SP21 compensates for her hairless, "unfeminine" head by wearing lots of make-up, thus resignifying herself as woman. Make-up is understood to partly compensate for head baldness, operating not only to conceal absence of eyelashes or eyebrows, but as a citational tool that reiterates femininity – bringing the bald-headed woman into existence. These accounts are marked by tension and contradiction; alongside the empowerment and agency of choosing to reveal their hairlessness, a sense of shame remains, a subjectivity produced through the defeminising effect of hair loss in a world where hair operates as such a powerful signifier of gender. Baldness is not only unfeminine but monstrous and freakish.

At times, rejection of the wig is explicitly claimed as an act of critical agency:

> *nowadays I don't even wear a wig. However, meeting anyone new or being out in public can always promote a mixture or responses both verbal and non-verbal. At times, I die inside feeling like the biggest freak show walking. A hundred eyes staring and pointing, making assumptions, making comments...and I just wish that I was normal. Although, on a good day, I realise what a positive role model I am for self body image, that it is only hair* (SP30, female, heterosexual).

This participant attempts to authenticate the "only hair" idea by positioning herself as a "positive role model". Yet she remains subject to both the dominant discourses, and the contradictions that exist between these and the desired, less distressing meanings. Her words capture the power of dominant discourses in restricting who and how it is possible to be in the world, the "hundred eyes" not only staring but bringing their own "assumptions" and "comments" to bear in a process that is experienced, painfully, as both discipline and punishment. That individuals are constituted as plural, contradictory and changeable subjectivities is shown in the words of this participant. She moves between a restricted, shameful, subjectivity and an agentic, subversive one; capacity for consciousness of, and resistance to, dominant discourses is contextually produced – on a "good day" this is possible, at other times this part of her literally "dies".

Playful performances

For some women, playfulness characterises both submission to an AA identity and resistance to dominant hair-related discourses. This takes various forms, including the deployment of humour, and the utilisation of wigs and scarves to present different identities according to mood and context. As with the choice to be “out and bald”, there is a complex and layered performative quality to these strategies in which contradictions and ambivalence are often discernible. However, the accounts often acknowledge this ambivalence and there are signs that such strategies can help manage distress.

In some cases, humour is explicitly named or referenced as a resource for negotiating the oppressive power of restrictive discourses:

> *Most days I'm OK, I'm quite a positive grounded person and I laugh it off. Use humour and dark humour quite a bit as coping strategies for life pressures anyway. The days that I don't feel as positive I can feel very irritable, low and try to be proactive, so buying svarces, headbands, looking into wigs etc* (SP54, female, heterosexual).

> *A lot of people around me know as I'm quite open about it and have a laugh and joke about it. I think people think I'm quite ok with it and positive about it as I often say it could be a lot worse.* (SP7, female, heterosexual).

In these examples, humour is constructed as a conscious way of coping, available to these participants due to “positive” and “open” subjective qualities – the “positive grounded person”. However, SP54 also acknowledge a “dark” dimension to humour, suggesting awareness that it may also operate unconsciously as a defense mechanism to regulate the deep subjective pain (Kramer, 2010; Vaillant, 2011) produced by restrictive and shaming discourses. This capacity to acknowledge a sense of self as both consciously positive/agentic and unconsciously restricted/oppressed, demonstrates the complex, multiple and contradictory nature of subjectivity.

This complexity and the layers of meaning that can shape its negotiation are exemplified by the interplay of humour and gender. In response to the survey question “how do you think other people perceive you?”, SP49 says:

> *A slightly 'crazy' bald woman, with a good sense of humour and always helping and supporting other's* (SP49, female, heterosexual).

By positioning herself as “crazy” she resists defeminisation – the “bald woman” does exist but only as a transgressive madness. She consciously utilises humour as a coping strategy in her playful presentation of self yet embedded within this is an unconscious signalling of the age-old impossibility that the non-conforming woman can be anything other than mad (Appignanesi, 2009; Ussher, 2011;). Strikingly, this participant also positions herself as altruistic which, like the use of humour, has been described as a mature unconscious defense (see Appendix A) in psychoanalytic theory (Vaillant, 2011). Mature defenses have further been theorised as operating similarly to adaptive coping, or as having a potentializing role in the development of effective coping strategies (Kramer, 2010).

In other accounts the playfulness of humour is accompanied by playfulness in the use of camouflage strategies:

> *I try to see the funny side. I love confusing people by changing my wigs and I have some of the most amazing colour wigs- Alopecia does not define me but has made me who I want to be. It's not been an overly negative experience for me- not all bad. Don't get me wrong I would prefer to be without it but I'm learning to get through it.”* (SP9, female, bisexual).
>
> *I have a different coloured wig for work which is in another town and the rest of the time I wear so I’m ginger for work blonde blonde for here* ((laughs)) (IP4, female, heterosexual).

In these examples, the wig becomes more than a tool for concealment and the coping strategy is more than simply camouflaging. These participants describe playing with different ways of presenting themselves to the world, of performing different identities. IP4 presents herself as “ginger” at work and “blonde” at home; hair colours carry their own gendered meanings (Burton, 2012; Kyle & Mahler, 1996; Shifman & Lemish, 2010; Synnott, 1987) so that this participant can be understood to perform different femininities in different contexts. As an interview participant, she gave this account to me verbally, face to face, rather than in the anonymous written form of the survey. She wore a blonde wig for our meeting and laughed after the words quoted here, communicating to me the humour contained within this decision to vary the identities she presents in different social situations. In addition to deploying humour as a coping strategy, there is a taking control, a claiming of agency; compelled to conceal her uncontrollable hair loss, IP4 finds new subjective possibilities through performing different identities at work and at home. This sense of agency through playfulness is also apparent in the account from SP9 who loves the empowering experience of “confusing people” by changing between her different “amazing colour” wigs. Here again a preference not to have to live with AA is acknowledged, but a way of surviving the distress and challenges associated with it is also demonstrated; the camouflage tool necessary to reiterate normative gender becomes simultaneously the tool of subversion, deployed to trouble people’s understanding of the subject they see.

An important aspect of this playfulness in presentation of psychological and physical appearance is the sense of control over self and interactions with others:

> *Its funny though I wear different wigs everyday short, long, red, pink,grey and I tell everyone I wear a wig but I feel more in control of it that way? As long as you look your best that's what counts...... isn't it??* (SP38, female, heterosexual).

This participant reiterates dominant femininity in which looking “your best” is what “counts”, yet also simultaneously subverts this by disclosing her defeminising hair loss and even playing with it through presenting different versions of woman every day; in the process, she achieves a sense of control within her gendered subjectivity.

Theme 2 summary

This second theme has set out the ways in which male and female participants work at performing gendered subjectivities through choices around grooming and camouflage that can be as risky as they are protective. These citational performances may both re-iterate and subvert dominant gender constructions in conscious and unconscious processes through which participants seek defence against the distressing meanings of non-normative appearance. Gendered discourses mean that the imperative to engage in these practices is perhaps stronger for women, but also that they also have more tools as their disposal than men. The complex and layered processes operating in these performances are especially striking in the interview data, where my role as the one called upon to recognise both the gender performed, and the participant’s agency in resisting subjugation, highlighted the intersubjectivity of meaning-making.

Theme 3: Changing subjects? Ambivalent acceptance, relationships and growth

> *Painful, dynamic, and promising, this vacillation between the already-there and the yet-to-come is a crossroads that rejoins every step by which it is traversed, a reiterated ambivalence at the heart of agency. (Judith Butler, The Psychic Life of Power, 1997, p.18).*

Throughout the data, participants make claims of acceptance and personal growth that often feel incomplete and not entirely convincing, but which also demonstrate attempts to resist restrictive discourses and the shameful subjectivities constituted through them. Relationships with self and others, are frequently mentioned in conjunction with these attempts which seem to involve processes of inter-subjective validation, grief for a lost part of the self, and efforts to materialise desired states. Through these processes, participants position themselves differently within dominant discourses and/or access alternative subjective meanings and practices. Change is discernible in a process that, as Judith Butler (1997) puts it, is painful and vacillating, yet filled with promise, revealing agency through the very ambivalence that produces contradictions in the accounts. Participants frequently demonstrate sophisticated awareness of dominant discourses and the ways they operate to restrict who and how it is possible for them to be in the world. Accounts show participants grappling with the oppressive power of such discourses, yet, in the process, demonstrating agency in which they find and become subject to new meanings that no longer crush them as shameful. The contradictions, the iterative nature of this process, and the role of relationships are captured through three subthemes: 1) Accepting ambivalently – “why fight a battle I can’t win?”; 2) Loving relationships and validating encounters – (re)constituting a subjectivity of worth; and 3) Mourning and growth - “it’s a highly personal journey”

Accepting ambivalently – “why fight a battle I can’t win?”

Acceptance is frequently referenced in the data but is often shrouded in an ambivalence that reveals it to be a reluctantly aspired to state rather than one that is willingly embraced and fully realised:

> *I think they believe I'm doing ok. Especially since I started running the local Alopecia UK support group. i've been described as brave - not sure that's correct. I'd use the word "accepting”. Why fight a battle I can't win.* (SP72, female, heterosexual).

The language of battle signals acquiescence by this participant, to the un-treatability of the condition, and the power wielded by the meanings associated with the hair loss it causes. She eschews the brave identity suggested by others, preferring the word “accepting” with the submission that it implies. Yet in making this assertion she demonstrates agency and subjective change; it is her choice not to fight the battle she cannot win and she thus avoids the shame of defeat. She is ambivalent about change because she is not entirely “ok” as others may assume, but she is creating new possibilities in accepting AA and choosing to run a support group rather than fighting by avoiding social contact or searching fruitlessly for cures, as so many report doing.

This complex and ambivalent relationship between submission and acceptance is a common feature in those accounts where a dynamic of change is apparent. It often involves a letting go of the hope that a cure for AA will be found or that permanent, spontaneous hair regrowth will occur:

> *As there is no medical help then you cannot spend your life chasing your hair, you must learn to live with it.* (SP73, female, heterosexual).
>
> *I don't feel like alopecia is any different to loosing something else you love or having another physical change (such as scaring of amputation)- it's just adjusting, accepting and trying to move on* (SP1, female, heterosexual).

These participants do not attempt to deny the significance of hair, or the power of hair loss in their lives, rather they emphasise them. The image of a life spent “chasing your hair” communicates the senseless energy taken up by the search for cures that fail, and camouflage products that cannot conceal from the self the knowledge that the AA is there. The imperative “must” indicates that through submission some kind of agentic sense of self can be found, a subject learning to “live with it”. Reference to scarring from amputation captures the ongoing pain produced by the reiterative discourses of hair, the subjective role of this loved lost part of the self. In acknowledging the power that hair loss exerts in their lives, these participants also create a sense of authenticity in their claim to acceptance; they are subjects “trying to move on” through “adjusting and accepting” in a process that is painful, and incomplete but happening nonetheless.

In some accounts, the desire to resist through acceptance is expressed, but the accompanying contradictions are so strong that the dynamic of change seems to be lacking:

> *I've become more oblivious to it as time has gone on but it still does get me down and have moments where I'm so insecure I won't leave the house.* (SP13, female, heterosexual).
>
> *You find ways to cope & conceal. I am very open about my condition but people never see it if I can help it.* (SP34, female, heterosexual).

Here, claims are made to the subjective change that might come with acceptance, but the self-reflection and awareness of ambivalence articulated in the previous two examples is missing. Instead, these statements are explicitly contradictory; desire to resist dominant meanings of hair loss through oblivion or openness is subordinate to the ongoing power of those discourses. Here, the longed-for state of acceptance remains a fantasy; subjectivities continue to be shameful and exposure to the disciplining gaze of the world is avoided.

The vacillating and iterative processes involved in working towards acceptance are particularly apparent in the interview data, partly, perhaps, because this format does not allow for editing of responses in the way that may happen in a written survey:

> *it feels a lot freer it feels like it has less control over as a condition erm I still ca-can't quite accept it erm but it it's okay you know it's kind of like what's the worst thing that's going to happen (in this) scenario erm if you're worried about your hair or someone finding out about it or it falling out actually you know what it's really not and I know there are many many worse things that I could experience once but it's just sort of kind of constantly having that visual vicious flower reminder of the impact of how it can kind of build and grow into something a bit more consuming than it needs to be ?* (IP6, female, heterosexual).

The dynamic nature of subjective change is shown here as IP6 moves from claiming greater freedom from the "control" exercised by the meanings associated with the "condition" to recognising she "can't quite accept it" and back to questioning what really is the "worst" that this power can produce. She then references the "vicious flower", a CBT tool for visualising and understanding this cycle, and implies that protection from re-subjugation might be achieved by remembering that ever-present cultural meanings of hair can "build and grow" over time into something "consuming". The process of acceptance is therefore tied up with acknowledgement that subjectivity is constituted within discourse; through this acknowledgement that AA and its meanings are a part of the self, resistance to the shameful subjugating force of those discourses becomes possible. IP6 had experienced a number of different therapies but only this one – CBT with a psychologist - was experienced as "beneficial".

The interview format allowed me to probe how the understanding offered by the vicious flower benefitted her. In response to my question "Are there very tangible things?" she returned to the role that the therapist played in helping her to apply the insights gained:

> *she's [therapist] sort of encouraged me to question and be more assertive in other areas of my life which erm and to to erm gain a greater sense of self-worth erm to kind of really see what my true value is rather than this kind of a perception that actually you know what I'm sor- I'm not that great and I'm you know with all my hair oh my hair this and I won't do that and my hair and all those things erm that I've built up over the years so she's really helped erm yep made me look at every other situation in my life really and think actually I don't need to be defined by my hair I need to have remember that I'm a person beyond someone with alopecia and to have actually connect more with and be a bit s- not stronger but less subjugated.*

It is apparent here that the therapist heard and understood the power of hair related meanings to constitute subjectivity. Importantly, she gave IP6 recognition that she is more than AA, thereby creating a therapeutic relationship that scaffolded the same (re)recognition within her. This validating and psychotherapeutic care contrasts with other experiences reported by other participants in which therapists failed to offer this crucial recognition:

> *The counsellor asked me what was the worst thing about it and I said that it was people staring at me. She stared at me for 2 sessions and it totally freaked me out. So she did exactly the things g which I had told her was the worst thing.* (P29, female, heterosexual).

It is possible that the encounters reported here were shaped by the therapist's theoretical orientation. For example, if she were a classical Freudian analyst she might have subscribed to the "blank screen" view of the therapist's role whereby silence allows for the therapeutic development of a transference relationship (Kahn, 1997). However, the experience recounted here highlights the importance for many clients of feeling heard, and of being recognised as more than thing that prompts them to seek therapy - particularly when this involves the difficulties of living with a visible difference.

The sense that acceptance and subjective change require recognition of the discursive force of hair loss is repeated elsewhere in the data:

> *As it appears I will be permanently affected by this disease - I am now trying to force myself to view my alopecia in a certain way - 'it doesn't matter', 'as long as I am healthy, I should be happy'. I want to be able to confidently talk about it, I want people to ask me about it, I want feel like I have accepted it and that it is just a part of me.* (SP82, male, heterosexual).
>
> *Now as an adult, while I still have bad days where get really down about my alopecia, I have come to a place of acceptance where I am able to see that having alopecia is just a part of who I am. That it doesn't define me as a person and if other people don't see that then I don't want those people in my life.* (SP2, female, heterosexual).

These participants position themselves as constituted within the discourses associated with AA but through this submission assert that they are more this this, the condition is “just a part of me”. The meanings are no longer entirely oppressive because the subject recognises them, including their constitutive power and through this recognition is no longer defined by it, no longer constituted as shameful. Instead, a new agency is found in which AA and its meanings may be spoken about, a chosen subjectivity that contributes to new discourses of hair loss.

Loving relationships and validating encounters – (re)constituting a subjectivity of worth

Just as shameful subjectivities are socially constituted through the restrictive power of dominant appearance norms, a subjectivity of worth may be produced through validating social encounters and the will to build a different relationship with the self. Where this is discernible, claimed or strived for in the accounts, the quality of personal relationships with friends and family is often mentioned:

> *The love and strength of my family and friends have got me to where I am today. I will not let alopecia rule my world it will not bring me down. I never go without my wig but that is a personal choice and I admire those who do* (SP16, female, heterosexual).
>
> *I have been married to a lovely man for 30 years and he has always said and acted as if alopecia didn't matter and this has helped me to heal and grow very much and thus to accept myself better as a woman.* (SP71, female, heterosexual).

These examples show how the (re)constitution of the self as a lovable subject through relationship with friends, family or intimate partner is often incomplete; ongoing struggles are indicated by the need to assert defiance at the power of AA to "rule my world" and in the conditional "as if it didn't matter". These women both acknowledge that they are engaged in a challenging process; the power of gendered discourses of hair and hair loss remains but validating relationships scaffold the exercise of agency and access to subjectivities located within discourses of choice, healing and growth. Elsewhere, however, expressions of love and support are viewed more ambivalently:

> *My family and friends all love and support me. I think some of them feel sorry for me, and I don't feel comfortable with that. I think I am very lucky to have great support.* (SP78, female, heterosexual).

Awareness that some of her family and friends "feel sorry" for her makes SP78 feel "uncomfortable" and she vacillates between thinking herself "lucky to have great support" and a sense of shame and disempowerment at having a condition that prompts pity.

Few survey participants had been offered psychological intervention and, as already illustrated, the data show that experiences were mixed for those who had accessed it. However, where effective therapeutic relationships were experienced, they were understood to promote agency, empowerment and self-worth, thus facilitating subjective change. While telling me about her various (positive and negative) experiences of therapy, IP5 described what was particularly helpful about her current therapist's approach:

> *okay so but now with the therapist I'm with is slightly different and really interesting erm she's perfect for I guess what I need and want now so erm she is amazing she's seriously seriously amazing erm in many ways how does she help me ? erm in making me think about alternatives and making me think about erm what is possible and what*

> *is not possible ((pause)) an- I guess in enabling myself to help myself so that's what I would say that would be the best description of erm ((pause))* (IP5).

This sense of being empowered through therapy to discover "alternatives" and "help myself" is apparent in all the interviews, including the data from IP6 presented earlier. These participants had been recruited on the basis that they had experienced counselling or psychological intervention. They may therefore have been keen to communicate positive features of their therapy in order to satisfy my interest and there were times during the interviews when I felt this might be happening. However, four of the six participants had experienced two or more therapists and described negative, unhelpful or neutral encounters as well as positive ones.

An interesting point to come out of the interviews was that although high levels of AA related distress were described in all six accounts, the subjective change seen to be supported by therapy did not necessarily involve talking specifically about alopecia. As IP5 explained:

> *I mean partly it's about giving yourself space to think about things I guess erm ((pause)) and ((pause)) why is it helpful I mean funnily enough the I went to therapy certainly when I was eighteen for the hair loss specifically ((pause)) I think (.) strangely hair loss has never been the main topic of the therapy erm(.)* (IP5, female, heterosexual).

This participant had accessed a number of therapies and spoke enthusiastically about most of them, describing therapy elsewhere in the data as "empowering it- that's what it is, incredibly empowering". It was only during the interview that she realised her hair loss had never been the main topic; her surprise, expressed here through the word "strangely", reflects the significant effect that she describes AA as having had on her sense of self and relationships.

IP1's interview provides a possible explanation as to why therapy might allow the impact of hair loss to be worked through without being the explicit focus in sessions:

> *Well, I think the counselling wasn't so much about me having alopecia. My counselling was more about going back before you can go forward. I don't think anybody (.) would just (.) after having sessions of counselling (.) after you know first*

> *experience of losing all their hair (.) get over it in a year. I think you have to go back (.) in order to go forward. And there's always a story behind everybody's condition* (IP1, male, heterosexual).

The process of therapy is associated here with space and time, a "going back" in a process of deconstruction through which understanding of the self is developed, making it possible to "go forward" re-constituted as a subject with a whole "story" rather than one defined only by AA. Importantly, this is understood as an ongoing process, the subjective changes produced by "losing all their hair" require sense-making over time; resistance to the meanings associated with it cannot be achieved quickly - it is not possible to "just get over it in a year". Multiple experiences of therapy may therefore be sought out at different times as encounters that support this ongoing process of change:

> *And it's just more about having the conversation because what you have to do with alopecia is you have to learn how to conversate again, you have to learn how to put yourself around people and (.) have a conversation without it going around in your head (.) they're thinking I've got no eyebrows (.) you have to because it (.) you can't block out the white noise until you got enough confidence to have a conversation about anything in the first place* (IP1, male, heterosexual).

IP1 describes here how therapy, as well as offering a space in which a meaningful self-narrative can be constructed, is a process in which it is possible to rediscover how to relate to others, to escape the "white noise" of dominant hair loss discourses and so find confidence to have new conversations with self and others. That this subjective re-constitution is a narrative process is important to reflect on here; at times I did not feel fully convinced of the "story" of change being presented in the interviews or indeed in the survey data. Yet this performative quality can also be understood as part of a process of resistance, a subversive re-iteration through which the possibility of authentic change may become manifest over time.

In addition to personal relationships and individual therapy, face to face and online groups are a third form of social interaction that feature prominently in the data as being helpful for coping, resisting and growing:

> *I also joined a support group through Alopecia UK and meeting others with Alopecia made a huge difference to me being able to cope with the condition. Having Alopecia*

> *then just became part of my life but not the defining part.* (SP56, female, heterosexual).
>
> *Alopecia U.K. Facebook group was most helpful as I don't feel alone and it's good to talk to others and most of all normalise alopecia (seeing bald people talking about wigs on Facebook everyday!). That helped more than anything.* (SP1, female, heterosexual).

Both online forums and face to face support groups offer normalising encounters and reduce the sense of isolation produced by AA. This not only makes it more possible for people to "cope" but also produces possibilities for more fundamental change; AA can become "just a part" of life, rather than "defining" it, loosening the restrictions produced by dominant discourses and opening access to other subjective possibilities become accessible.

However, involvement with groups of people brought together through a shared AA identity can also present risks to possibilities for resistance and change:

> *But they [other people in the support group] seemed to have money and so they were affording these really lovely human hair wigs that they could get personally fitted and tattooed eyebrows at three hundred pounds a pop and tattooed eyeliner at three hundred pound a pop and I was like I cannot do that I can't afford that and so in end I just felt I wasn't being helped by that cos I could see they had something better than what I had but I couldn't afford it.* (IP4, female, heterosexual).
>
> *Being on a Facebook support community group I see lots of pictures of beautiful bald women and I think they look fantastic and very attractive. As a 50 something, tubby woman I don't feel it is easy to get away with it.* (SP25, female, heterosexual).

In these examples, dominant discourses of beauty are reiterated in the conversations and images present within the groups. In the first case, the group is experienced as promoting the idea that a normative beauty ideal that must be strived for by women can be attained if you just have enough money. In the second, bald can be beautiful but only for thin women.

Groups may therefore operate to sustain distressing ideas and practices, reinforcing shame through guilt at not being bald enough or simply by acting as a reminder of the AA and its impact, thus perpetuating a restricted sense of self:

> *I don't wanna' meet with other people who've got it any more so that's just a reminder so despite the money thing that was the reason I stopped at the time* (IP4, female, heterosexual).
>
> *I have previously used web based groups & social media etc but often get made to feel guilty as my areata is not obvious.* (SP26, female, heterosexual).

Constitution of subjectivity arises within multiple, contradictory discourses; it is therefore unsurprising that social encounters entail varied and complex meanings which influence subjective resistance and subjugation over time. However, inter-subjective relationships do seem to have a key role in challenging the shame of a non-normative appearance and facilitating constitution of a subjectivity of worth.

Mourning and growth – "it's a highly personal journey"

Despite the restrictions, pain and suffering shown in the data to be so prevalent in people with AA, the accounts also include expressions of hope that a life free from restrictions and shame is possible:

> *There is hope of a full life with alopecia, many men and women suffer, getting other alopecia 'friends' really helps!* (SP77, female, heterosexual).

This was SP77's answer to the final survey question which asked "Is there anything else that you think it is important for me to know about what it is like for you to live with alopecia? Please include anything that feels relevant or significant to you". Her final word on her experience of living with AA was therefore to claim agency, the power to choose hope and "a full life" in place of one formed in submission to distressing meanings that restrict who and how she is able be. Like other participants, she highlights here the importance of validating relationships, her "alopecia friends", in making this kind of hope realisable.

While inter-subjective relationships are understood to be important for the development of hope, coping and growth, the data also suggest that mourning for what has been lost is necessary for these to take place:

> *It's like loosing a piece of you. Nothing makes sense and you cannot recognise yourself. It's a highly personal journey which has to be taken at an individual pace.* (SP34, female, heterosexual).

SP34 implies that there is a need to recognise what has been lost before it is possible to move on. This "highly personal" process can be understood to involve recognition of the changed physical appearance that AA brings, but also the lost subjectivities produced through loss of this normative appearance. This sense that a part of the self has been lost is repeated throughout the data, as are references to grief and bereavement:

> *I've been through the change cycle, dealt with the grief of loss and now embrace my uniqueness.* (SP52, female, heterosexual).
>
> *losing hair is a grieving process and the emotions felt mirror those experienced by those suffering a bereavement.* (SP3, female, heterosexual).

These accounts can be understood to describe a need to mourn the lost object produced by the symbolic meanings of hair, and the idealised, normative subjectivity that is lost with it. As with other forms of loss and bereavement, the process of mourning can produce healing, thereby creating possibilities for new meanings and subjectivities such as SP52's "uniqueness".

However, even where hope and new possibilities are realised, subjectivity frequently remains characterised by ambivalence:

> *I really struggled with feelings of depression and anger in the first year. I resented having alopecia for the following couple of years but I no longer feel that way. I'm grateful for some of the things alopecia has brought to my life - new friends, new experiences, new career(!) and I just feel it's shaped me into a better person. Sounds dramatic but it's how I feel about it. It's not to say i'm grateful to have alopecia and pleased it's occurred. I think I'd still prefer overall to have never lost my hair but I*

> *can see the positives in it and I don't resent it in the same way.* (SP3, female, heterosexual).

Once again, a sense of authenticity is produced by the ambivalence expressed in the account; SP3 would prefer not to have AA, but has struggled through the depression that accompanied its onset to reconstitute herself within a discourse of post-traumatic growth (Tedeschi and Calhoun, 2004). At the same time as acknowledging that she would prefer never to have lost her hair, SP3 claims a subjectivity of hope and self-worth in which the journey through meanings of hair and hair loss have shaped her “into a better person” living a full life with “new friends, new experiences, new career”.

New experiences, relationships and opportunities are frequently described in those accounts that suggest change and growth. Notably, a sense of altruism frequently features in these accounts:

> *when I started up the alopecia group I actually put my phone number on there so that people could ring me because I knew how desperate I'd felt at times and actually somebody did ring (.) and they felt really really down and so I felt I'd helped them erm (.) so yeah that might help ((pause))* (IP4, female, heterosexual).
>
> *what I've found through alopecia and I noticed since I've had alopecia I've been doing more and more talking in relation to equality and stuff like that even before I was a school governor which then kinda set me on that path erm which I think is really important.* (IP1, male, heterosexual).

These participants describe a transformational move in which they reposition themselves from restricted subjects of distressing discourses to subjects who are empowered through those oppressive experiences to help others. As already mentioned, within psychoanalytic theory it has been proposed that altruism and other “mature defenses” (Vaillant, 2011) may be related to, or facilitative of, the development of effective coping strategies (Kramer, 2010). Here, it can be understood as both the suppression of oppressive hair-related meanings, and the realisation of desire to overcome restrictions and shame. This offers a way to understand the ambivalence and vacillation that can be identified throughout the data as participants struggle to live with this appearance-changing condition in a world that places such value on physical appearance (Dittmar, 2007; Grogan, 2016).

Theme 3 summary

This final theme shows that resistance to the restricting and shaming power of dominant hair-related discourses is possible, if characterised by ambivalence, vacillation and contradiction. Relationships with other people are shown to be crucial in enabling resistance, whether in the form of loving friendships, sensitive professional encounters, or mutually supportive contact with others living with AA. These relational experiences can offer people with AA both validating acknowledgement of the suffering it can produce, and recognition that they are more than the condition. Alongside these validating encounters, resistance and growth involve acknowledgement that living with AA involves loss, theorised here as loss of an "ideal" (Butler, 1997, p.172) gendered subject, the heteronormative and desired object produced by dominant discourses, and reinforced in media images, insensitive health care, and even AUK support meetings. The gendered meanings associated with hair loss mean that for people with AA, the possibility of becoming this gendered ideal subject is foreclosed, a loss that brings distress akin for many to the depression defined in psychoanalytic theory as "melancholia" (Freud & Ellman, 2005; Leader, 2008). Recognition of this loss allows for mourning through which desire and hope can be reborn, bringing new possibilities for growth and the formation of a subjectivity of worth.

Discussion

From abstract theory to real world difficulties: applying poststructuralist feminism

In the introduction I proposed that poststructuralist feminist analysis can produce knowledge with value to the practice of health care professionals working with people who have an appearance-altering condition. I put the case that this analytical approach can help therapists and other practitioners to understand the socially constructed meanings that operate to produce subjective distress in the clients and patients they work with. The data presented in the analysis offers such insights and demonstrates their vital importance to the provision of care for people with AA, as well as, I would argue, others with a visible difference or appearance-related distress.

The mix of discursive and psychoanalytic ideas in Butler's (1990; 1993; 1997) theorising of the body, subjectivity and agency made possible an exploration of the complex, contradictory and ambivalent processes that operate in the subjectivities of people with AA. Application of these abstract theories to real world experiences (Speer & Potter, 2002) generated an understanding of the existential threat that is produced when uncontrollable biochemical processes reveal gender to be socially constructed in a cultural and economic world that continues to subjugate through gendered regulatory norms. Importantly, this approach also generated insights into sources and processes of resistance, whereby supportive, sensitive and loving relational encounters can facilitate recognition in people with AA that they are more than this condition. Through such recognition, it becomes possible for the lost ideal, constituted through dominant discourses, to be mourned, and for other subjectivities to be (re)recognised and formed. These findings have implications for the health care offered to be people with AA and can additionally inform how psychological therapists might work with clients who present with this condition. The discussion that follows will reflect on the processes through which this analysis was generated before setting out recommendations for practice based on the knowledge that it produced.

Representations and readings of subjectivities: Reflections on surveys and interviews

I chose to analyse the survey responses and interview transcripts as a single dataset in order to look for broad patterns that answer my questions about discourse, subjectivity, coping strategies and helpful resources in the experiences of people with this untreatable, appearance-altering condition. One of the most striking features of this full dataset is the sense of ambivalence and vacillation in participants' accounts; in this respect there is no difference between those provided in writing, anonymously, and those given verbally, face to face. However, my place in generating the data was different for the two sources, and this influenced my responses and the development of my interpretations. Equally influential was the process of moving iteratively between designing the data collection tools, collecting the data, preparing downloads and transcriptions for analysis, and coding and organising the data into candidate themes. It is therefore important to reflect on these processes and their role in producing the representations and readings that resulted in the analysis in this thesis.

As planned in the original project design, I completed preliminary analysis of the majority of the survey data in order to decide what to probe further through face-to-face interviews. At this stage, I identified dominant discourses of hair and hair loss and looked for other significant features or gaps in the accounts. I noted the lack of diversity in the sample and therefore sought targeted channels through which to recruit additional participants. These proved to be of limited success, as outlined in the Method chapter. However, it meant that I left the survey open for as long as possible to allow for submissions resulting from these efforts, and consequently the final survey data were incorporated into the analysis after transcription of the interviews, many hours of coding, and the development of a number of preliminary themes. This process influenced my recursive engagement with the data which occurred over an extended period, alongside ongoing exploration of relevant research and theoretical literature, before I began to finalise the themes. This resulted in a greater theoretical structure to the analysis than might otherwise have been the case.

In the preliminary analysis of the survey data I was also struck by the gendered nature of the identifiable discourses, the high emotional content in the accounts, the contradictory and ambivalent nature of attempts to resist distressing meanings, and the inadequacy of health care provision for people with AA. Few participants had been offered any form of psychological support, an important finding given the levels of distress expressed and the recommendations by both BAD and NICE that it should be considered. As a therapeutic practitioner, however, I was disappointed by the lack of data relating to experiences of therapy. Woven through the distress described in the accounts, I could see attempts to claim alternative, freer and more hopeful subjectivities and was curious to know whether psychological and psychotherapeutic interventions might have a role to play in facilitating these possibilities. This drove the decision to recruit interview participants who had experienced some form of counselling or psychological support since developing AA.

My hope was that the interviews would generate insights into what forms or features of therapy are experienced as helpful or unhelpful by people with AA. However, I was unable to identify any meaningful patterns around this, even when I conducted selective coding in which the data corpus consisted of all therapy-related data items from both the interviews and the survey (Braun & Clarke, 2013). This was partly due to the fact that not all participants were able to name the type of therapy they had accessed, while those therapies that were identified were very diverse - CBT, psychodynamic counselling, person-centred counselling, kinesiology and hypnotherapy were all among those named. On reflection, I can see that a more comparative design would be needed to generate data to support such an analysis. My questioning in both the survey and the interviews was on the broad experience of living with AA, and questions about therapy were included as one aspect of this. I chose to frame the questions in this way for the interviews as well as the surveys as an attempt to leave space for participants to describe therapy as either neutral or unhelpful. To investigate the forms or characteristics of therapy that are helpful for people with AA, it would be more fruitful to recruit participants who had experienced named therapies, to ask them to say whether or not they thought it had been impactful and then ask questions relating to which approaches, tools and techniques were or were not effective. This presents an area for future research; the anonymity offered by online qualitative surveys and their potential to generate sufficiently large samples for comparative analysis (Terry & Braun, 2017) mean that this method would offer a good data collection tool for such a study.

The interviews did compliment the wide-angle lens offered by the survey in that they generated greater depth of data around the subtle and complex processes of subjective resistance and change that had struck me in the preliminary analysis. The patterns identifiable in these processes provide important insights into what can help people with AA to resist restrictive and shaming discourses and access other subjectivities. One notable finding is that the interview participants believed therapy to be a significant resource for developing ways of coping with the challenges of living in this “image-orientated society” (Delamere et al., 2008, p.4) where, as shown here and elsewhere, the presence, absence and grooming of hair is central to the construction and performance of identity (Barber, 2008; Basow, 1991; Clarke & Braun, 2019; Fahs, 2011; Frank, 2014; Terry & Braun, 2016). Consequently, the third theme, organised around the complex relational processes and resources involved in change and growth, draws more heavily on the interview data.

The interview participants knew that I had a particular interest in their experiences of therapy, and that the study forms part of my training as a practitioner. Some of them expressed curiosity around the relationship between my research and my practice, and I understand this to have influenced their accounts, particularly in relation to their reflections on the value of therapy. As is consistent with ethics and quality frameworks for qualitative research (Brinkman & Kvale, 2017) I also disclosed in both the survey and interview participant information sheets (see Appendix K for the interview Participant Information Sheet) that my interest in AA is partly motivated by the experiences of someone close to me. Several interview participants were also curious about this. The ethics of self-disclosure in research, as in the therapy room, can be complex (Clarkson, 2003; Hayfield & Huxley, 2015; Tribe & Morrisey, 2015). I was asking permission to probe these participants’ sensitive personal experiences, but their questions related to another person’s story as well as my own. In the contained privacy of the interview context, I considered it ethical to answer openly, albeit in a boundaried way, providing additional information that would not be appropriate in the more public and written contexts of the survey or this report. As an “outsider” researcher in that I do not have AA, my willingness to share something of myself is likely to have influenced these participants’ engagement in the interviews during which they shared very painful and sensitive experiences with me (Hayfield & Huxley, 2015).

In navigating the ethical complexities around self-disclosure, I drew upon the reflections and skills nurtured through my development as a therapist, a helpful intersection between the practitioner and researcher roles (Hanley & Amos, 2017; Strawbridge & Woolfe, 2010). At other times, however, this intersection felt more challenging and my identity as a practitioner may have hindered my role as a researcher. For example, the experiences of therapy that the interview participants reported ranged from transformational to helpful, neutral and unhelpful, but four of the six had accessed multiple therapies and all described at least one positive experience. Although I was convinced by their accounts of therapy as helpful, I felt at times that they were working hard to show or perform the change they were ascribing to it. Consequently, there were moments when I noticed contradictions or inconsistencies in their accounts but consciously resisted the impulse to probe, concerned about the ethics of drifting into socratic questioning (Padesky, 1986), or reflections on possible unconscious processes (Clarkson, 2003) thereby inappropriately confusing the researcher and practitioner roles.

I wonder if this concern to maintain an ethical boundary around my less familiar researcher identity led me to avoid questions that could have generated further depth or illumination in the data. The ways that I draw upon myself in my therapeutic practice have developed through many client hours and with the passage of time; through each interview I found myself adjusting the ways I drew upon my practitioner experience to inhabit the role of research interviewer, learning skills that I can see also take many encounters to hone (Braun & Clarke, 2013). Ultimately, my experience in this study has been that qualitative research, like relational therapy, involves reflexive processes in which multiple subjectivities are recognised and acknowledged in intra- and inter-subjective dialogues that can generate new meanings and new subjective possibilities.

Discourse, subjectivity and affect: Performing restriction and growth

In my reading of the data collected for this study, I saw a story in which dominant social and cultural meanings constituted subjects as restricted and shameful, crushingly punished for appearances that transgress gendered norms as a result of a condition that biomedicine is powerless to treat. Yet interwoven with this I also saw subjective desire for change, the will to survive and grow, and processes through which such changes are performed. I was unsurprised by the striking operation of discourses in constituting and regulating subjectivities, but I was taken aback by the force and depth of pain, suffering and shame that were communicated in the accounts. These elicited in me unanticipatedly strong emotional responses, including feelings of sadness, anxiety and frustration that were manifested in embodied affects of raised pulse, tingling skin and watering eyes.

A criticism of social constructionist and poststructuralist research is that it can neglect the emotional and affective dimensions of being (Cromby, 2011). Yet the rich emotional and symbolic language deployed by participants in this study produced for me an “affect-laden intersubjective encounter” (Cromby, 2012, p. 91) precisely because of the discursive meanings that I understood to be referenced, and the oppressive power I saw these to have in constituting subjectivities. The poststructuralist feminist approach used to analyse this data therefore made possible an engagement with the embodied, affective nature of subjectivity, *together with* its constitution through socially produced meanings (Grosz, 1994; Ussher, 1997; Flax, 1990). I have attempted to write this embodied affectivity into the analysis I have presented – whether I have been successful in my endeavour lies in your reading.

Many of those participants who had found, or were developing, ways to adjust to living with AA, communicated a desire to share their learning, through setting up support groups, offering a sympathetic ear at the end of the telephone, or simply by communicating to others that things can get better. In fact, it seemed to me that many people were motivated to take part in the study because it offered them the opportunity to tell their story, to describe the challenges produced by their hair loss, have their achievements in overcoming these difficulties heard, and argue for better health care. While I believe that altruistic motives in part underlie such impulses, I also see an element of performativity at work, whereby the change that strives to be communicated is not always entirely convincing, not complete, yet becomes more formed through reiteration of the alternative meanings that are claimed. Through offering their discourses of growth to me and any audience this study might reach, these participants inscribe their embodied existence with new, more empowered meanings. This process is ultimately relational, often involving re-connection with repressed subjectivities and with the social world. In the data, validating encounters with other people are key in facilitating resistance and re-connection. Insensitive intersubjective experiences reinforce distressing meanings, but insightful, kind and loving encounters can operate as an antidote to shame, making possible a more hopeful sense of self. By repeating these hopeful meanings in their accounts, while also repeating contradictory and ambivalent positions, the participants engage in a performative process of subversive reiteration - the research process offered one intersubjective channel through which this could be enacted.

I am conscious that performativity also shapes the analysis itself; the structure I have imposed in my presentation of the data enacts my own subjectivities, reflecting my ontological belief that we are constituted through unconscious as wells as conscious processes (Clarke et al., 2008; Flax, 1990), and my orientation towards hope and optimism. In part, it was this orientation that led me to counselling psychology, a profession that allows for reiteration of this kind of subjectivity through research-informed practice in which relationship with self and other are understood to constitute the heart of therapeutic change (BPS, 2005; Jordan, 2017). I was drawn to this profession because the constitutive power of relationships is my subjective experience and I believe in the power of relational therapy (Clarkson, 2003; Greenberg & Mitchell, 1983; Kahn,1997; Loewenthal & Samuels, 2014) to facilitate helpful change and growth, a position consistently supported by common factors research into client outcomes (Cooper, 2008; Wampold, 2015). These ontological commitments and beliefs colour and shape the analysis I have presented just as much as my epistemological position that what is knowable is socially constituted (Lyotard, 1979).

It is important to acknowledge that the participants' subjectivities and intersubjective encounters are also constituted by more than the discourses referenced in this thesis. An approach focusing on individual narratives, exploring the intersection of AA related discourses with other life experiences and meanings, deploying, for example, a narrative inquiry approach (Hiles, Cermak, & Chrz, 2017), would add a different layer of understanding to that offered by this analysis. Alternatively, a study designed as pluralistic at the outset could apply narrative and psychosocial lenses to the same dataset to produce multiple, layered interpretations (e.g. Josselin & Willig, 2015). However, the aim of this study was to identify themes across the dataset that could provide insights into the meanings of AA, the ways these can operate in the constitution of subjectivities, and how practitioners might utilise this knowledge to ameliorate distress for people with the condition. Butler's (1990; 1993) concept of performativity proved a valuable analytic tool for making sense of the psychic power of discourses, their operation in restricting who and how it is possible to be, and the shame that can shape this embodied existence. It also offered a conceptual tool for identifying and reflecting upon conscious and unconscious relational dynamics of resistance and subversion, which generated insights that can usefully inform practice in health care and psychological provision for people with AA.

In the data, encounters with health care professionals were often distressing because, through their words and manner, practitioners reiterated distressing meanings and therefore deepened the very wounds that had prompted participants to seek help. Such performances are embodied, intersubjective and intrasubjective; in medical consultations and in therapy, the bodies of client and practitioner are both present, constituted through discursive meanings that may or may not be shared or conscious for either person (Orbach, 2009). Awareness of these meanings and affective sensitivity to their emotional and psychological impact has the potential to influence the quality of interaction provided by practitioners. In the context of psychological therapy, there is the opportunity to notice, speak of, and explore these discursively shaped performances, although the skill to do this ethically and helpfully requires a developed reflexive capacity on the part of the therapist (Willig, 2019). Approached in this way, the potential is created for distressing meanings to be subversively re-iterated through a therapeutic relationship which creates new discursive, and therefore new subjective, possibilities (Gergen, 2015; McNamee & Gergen, 1992).

Shared subjectivities – promoting social justice and communities of knowledge

When I embarked on this research project I was committed, for both ethical and personal reasons, to ensuring that the knowledge produced would have the potential to impact positively on the lives of people with AA. The paper published in the *BJD* is one channel through which this might occur in that it promotes better-informed and more sensitive health care for people with the condition. However, an ethical stance that includes a social justice perspective also challenges us to share knowledge produced through academic study with people affected by the topic of exploration (Kagan, Tindall & Robinson, 2010; Kagan, 2015). This means developing ways of communicating research that extend beyond the traditional academic media of published papers and conference presentations.

Community psychology shares counselling psychology's social justice agenda (Kagan, Tindall & Robinson, 2010; Kagan, 2015), but is also defined by an explicit commitment to praxis - the integration of theory, research and practice (Malpert et al, 2017). This commitment has led community psychologists to generate examples of creative research design and communication that utilise diverse and accessible media (Malpert et al., 2017). For the research presented in this thesis, there is a threefold rationale for taking such a community psychology informed approach to communicating the knowledge produced:

1) To offer validation and hope to people with the condition by sharing the themes identified in the analysis. Specifically, to acknowledge shared subjectivities of shame and restriction that can accompany this condition, and to share possibilities for resistance, acceptance and growth.
2) To provide a resource that can be shared with the family and friends of people with AA, thereby facilitating awareness and understanding about its impact. Through this, to help create communities of knowledge that can offer the loving and validating relationships that promote resistance to distressing meanings and access to subjectivities of worth.
3) To promote a wider social justice agenda by demonstrating how the distress associated with AA is socially produced. Significantly, the psychological impact of socially dominant meanings in people with this appearance-changing condition creates an imperative for psychologically informed health care that better supports resistance to these distressing meanings.

The visual power of the discourses present in the data has prompted suggestions that the knowledge produced in this research might be effectively shared in the form of a documentary film. I share this view, and it is an idea that I may explore in the future. However, the resources and challenges involved in developing such a project prompted me to explore alternative media, in conversation with the person in my life who lives with AA. Together, we are developing an idea whereby the themes I generated in my analysis could be shaped into a series of podcasts. This would be more time and cost-effective than a film documentary, and potentially just as impactful given the vivid and emotive quality to the language in the participants' accounts. Audio media also allow people to speak without being seen, an important consideration given that such a project would ideally involve the voices of people with AA and, as this study has shown, visual exposure can involve complex challenges for people with the condition.

This idea is currently at an early stage of development; careful consideration of ethical questions is called for, particularly regarding use of quotations from the data, development of a participatory approach to production, and appropriate channels for publishing the podcasts. Additionally, the themes would need to be renamed and therefore redefined somewhat in order to make them accessible to a non-academic audience, a process through which some richness and nuance is likely to be lost. However, the data show that online resources can offer people with AA access to both validating acknowledgement, and strategies through which to resist or at least cope with distressing meanings. Production of a series of podcasts therefore offers a promising means of reaching beyond the confines of academic publishing to share knowledge in ways that speak to, and benefit, people with AA.

Relational subjects – implications for health care practice with people who have AA

This study demonstrates how subjectivities are relationally constituted and shaped. Socially produced and performed meanings therefore operate both to restrict and shame people with AA, and to engender (ambivalent) acceptance and growth in them. Existing studies on experiences of living with AA, including its psychological effects, highlight the shame, distress and social avoidance that it can produce in people (Hunt & McHale, 2005; Matzer et al., 2011; Rafique & Hunt, 2015; Rencz et. al., 2016; Tucker, 2009; Welsh & Guy, 2009; Wiggins et al., 2014). However, what is missing from almost all these studies is consideration of how and why these difficulties in living are produced, and what might therefore ameliorate them. The exception is the Wiggins et al., (2014) study which provides some insights into the discursive production of meaning in relation to wig use as a tool for coping with hair loss. The poststructuralist feminist approach used in this study allowed for a broader and deeper analysis that demonstrates the problematic ways in which culturally located meanings can operate to shape interpersonal encounters with professionals, friends, family and others. These findings have implications for health care systems and the practice of professionals involved in the care of people with AA, as detailed in the following six recommendations:

1. Practitioners need to be aware of the social and cultural meanings associated with hair loss in order to ameliorate distress by offering insightful and sensitive consultations.

As shown in this study, a failure to recognise the symbolic and cultural associations of hair and hair loss can result in dismissive and insensitive provision by doctors, nurses and psychological practitioners. This failure operates to reinforce distressing meanings, thereby exacerbating the negative effects of AA on patient identity and quality of life. Conversely, sensitive, discursively informed encounters can reframe participants' sense of self in the world, and so ameliorate the impact of AA in their lives. The problematic encounters with doctors in this study are consistent with experiences reported by other dermatology patients (Papadopoulos & Walker, 2003) and provide further support to calls for training to improve dermatologists' sensitivities to the psychological effects of skin conditions (Bewley et al., 2013). The analysis presented here shows that any such training should emphasise how social and cultural meanings operate to produce distress. In particular, the significance of gendered discourses to experiences of anxiety and depression needs to be highlighted. However, given the current lack of such training, it is important that GPs, specialist nurses and dermatologists engage with qualitative research literature in order to develop insights into patients' experiences that can promote reflexive and sensitive care.

2. *Practitioners need to be aware of specialist support and information, and provide effective signposting to it.*

Although interaction with AUK and other people with AA can be complex - for example, by reinforcing a victim identity or highlighting the impact of wealth disparities on access to camouflage products - many participants emphasised the importance of these sources of information and support. There were also frequent expressions of anger and frustration that doctors had failed to mention such resources, meaning that participants had found them independently, often after prolonged periods of isolation which had resulted in increased distress. Practitioners should provide information about how to access AUK, online forums and face-to-face support groups, and explain that many people find them to be helpful sources of social support, as well as sources of information and tips about camouflage products and techniques. Moreover, by signposting to these resources, professionals can demonstrate sensitivity to the lived experience of AA as more than "just hair" loss through explicit acknowledgement that the meanings associated with the condition have significant psychosocial effects. They would then be providing the supportive and validating form of social encounter that is shown in the data to be so crucial to the development of a subjectivity of worth.

3. Specialist services should develop information resources for the families of people with AA that explain the impact of social and cultural meanings of hair loss and include attention to its possible effects on intimate partner relationships.

In the data, personal relationships were particularly powerful in shaping the subjective power of AA related discourses. Sensitive support over time from family, friends and intimate partners seemed to mediate against the shaming and restrictive meanings of hair loss. Given that partners, family, and friends, like doctors, nurses and psychological practitioners, are subject to the same cultural discourses as the wider public, they may (unwittingly) reinforce distressing meanings. Particular difficulties may arise in romantic and sexual situations, as highlighted in previous research into the experiences of people with visible difference, including AA (Sharratt, Jenkinson, Moss, Clarke & Rumsey, 2018). There is therefore a need for accessible information that can inform understanding of the condition, the meanings of hair loss, and the impact it can have on identity, social interactions and personal relationships. Such resources could facilitate discussion and understanding between the person with AA and the people in their lives. This may help nurture the supportive personal relationships that have such power to interrupt reiteration of restricted and shameful subjectivities.

4. Intervention needs to be offered soon after first onset of hair loss

Many participants who had not received counselling or psychological intervention said they thought it would have been helpful but had not been offered it. However, many of these participants also said they felt it was now too late and that it needed to be offered soon after first onset of hair loss. This, together with the failure of GPs and dermatologists to signpost to AUK and other forms of social support, demonstrates operation of the dismissive “just hair” discourse that is so significant in the constitution of shameful subjectivity. The contradictory meanings of hair loss produced by discourses of gender and of illness, operate in particularly crushing and insidious ways to isolate and alienate people with AA from others and themselves. Early access to validating social encounters through therapy, or just knowing that others share their experiences, has the potential to significantly affect subjectivities and quality of life over time.

5. People with AA should have consistent access to wigs via the NHS by suppliers who understand the condition and its psychosocial effects.

Some participants described being unable to access wigs via the NHS, and others reported insensitive treatment by staff more used to fitting wigs for chemotherapy patients. Both kinds of experience reinforced the distressing “just hair” discourses that so significantly shaped participants’ subjectivities. These findings are consistent with recent research that has identified a post code lottery in NHS provision of wigs; some Trusts approached under Freedom of Information legislation explained their failure to provide wigs to patients with AA on the basis that “alopecia is a cosmetic issue” (Johnson & Montgomery, 2017, p.4). As with previous studies (Wiggins et al., 2014; Montgomery et al., 2017), the data reported here show that wig use can involve complex psychological challenges for people with AA, but that many consider wearing a wig to be less distressing than going “out and bald”.

6. There is a need to develop specialist psychological provision for people with AA

Few participants had been offered counselling or psychological therapy either by their GP when they initially sought help for their hair loss, or by a dermatologist if they had been referred for specialist consultation and diagnosis. Very little research exists into what forms of psychological intervention are helpful, although group therapeutic interventions have shown promise. A Mindfulness-based course that offered the opportunity to develop coping strategies alongside others with the condition reported positive outcomes (Gallo et. al, 2017), and a recent study demonstrated the benefits of online peer support for people with AA (Iliffe & Thompson, 2019). However, ultimately, the absence of a meaningful research base may help explain the lack of detail around psychological provision in the NICE Guidelines for AA.

Given the evidence-based framework that drives access to treatment with the NHS, there is a need to build an evidence base that can support development of clear pathways to psychological interventions that meet the needs of people with AA. In the absence of this research literature, the key relevant finding offered by this study to doctors and dermatologists is that development of effective coping strategies and cultivation of acceptance require validating relational encounters. These can be provided through group interventions that facilitate sharing of experiences and within any form of individual therapy that places high value on the therapeutic relationship. This relational orientation may be found within a wide range of therapies including psychodynamic counselling, cognitive behavioural psychotherapy, existential therapy and person-centred counselling (Loewenthal & Samuels, 2014). Referral to available psychology or High Intensity IAPT services should therefore always be offered to patients at initial and subsequent consultations.

Disrupting restrictive discourses and facilitating a subjectivity of worth: Psychotherapeutic possibilities for people with AA

Within the medical model that dominates NHS culture, referral for psychological support continues to be tied to diagnostic conceptualisations of mental health. Although some participants used diagnostic terms such as depression, anxiety and Post Traumatic Stress Disorder (PTSD) to describe the impact that AA has had on them, the onset of AA itself does not constitute a mental disorder. Systemic biomedical discourses and their influence on referral practices for psychological support may therefore explain why so few participants were offered referral to psychology or talking therapies services (Wade & Halligan, 2017).

The Power Threat Meaning Framework recently published by the Division of Clinical Psychology (BPS, 2018) is an attempt to move beyond reductionist diagnostic approaches to psychological and emotional distress, to one that is located within dynamics of power and subjective meanings. However, its focus is on the impact of interpersonal trauma, the threat this can produce to sense of self over the long term, and the very severe distress and psychological fragmentation that can consequently occur. This focus is explained by the much-needed challenge that the framework makes to the dominance of psychiatry and reductionism in discourses of mental distress, and their problematic consequences for the nature and accessibility of psychological intervention. However, such an approach also risks perpetuating a model designed around people presenting to services for the long-term consequences of difficult experiences, rather than one that offers opportunities for meaning to be explored at the point when subjective challenges arise.

The analysis in this study shows how the emotional and psychological difficulties described by so many participants are constituted within a discursive net that is woven by layered meanings enacted through subjective and intersubjective responses to the hair loss of AA. The ways in which subjectivities are influenced over time is therefore dependent on the subjective power of dominant discourses, which in turn is influenced by access to alternative discourses, particularly through validating relational encounters. Psychological therapy can offer one such relational encounter; consistent access to this for people with AA lies in recognition and normalisation of therapy as spaces for meaning making in response to the difficult or painful events that are a part of life (Strawbridge & Woolfe, 2010; Woolfe, 2016). Access to therapy for people with AA therefore calls for recognition within NHS primary care, specialist dermatology services and at a policy level, that significant events, including the onset of non-life-threatening but subjectivity challenging conditions, warrant the offer of psychological intervention to support negotiation of associated meanings.

The profession of counselling psychology was formed to generate research and practice that promote this kind of approach, challenging the simplifying objectification of mainstream psychology through commitment to subjectivity and relationship in all their complexity (Strawbridge & Woolfe, 2010; James, 2017). Counselling psychology practitioners are therefore well equipped to provide leadership in advocating for access to psychological support at the policy and service levels, and to provide therapy to people with AA. As reflective-scientist-practitioners (BPS, 2005) with a postmodern sensibility (Milton, 2010; Strawbridge & Woolfe, 2010) we are equipped to hear the multiplicity of meanings associated with hair loss, to recognise the potentially contradictory subjectivities these constitute in people with AA, and to draw upon diverse knowledges to meet the needs of individual clients.

Collaborative, empathic and respectful formulation of the subjective difficulties (Simms, 2017) experienced by an individual with AA calls for a therapeutic approach that fits with the client’s frames of reference (Willig, 2019). Trained in a minimum of two therapeutic orientations which are often located within contradictory epistemological and ontological frameworks, counselling psychologists can potentially work flexibly and creatively to offer this. Crucially, this requires developed capacity for epistemological and ontological reflexivity, with the awareness this brings of personal subjectivities and assumptions that can mediate against the risk of imposing meanings upon clients (Willig, 2019). This quality of reflexive, postmodern engagement can enable therapists to recognise and respect client subjectivities, and to work transparently at relational depth, being mindful of the risks of imposing their own subjective positions. This combination of skills, qualities and knowledges allows for a creative and flexible approach to therapy that draws upon diverse ideas and tools that may help to ameliorate the difficulties of living with AA.

The concept of trauma is referenced throughout the data generated for this study, suggesting that concepts and therapeutic approaches developed within the trauma field may make sense and be of value to people with AA. The kind of personal transformation through struggle with adversity suggested in the data has been identified in previous visible difference research (Egan, Harcourt & Rumsey, 2011) and can be understood within a conceptual framework of post traumatic growth (Tedeschi and Calhoun, 2004). This cognitive model of explanation for a phenomenon noted throughout history, proposes that focussed cognitive processing can facilitate access to growth in the wake of distressing experiences. It suggests that this kind of intervention allows a lost identity to be grieved and new narratives to be developed that make sense of past or ongoing adversity. Notably, research in this field also emphasises the importance of mutual and other forms of social support in facilitating the processes that enable possibilities for growth through experiences of suffering (Calhoun and Tedeschi, 2006). This fits with the findings in this study and suggests that the post traumatic growth evidence base and practice guidance offer useful resources for therapists thinking about how to work with clients who have AA, particularly where CBT offers the best therapeutic fit with the client’s beliefs.

The disturbance to available subjectivities that is apparent in the data, the profound sense of loss expressed by participants, and the complex, ambivalent sense of acceptance and growth associated with resistance to dominant discourses, suggest that a staged trauma-informed approach may also offer relevant guidance to therapists (Herman, 1992). In *Trauma and Recovery*, Judith Herman (1992) argues that psychological wounds caused by other humans can only be healed in relationship. She describes a relational therapeutic approach in which sense and meaning making are facilitated in an iterative process of: 1) safety and stabilisation; 2) remembrance and mourning, and 3) reconnection and integration (Herman, 1992). The themes analysed in this study show that negative encounters with other people operate to produce and reinforce distressing meanings, but that positive relational encounters can stabilise this disturbance creating possibilities for agency, healing and growth. This kind of "deeply personal journey" is shown in the analysis to involve acknowledgement of loss and the complex ambivalence of mourning (Butler, 1997; Leader, 2008). Relational therapy, whether offered within a cognitive behavioural (Grant & Townend, 2010), psychodynamic (Clarkson, 2003), existential (Van, Deurzen, 2007) or other theoretical orientation (Loewenthal & Samuels, 2014) can offer a space in which these processes may take place. It may also facilitate a third therapeutic stage (Herman, 1992) in which the client is able to re-connect with repressed subjectivities of worth, or access new ones alongside, or in place of, those of shame and restriction. An understanding that subjective meanings are shaped by dominant discourses can help therapists to hear the (traumatic) loss experienced by clients with AA and then to provide the scaffolding recognition that they are more than this condition.

As a guide for counselling psychologists and other psychotherapeutic practitioners, the findings of this study therefore suggest that therapy for people with AA would helpfully involve:

- Hearing their distress and understanding the traumatic challenge to subjectivity produced by gendered discourses of hair and hair loss.
- Facilitating exploration and understanding of what has been lost so that mourning can take place.
- Scaffolding new subjective possibilities by recognising the client as a whole person and therefore more than the restricted and shameful subjectivities constituted through dominant discourses.

Constructing a subject: Critical thinking and counselling psychology

The case has been put throughout this discussion for therapeutic intervention that is relational, regardless of modality or therapist theoretical orientation. In recent decades there has been a “relational turn” across the counselling and psychotherapeutic professions (Clarke, et al, 2008; Loewenthal & Samuels, 2014), a context which, together with the pluralism afforded by postmodern ideas, has shaped the development of counselling psychology as a profession (Galbraith, 2017; Rizq, 2010). However, while valuing and embodying this relational stance, it is also incumbent upon counselling psychologists as reflective-scientist-practitioners to maintain a critical perspective in considering what this relational turn actually means and whether it is unequivocally positive (Loewenthal & Samuels, 2014). One problem arises through differences in understanding around what it means to work relationally; this can produce divisive assumptions and judgements about therapeutic approaches with which we are unfamiliar, particularly if they occupy privileged positions within funding and service frameworks (House and Loewnthal, 2008).

In my own development as a counselling psychologist, the prospect of CBT training provoked dismissive disdain, influenced as I was by views from the (also frequently mutually disdaining) worlds of psychodynamic and person-centred therapy (Kahn, 1997). When I actually encountered the possibilities offered by cognitive and behavioural approaches, I not only realised their value, but recognised that they already informed my practice. This humbling realisation was pivotal to my development as a counselling psychologist, not least because it prompted me to engage more deeply in critical epistemological and ontological dialogues, including in relation to different therapeutic approaches (House & Loewenthal, 2008; Loewenthal & Samuels, 2014; Grant, Townend, Mulhern & Short, 2010; Draghi-Lorenz, 2010). This has helped me to cultivate an open and flexible curiosity in my engagement with both clients and psychological theory, and has shaped the development of this research. Yet despite all the talking, thinking and reading about the “relational” over the course of my training, a solid understanding of what it really means continues to elude me. However, as shown in this study, there is something about relationships, with ourselves and with others, that is crucial to the constitution of a subjectivity of self-worth. Perhaps this “magic” quality of the relational (Loewnthal, 2014) is too complex and too precious for reductive definition and it is in the process of thinking, reflecting and exploring its meaning that its enriching potential lies.

The process of thinking and talking about the illusive meaning of "relational" involves its organisation into communicable ideas. Similarly, the themes presented in this study impose structure on the dataset in a way that makes it possible to talk about it and to communicate salient strands of meaning within it. In reality, the patterns I see in this data are more multiple, complex and intermingled than I have found it possible to articulate in the analysis. This mirrors my experience of formulation in my therapeutic practice (Simms, 2017); there is a need to organise in some way the complexity of what the client shares in order to produce a framework for meaning making and possibilities for change. Whether approaching this from a psychodynamic, cognitive behavioural or other position, we make choices as therapists about which information and patterns of thought, action and meaning to privilege in order to make sense of what brings the client to therapy, their life experiences and what change they may experience as a result of this process. I believe that one of our strengths as counselling psychologists is the dialectical flexibility that our training equips us with. Combined with reflexivity, this can enable us as practitioners to hear what the client is looking for in therapy and what they are giving permission for us to work with, and to formulate an understanding that can shape the therapeutic approach that is offered. However, this process is as creative as it is empirical, and so too is the process of undertaking a thematic analysis. Crucially, both demand personal, epistemological and ontological reflexivity if a necessary and sufficient level of theoretical coherence and collaborative respect are to be possible (Braun & Clarke, 2019; Willig, 2019).

In her preface to the second edition of *Gender Trouble*, Judith Butler makes these statements:

> *"It seemed to me, and continues to seem, that feminism ought to be careful not to idealise certain expressions of gender that, in turn, produce new forms of hierarchy and exclusion." (Judith Butler, Gender Trouble, 1999, p.viii).*
>
> *"the aim of the text was to open up the field of possibility for gender without dictating which kinds of possibilities ought to be realised. (Judith Butler, Gender Trouble, 1999, p.viii).*

As a developing counselling psychologist with a commitment to social justice and a belief in the rich potential of each life, I share the sentiments expressed in these statements. In both my research and my therapeutic practice, I aspire to open up possibilities without idealising particular subjectivities or dictating what ought to be realised. I therefore do not claim that this study conclusively describes the impact of AA in producing who and how it is possible to be in this world. Instead it offers an analysis, *my* analysis, framed and informed by my subjectivities. These include my epistemological position, my evolving ontological assumptions, and my experience as a practitioner in which the predominance of work with people who have experienced sexual violence means that discourses of sex and gender have been especially salient. Critical qualitative research and theory have guided and nurtured me in these developing subjectivities and continue to offer me surprising new perspectives, reminding me always to be open and curious so that I can hear and recognise meanings, restrictions and possibilities.

Relationship lies at the heart of counselling psychology and this study highlights the relationality of human subjectivity. However, it also adds to the body of critical qualitative research produced by experienced and trainee counselling psychologists that can facilitate the culturally informed, dialogical, reflective and ethical practice that defines the profession (e.g. Coyle & Rafalin, 2001; Hadjiosif, 2015; Hadjiosif & Coyle 2017; Josselin & Willig, 2015; Shah-Beckley, 2017). The dominant discourses that locate us, distressingly or otherwise, in historical time and cultural place are social productions (Foucault, 1975; 1976) and it is in relationships that dominant and alternative discourses are performed in processes of reiteration, resistance and change (Butler, 1990; 1993; 1997). This psychic life is social, but inscribed on the bodies, acts and emotions of the individuals who together constitute the social life.

The call to adopt a social justice agenda in order to more clearly define the professional identity of counselling psychology (Moller, 2011) stimulated energetic discussion (Milton, 2011) and contributed to the development of an explicit divisional focus on equality and diversity (BPS, 2013). This focus reflects and draws upon critical, social constructionist and poststructuralist research to raise awareness and deepen understanding of issues relating to “race, culture and difference” in the practice of counselling psychology (Ade-Serrano, Nkansa-Dwamena & McIntosh, 2017, p.1). A similarly explicit divisional commitment to critical qualitative inquiry could promote the broad, deep understanding of culturally located meanings, distress and possibilities across diverse, psychologically relevant questions, that is present in the wider counselling psychology literature. It would additionally offer a dialogical framework to better consider and theorise the "relational approach", thereby contributing to the construction of a more distinctive professional identity for the discipline of counselling psychology.

Closing reflections

This study set out to explore the subjectivities of people living with AA using a critical qualitative approach to produce knowledge that can inform applied psychology practice. A feminist poststructuralist framework enabled me to produce a complex and nuanced analysis which generated insights that I have shown to be of relevance and value to both medical and psychological practitioners. By locating this within a broader critical qualitative framework, I was able to work pluralistically, producing an analysis that speaks more accessibly to the medical professionals most empowered to effect change in the experiences of people with AA. Although limited by the lack of diversity in the sample, this research project has therefore produced knowledge that contributes to our understanding of subjectivities in people living with AA, and with visible difference and appearance-related distress more generally. In particular, it demonstrates the ongoing dominance of gendered discourses in shaping embodied experience, and the potentially devastating implications of this for sense of self and engagement with the world. Importantly, the analysis also identifies resources and processes through which people are able to resist these restricting and shaming meanings, allowing me to offer some thoughts on how practitioners might facilitate resistance and growth.

I believe that my findings in this study have value for the time, society and culture in which they have been produced. I also believe that we must be mindful always to reflect upon the constitution of subjectivities in context; this is the crucial contribution of critical, reflexive research to the field of applied psychology practice. It reminds us that what it is to be a person in the world cannot be fixed as an object of study because we exist fluidly, in ever changing process, and it is in an understanding of this that hope can be nurtured and sustained. For me as a practitioner, the process of completing this study has deepened my understanding of subjectivity and how discourses operate in subjectification (see Appendix A). It has also given me insights into how I might support clients in processes of resistance and change that can alleviate their suffering. Perhaps most significantly, it has demanded of me a sustained reflexive engagement with the ontological and epistemological assumptions that shape my thinking and actions. My awareness and understanding of these remain partially conscious, partially formed contributors to the constitution of my own fluid, dynamic subjectivities. This kind of critical perspective, able to generate insights into relationality through questioning, challenging and subverting restrictive dominant discourses, is not only congruent with the discipline of counselling psychology, but has the potential to construct it as a more clearly theorised and defined subject.

References

Ade-Serrano, Y. Nkansa-Dwamena, O. & McIntosh, M. (2017) Race, Culture and Diversity: A Collection of Articles, BPS, Milton Keynes.

Aguilar-Duran, S., Ahmed, A., Taylor, R., & Bewley, A. (2014). How to set up a psychodermatology clinic. *Clinical and experimental dermatology*, *39*(5), 577-582.

Alfani, S., Antinone, V., Mozzetta, A., Pietro, C. D., Mazzanti, C., Stella, P., ... & Abeni, D. (2012). Psychological status of patients with alopecia areata. *Acta dermato-venereologica*, *92*(3), 304-306.

Alopecia UK, *Treatments and wigs,* retrieved from http://www.alopeciaonline.org.uk/treatments-and-wigs.asp.

Anstey, A., & Reynolds, N. J. (2015). What does the BJD now stand for? A position statement. *British Journal of Dermatology*, *172*(6), 1463-1465.

Appignanesi, L. (2009). *Mad, Bad, and Sad: A History of Women and the Mind Doctors*. WW Norton & Company.

Aschenbeck, K. A., McFarland, S. L., Hordinsky, M. K., Lindgren, B. R., & Farah, R. S. (2017). Importance of Group Therapeutic Support for Family Members of Children with Alopecia Areata: A Cross-Sectional Survey Study. *Pediatric dermatology*, *34*(4), 427-432.

Barber, K. (2008). The Well-Coiffed Man Class, Race, and Heterosexual Masculinity in the Hair Salon. *Gender & Society*, *22*(4), 455-476.

Bailly, L. (2012). *Lacan: A beginner's guide*. Oneworld Publications.

Basow, S. A. (1991). The hairless ideal: Women and their body hair. *Psychology of Women Quarterly*, *15*(1), 83-96.

Basow, S. A., & Braman, A. C. (1998). Women and Body Hair Social Perceptions and Attitudes. *Psychology of Women Quarterly*, *22*(4), 637-645.

Beale, K., Malson, H., & Tischner, I. (2016). Deconstructing “real” women: Young women's readings of advertising images of “plus-size” models in the UK. *Feminism & Psychology, 26*(3), 378-386.

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*(3), 227-238.

Bewley, A., Affleck, A., & Bundy, C. (2012). WORKING PARTY REPORT ON MINIMUM STANDARDS FOR PSYCHO-DERMATOLOGY SERVICES 2012.

Bewley, A., Affleck, A., Bundy, C., Higgins, E., & McBride, S. (2013). Psychodermatology services guidance: the report of the British Association of Dermatologists'

Psychodermatology Working Party. *British Journal of Dermatology*, *168*(6), 1149-1150.

Blackman, L., Cromby, J., Hook, D., Papadopoulos, D., & Walkerdine, V. (2008). Creating subjectivities. **22,** 1–27 (2008). https://doi.org/10.1057/sub.2008.8

Bordo, S. (2000). *The male body: A new look at men in public and in private*. Macmillan.

Bordo, S. (2003). *Unbearable weight: Feminism, Western culture, and the body*. (2nd ed.) University of California Press.

Bower, P., & Gilbody, S. (2005). Managing common mental health disorders in primary care: conceptual models and evidence base. *Bmj*, *330*(7495), 839-842.

Braun, V. (2000). Conceptualizing the body. *Feminism & psychology*, *10*(4), 511-518.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597.

Braun, V., Tricklebank, G., & Clarke, V. (2013). “It Shouldn’t Stick Out from Your Bikini at the Beach” Meaning, Gender, and the Hairy/Hairless Body. *Psychology of Women Quarterly, 37*(4), 478-493.

Brinkmann, S. & Kvale, S. (2017). Ethics in qualitative psychological research. In C. Willig, W.(Eds.) *The SAGE Handbook of qualitative research in psychology (2nd Ed.* pp. 259-273). London: SAGE Publications Ltd.

The British Psychological Society, Division of Counselling Psychology (2005). Professional Practice Guidelines for Counselling Psychologists. Leicester: BPS
British Psychological Society's Code of Human Research Ethics, 2nd Edition, BPS, Milton Keynes (BPS, 2014).

Burton, L. (2012). nobody's fool: Power and agency in performing 'the Blonde'. *Critical Studies in Fashion & Beauty*, *3*(1-2), 131-140.

Burman, E. (Ed.). (1998). *Deconstructing feminist psychology*. Sage.
Butler, J. (1990). *Gender Trouble*. *Feminism and the subversion of identity* Routledge.
Butler, J. (1993). *Bodies that matter: On the discursive limits of sex*. Routledge.

Butler, J. (1997). *The psychic life of power: Theories in subjection*. Stanford University Press.

Butler, J. (1999). *Gender Trouble*. *Feminism and the subversion of identity* (2nd ed.). Routledge.
Burr, V. (2015). *Social constructionism*. (3rd ed.). Routledge.

Calhoun, L. G., & Tedeschi, R. G. (Eds.). (2006). *Handbook of posttraumatic growth: Research and practice*. Routledge.

Campbell, K. (2001). Theory: The Plague of the Subject: Psychoanalysis and Judith Butler's Psychic Life of Power. *International Journal of Sexuality and Gender Studies*, *6*(1-2), 35-48.
Cartwright, T., Endean, N., & Porter, A. (2009). Illness perceptions, coping and quality of life in patients with alopecia. *British Journal of Dermatology*, *160*(5), 1034-1039.
Cash, T. F. (1990). Losing Hair, Losing Points?: The Effects of Male Pattern Baldness on Social Impression Formation 1. *Journal of Applied Social Psychology*, *20*(2), 154-167.
Chamberlain, K. (2000). Methodolatry and qualitative health research. *Journal of Health Psychology*, *5*(3), 285-296.
Chamberlain, K., Cain, T., Sheridan, J., & Dupuis, A. (2011). Pluralisms in qualitative research: From multiple methods to integrated methods. *Qualitative Research in Psychology*, *8*(2), 151-169.
Changing Faces (2014), *Look at Me: Integrated care for people with skin conditions, Second Campaign Report and Recommendations,* retrieved from https://www.changingfaces.org.uk/show/feature/NEWS-Look-At-Me-Report-Oct-14

Charlton, R., Rumsey, N., Partridge, J., Barlow, J., & Saul, K. (2003). Disfigurement-neglected in primary care?. *Br J Gen Pract*, *53*(486), 6-8.

Clarke, A., Thompson, A., Jenkinson, E., Rumsey, N., & Newell, R. (2014). *CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety Due to Visible Difference*. Wiley

Clarke, S., Hahn, H., & Hoggett, P. (Eds.). (2008). *Object relations and social relations: The implications of the relational turn in psychoanalysis*. Karnac Books.

Clarke, V. (2019). "Some University Lecturers Wear Gay Pride T-shirts. Get Over It!": Denials of Homophobia and the Reproduction of Heteronormativity in Responses to a Gay-Themed T-shirt. *Journal of homosexuality, 66*(5), 690-714.

Clarke, V., & Braun, V. (2019). Feminist qualitative methods and methodologies in psychology: A review and reflection. *Psychology of Women & Equalities Section Review*

Clarke, V., & Smith, M. (2014). "Not Hiding, Not Shouting, Just Me": Gay Men Negotiate Their Visual Identities. *Journal of homosexuality*, *62*(1), 4-32.

Clarke, V., & Spence, K. (2013). 'I am who I am'? Navigating norms and the importance of authenticity in lesbian and bisexual women's accounts of their appearance practices. *Psychology & Sexuality*, *4*(1), 25-33.

Clarkson, P. (2003). *The therapeutic relationship*. Whurr Publishers.

Colón, E. A., Popkin, M. K., Callies, A. L., Dessert, N. J., & Hordinsky, M. K. (1991). Lifetime prevalence of psychiatric disorders in patients with alopecia areata. *Comprehensive psychiatry*, *32*(3), 245-251.

Cooper, M. (2008). *Essential research findings in counselling and psychotherapy: The facts are friendly*. Sage.

Cornforth, S. (2010). Bridging the gap: weaving humanism and poststructuralism. *British Journal of Guidance & Counselling*, *38*(2), 167-178.

Coyle, A., & Rafalin, D. (2001). Jewish gay men's accounts of negotiating cultural, religious, and sexual identity: A qualitative study. *Journal of Psychology & Human Sexuality*, *12*(4), 21-48.

Craddock, N., Ramsey, M., Spotswood, F., Halliwell, E., & Diedrichs, P. C. (2019). Can big business foster positive body image? Qualitative insights from industry leaders walking the talk. *Body image*, *30*, 93-106.

Cromby, J. (2011). Affecting qualitative health psychology. *Health Psychology Review*, *5*(1), 79-96.

Cromby, J. (2012). Feeling the way: Qualitative clinical research and the affective turn. *Qualitative Research in Psychology*, *9*(1), 88-98.

Cromby, J. & Nightingale, D. J., (1999). What's wrong with social constructionism? In: D.J. Nightingale & J. Cromby (Eds.) *Social constructionist psychology: a critical analysis of theory and practice.* (pp. 1-19). Open University Press.

Davey, L., Clarke, V., & Jenkinson, E. (2019). Living with alopecia areata: an online qualitative survey study. *British Journal of Dermatology*, *180*(6), 1377-1389.

Delamere, F. M., Sladden, M. J., Dobbins, H. M., & Leonardi-Bee, J. (2008). Interventions for alopecia areata. *The Cochrane Library*.

Dewe, M., & Coyle, A. (2014). Reflections on a study of responses to research on smoking: A pragmatic, pluralist variation on a qualitative psychological theme. *Review of Social Studies*, *1*(1), 21-36.

Dittmar, H. (2007). The costs of consumer culture and the "cage within": the impact of the material "good life" and "body perfect" ideals on individuals" identity and well-being. *Psychological Inquiry*, *18*(1), 23-31.

Douglas, H. A., Hamilton, R. J., & Grubs, R. E. (2009). The effect of BRCA gene testing on family relationships: a thematic analysis of qualitative interviews. *Journal of genetic counseling*, *18*(5), 418-435.

Douglas, B., Woolfe, R., Strawbridge, S., Kasket, E. & Galbraith, V. 2016, *The handbook of counselling psychology, (*4th Ed.). SAGE.

Draghi-Lorenz, R. (2010). Different theoretical differences and contextual influences. In: M. Milton (Ed.) *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*.(pp. 105-121). Wiley-Blackwell.

Egan, K., Harcourt, D., Rumsey, N., & Appearance Research Collaboration. (2011). A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *Journal of Health Psychology*, *16*(5), 739-749.

Ehlers, A., Stangier, U., & Gieler, U. (1995). Treatment of atopic dermatitis: a comparison of psychological and dermatological approaches to relapse prevention. *Journal of Consulting and Clinical Psychology*, *63*(4), 624.

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: an overview. *Historical Social Research/Historische Sozialforschung*, 12 (1), 273-290.

Emilee, G., Ussher, J. M., & Perz, J. (2010). Sexuality after breast cancer: a review. *Maturitas*, *66*(4), 397-407.

Enable Magazine (2018)

Endo, Y., Miyachi, Y., & Arakawa, A. (2012). Development of a disease-specific instrument to measure quality of life in patients with alopecia areata. *European Journal of Dermatology, 22*(4), 531-536.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*(4286), 129-136.

Fabbrocini, G., Panariello, L., De Vita, V., Vincenzi, C., Lauro, C., Nappo, D., ... & Tosti, A. (2013). Quality of life in alopecia areata: a disease-specific questionnaire. *Journal of the European Academy of Dermatology and Venereology, 27*(3), e276-e281.

Fairfax, H. (2016) The Role of Counselling Psychologists in Adult Seocndary Mental Health In: B. Douglas, R. Woolfe, S. Strawbridge, E. Kasket& V. Galbraith (Eds.). (2016). *The handbook of counselling psychology*. (pp. 511-529). Sage.

Feely, M. (2019). Assemblage analysis: an experimental new-materialist method for analysing narrative data. *Qualitative Research*, 1-20. DOI: 10.1177/1468794119830641

Flax, J. (1990). *Thinking fragments: Psychoanalysis, feminism, and postmodernism in the contemporary West*. Univ of California Press.

Fahs, B. (2011). Dreaded "otherness" heteronormative patrolling in women's body hair rebellions. *Gender & Society*, *25*(4), 451-472.

Fahs, B. (2013). Shaving it all off: Examining social norms of body hair among college men in a women's studies course. *Women's Studies*, *42*(5), 559-577.

Fahs, B. (2014). Perilous patches and pitstaches: Imagined versus lived experiences of women's body hair growth. *Psychology of Women Quarterly, 38*(2), 167-180.

Fahs, B., & Delgado, D. A. (2011). Race, Class, and Gender in Women's Body Hair Narratives. *Embodied resistance: Challenging the norms, breaking the rules*, 13-25.

Frank, E. (2014). Groomers and Consumers The Meaning of Male Body Depilation to a Modern Masculinity Body Project. *Men and Masculinities*, *17*(3), 278-298.

Frith, H. (2015). Sexercising to orgasm: Embodied pedagogy and sexual labour in women's magazines. *Sexualities, 18*(3), 310-328.

Frith, H., & Gleeson, K. (2008). Dressing the body: The role of clothing in sustaining body pride and managing body distress. *Qualitative Research in Psychology*, *5*(4), 249-264.

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.

Frost, N. A., & Nolas, S. M. (2011). Exploring and expanding on pluralism in qualitative research in psychology. *Qualitative Research in Psychology*, 8:2, 115-119, DOI: 10.1080/14780887.2011.572728

Foucault, M. (1979). *Discipline and Punish [1975]*. Penguin.

Foucault, M. (1976). The History of Sexuality: Volume I-An Introduction. Penguin

Freud, S., & Ellmann, M. (2005). *On murder, mourning and melancholia*. Penguin UK.

Galbraith, V. (2017). *Counselling Psychology*. Routledge.

Gallo, R., Chiorri, C., Gasparini, G., Signori, A., Burroni, A., & Parodi, A. (2017). Can mindfulness-based interventions improve the quality of life of patients with moderate/severe alopecia areata? A prospective pilot study. *Journal of the American Academy of Dermatology*, *76*(4), 757.

García-Hernández, M. J., Ruiz-Doblado, S., Rodriguez-Pichardo, A., & Camacho, F. (1999). Alopecia areata, stress and psychiatric disorders: a review. *The Journal of dermatology*, *26*(10), 625-632.

Gavey, N. (2005), *Just sex?: the cultural scaffolding of rape*, Routledge, London.

Gergen, K. J. (2015). *An invitation to social construction*. (2nd ed.). Sage.

Guest, E., Costa, B., Williamson, H., Meyrick, J., Halliwell, E., & Harcourt, D. (2019). The effectiveness of interventions aiming to promote positive body image in adults: A systematic review. *Body image*, *30*, 10-25.

Ghanizadeh, A., & Ayoobzadehshirazi, A. (2014). A review of psychiatric disorders comorbidities in patients with alopecia areata. *International journal of trichology*, *6*(1), 2.

Gillies, V., Harden, A., Johnson, K., Reavey, P., Strange, V., & Willig, C. (2004). Women's collective constructions of embodied practices through memory work: Cartesian dualism in memories of sweating and pain. *British Journal of Social Psychology*, *43*(1), 99-112.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. Penguin.

Gough, B., & Madill, A. (2012). Subjectivity in psychological science: From problem to prospect. *Psychological methods*, *17*(3), 374.

Gough, B., Hall, M., & Seymour-Smith, S. (2014). Straight guys do wear make-up: Contemporary masculinities and investment in appearance. In *Debating modern masculinities: Change, continuity, crisis?* (pp. 106-124). Palgrave Pivot, London.

Grant, A. & Townend, M. (2010) The Therapeutic Relationship. In: Grant, A., Townend, M., Mulhern, R., & Short, N. (Eds.) *Cognitive behavioural therapy in mental health care*. (pp. 9-19). Sage.

Grant, A., Townend, M., Mulhern, R., & Short, N. (2010). *Cognitive behavioural therapy in mental health care*. Sage.

Greenberg, J. and Mitchell, S. (1983). *Object relations in psychoanalytic theory*. Harvard University Press.

Grogan, S. (2016). *Body image: Understanding body dissatisfaction in men, women and children*. Routledge.

Grosz, E. A. (1994). *Volatile bodies: Toward a corporeal feminism*. Indiana University Press.

Guardian Newspaper (2007) https://www.theguardian.com/world/2007/feb/20/gender.music

Guardian Newspaper (2008) https://www.theguardian.com/lifeandstyle/2008/aug/03/celebrity.gailporter

Gupta, M. A., Jarosz, P., & Gupta, A. K. (2017). Posttraumatic stress disorder (PTSD) and the dermatology patient. *Clinics in dermatology*, *35*(3), 260-266.

Hadjiosif, M. (2015). Professional and ethical practice during training. In: R. Tribe & J. Morrissey (Eds.) *Handbook of professional and ethical practice for psychologists, counsellors and psychotherapists*, (pp. 310-321). Routledge.

Hadjiosif, M., & Coyle, A. (2017). ‘That boy needs therapy’: Constructions of psychotherapy in popular song lyrics. *European Journal of Psychotherapy & Counselling*, *19*(4), 357-377.

Hall, M., Gough, B., & Seymour-Smith, S. (2012). “I'm METRO, NOT Gay!”: A Discursive Analysis of Men's Accounts of Makeup Use on YouTube. *The Journal of Men’s Studies*, *20*(3), 209-226.

Hallpike, C. R. (1969). Social hair. *Man*, *4*(2), 256-264.

Hanley, T. & Amos, I. A. (2017). The scientist-practitioner and the reflective practitioner. *Counselling Psychology*, In: V. Galbraith (Ed.) *Counselling Psychology*. (pp. 167-183). Routledge.

Hanna, P. (2013). Reconceptualizing subjectivity in critical social psychology: Turning to Foucault. *Theory & Psychology*, *23*(5), 657-674.

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.

Harper, D. (2003). Developing a critically reflexive position using discourse analysis. In: L. Finlay & B. Gough (Eds.) *Reflexivity: A practical guide for researchers in health and social sciences*, (pp. 78-92). Wiley-Blackwell.

Harvey, K. (2013). Medicalisation, pharmaceutical promotion and the Internet: a critical multimodal discourse analysis of hair loss websites. *Social Semiotics*, *23*(5), 691-714.

Hayfield, N., & Huxley, C. (2015). Insider and outsider perspectives: Reflections on researcher identities in research with lesbian and bisexual women. *Qualitative Research in Psychology*, *12*(2), 91-106.

Henriques, J. F., Hollway, W., Urwin, C., Venn, C., & Walkerdine, V. (1984). *Changing the Subject: Psychology, Social Regulation and Subjectivity*. Psychology Press.

Herman, J. L. (1992). Trauma and Recovery. Basic Books.

Hiles, D., Cerrmak, I., & Chrz, V. (2017). Narrative inquiry. InWillig, C. & Stainton-Rogers, W. (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 157–175). Thousand Oaks, CA: Sage.

Hilton, S., Hunt, K., Emslie, C., Salinas, M., & 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.

Hollway, W. (1984,). Women's power in heterosexual sex. In *Women's studies international forum* (Vol. 7, No. 1, pp. 63-68). Pergamon.

House, R., & Loewenthal, D. (Eds.). (2008). *Against and for CBT: Towards a constructive dialogue?*. Pccs Books.

Hunt, N., & McHale, S. (2004). Reported experiences of persons with alopecia areata. *Journal of loss and trauma*, *10*(1), 33-50.

Hunt, N., & McHale, S. (2005). The psychological impact of alopecia. *BMJ: British Medical Journal*, *331*(7522), 951.

Iliffe, L. L., & Thompson, A. R. (2019). Investigating the beneficial experiences of online peer support for those affected by alopecia: An interpretative phenomenological analysis using online interviews. *British Journal of Dermatology*. 181(5), 992-998.

Islam, N., Leung, P. S., Huntley, A. C., & Gershwin, M. E. (2015). The autoimmune basis of alopecia areata: A comprehensive review. *Autoimmunity reviews*, *14*(2), 81-89.

Jagger, A. & Bordo, S.(1989). *Gender/Body/Knowledge*: *Feminist reconstructions of being and knowing.* Rutgers University Press

James, P. E. (2017). What is counselling psychology?. In V. Galbraith (ed.) *Counselling Psychology* (pp. 15-30). Routledge.

Jenkinson, E., Williamson, H., Byron-Daniel, J., & Moss, T. P. (2015). Systematic review: psychosocial interventions for children and young people with visible differences resulting from appearance altering conditions, injury, or treatment effects. *Journal of pediatric psychology*, 40(10), 1017-1033.

Joffe, H. (2012). Thematic analysis. *Qualitative research methods in mental health and psychotherapy, 1*.

Johnson, A., & Montgomery, K. (2017) NHS Wig Provision: A report into NHS England's provision of wigs to patients with alopecia, alopecia UK https://www.alopecia.org.uk/nhs-england-eport

Johnstone, L., & Dallos, R. (2013). *Formulation in psychology and psychotherapy: Making sense of people's problems*. Routledge.

Jordan, L. (2017). Developing a therapeutic relationship. In: V. Galbraith (Ed.) *Counselling Psychology*. (pp. 53-68). Routledge.

Josselin, D., & Willig, C. (2015). Making sense of self-injury: A pluralistic case-study. *Counselling Psychology Review*, *30*(4), 5-15.

Jowett, A., & Peel, E. (2009). Chronic illness in non-heterosexual contexts: An online survey of experiences. *Feminism & Psychology*, *19*(4), 454-474.

Jowett, A., Peel, E., & Shaw, R. L. (2012). Sex and diabetes: A thematic analysis of gay and bisexual men's accounts. *Journal of Health Psychology, 17*(3), 409-418.

Kagan, C., Tindall, C., & Robinson, J. (2010). Community psychology: Linking the individual with the community. In: R. Woolfe, S. Strawbridge, B. Douglas & W.Dryden (Eds.), *Handbook of counselling psychology*, (3rd Edition ,485-504). Sage.

Kahn, M. (1997). *Between therapist and client: The new relationship*. Macmillan.

Kidder, L. H., & Fine, M. (1987). Qualitative and quantitative methods: When stories converge. *New Directions for Evaluation*, (35), 57-75.

Koblenzer, C. S. (1995). Psychotherapy for intractable inflammatory dermatoses. *Journal of the American Academy of Dermatology*, *32*(4), 609-612.

Koo, J. Y., Shellow, W. V., Hallman, C. P., & Edwards, J. E. (1994). Alopecia areata and increased prevalence of psychiatric disorders. *International journal of dermatology*, *33*(12), 849-850.

Kramer, U. (2010). Coping and defence mechanisms: What's the difference?–Second act. *Psychology and psychotherapy: theory, research and practice*, *83*(2), 207-221.

Kyle, D. J., & Mahler, H. I. (1996). The effects of hair color and cosmetic use on perceptions of a female's ability. *Psychology of women quarterly*, *20*(3), 447-455.

Lather, P., & St. Pierre, E. A. (2013). Post-qualitative research. *International journal of qualitative studies in education*, *26*(6), 629-633.

Lather, P. (2016). Top Ten+ List: (Re) Thinking Ontology in (Post) Qualitative Research. *Cultural Studies? Critical Methodologies*, *16*(2), 125-131.

Leader, D. (2008). *The new black: Mourning, melancholia and depression*. Penguin UK.

Larsson, P., Loewenthal, D., & Brooks, O. (2012). Counselling psychology and schizophrenia: A critical discursive account. *Counselling Psychology Quarterly*, *25*(1), 31-47.

Lavda, A. C., Webb, T. L., & Thompson, A. R. (2012). A meta-analysis of the effectiveness of psychological interventions for adults with skin conditions. *British Journal of Dermatology*, *167*(5), 970-979.

Layton, L. (2008). Relational thinking: From culture to couch and couch to culture. In: S. Clarke, H. Hahn & P. Hoggett, *Object relations and social relations.* Karnac.

Leach, E. R. (1958). Magical hair. *The Journal of the Royal Anthropological Institute of Great Britain and Ireland*, *88*(2), 147-164.

Lewis, J. M. (1987). Caucasian body hair management: A key to gender and species identification in US culture? *Journal of American Culture*, *10*(1), 7-14.

Lleo, A., Invernizzi, P., Gao, B., Podda, M., & Gershwin, M. E. (2010). Definition of human autoimmunity—autoantibodies versus autoimmune disease. *Autoimmunity reviews*, *9*(5), A259-A266.

Loewenthal, D., & Samuels, A. (Eds.). (2014). *Relational psychotherapy, psychoanalysis and counselling: Appraisals and reappraisals*. Routledge.

Loewenthal, D., (2014). The magic of the relational? An introduction to appraising and reappraising relational psychotherapy, psychoanalysis and counselling. In: D. Loewenthal, & A. Samuels (Eds.). *Relational psychotherapy, psychoanalysis and counselling: Appraisals and reappraisals*. (pp.3-11). Routledge.

Lovell, K., & Richards, D. (2000). Multiple access points and levels of entry (MAPLE): ensuring choice, accessibility and equity for CBT services. *Behavioural and Cognitive Psychotherapy*, *28*(04), 379-391.

Lyddon, W. J. (1998). Social construction in counselling psychology: A commentary and critique. *Counselling Psychology Quarterly*, *11*(2), 215-222.

Lyotard, J. F. (1979). *The postmodern condition: A report on knowledge* (Vol. 10). U of Minnesota Press.

Macbeth, A. E., Tomlinson, J., Messenger, A. G., Moore-Millar, K., Michaelides, C., Shipman, A. R., ... & Robinson, R. (2017). Establishing and prioritizing research questions for the treatment of alopecia areata: the Alopecia Areata Priority Setting Partnership. *British Journal of Dermatology*, *176*(5), 1316-1320.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British journal of psychology*, *91*(1), 1-20.

Malson, H., & Burns, M. (Eds.). (2009). *Critical feminist approaches to eating dis/orders*. Routledge.

https://www.marketwatch.com/investing/stock/hair

Matzer, F., Egger, J. W., & Kopera, D. (2011). Psychosocial stress and coping in alopecia areata: a questionnaire survey and qualitative study among 45 patients. *Acta dermato-venereologica*, *91*(3), 318-327.

McAteer, D. (2010). Philosophical pluralism: Navigating the sea of diversity in psychotherapeutic and counselling psychology practice. In: M. Milton (Ed.) *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*. (pp. 5-19). Wiley-Blackwell.

McNamee, S., & Gergen, K. J. (Eds.). (1992). *Therapy as social construction* (Vol. 10). Sage.

McNay, L. (1999), "Subject, Psyche and Agency: The Work of Judith Butler", *Theory, Culture & Society*, vol. 16, no. 2, pp. 175-193.

Messenger, A. G., McKillop, J., Farrant, P., McDonagh, A. J., & Sladden, M. (2012). British Association of Dermatologists' guidelines for the management of alopecia areata 2012. *British Journal of Dermatology*, *166*(5), 916-926.

Millsted, R., & Frith, H. (2003, September). Being large-breasted: Women negotiating embodiment. In *Women's Studies International Forum* (Vol. 26, No. 5, pp. 455-465). Pergamon.

Milton, M. (Ed.). (2010) *Therapy and Beyond: Counselling psychology contributions to therapeutic and social issues.* Wiley-Blackwell.

Milton, M., (2011). A response to Moller (2011): Diversity still requires epistemological clarity. *Counselling Psychology Review*, *26*(3), pp.89-91.

Milton, M., Craven, M., & Coyle, A. (2010). Understanding human distress: Moving beyond the concept of 'psychopathology'. In: M. Milton (Ed.) *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*. (pp. 57-72). Wiley-Blackwell.

Mirzoyev, S. A., Schrum, A. G., Davis, M. D., & Torgerson, R. R. (2014). Lifetime incidence risk of Alopecia Areata estimated at 2.1 percent by Rochester Epidemiology Project, 1990–2009. *The Journal of investigative dermatology*, *134*(4), 1141.

Moller, N. (2011). The identity of counselling psychology in Britain is parochial, rigid and irrelevant but diversity offers a solution. *Counselling Psychology Review*, *26*(2), 8-16.

Moller, N. P., Timms, J., & Alilovic, K. (2009). Risky business or safety net? Trainee perceptions of personal therapy: a qualitative thematic analysis. *European Journal of Psychotherapy and Counselling*, *11*(4), 369-384.

Montgomery, K., White, C., & Thompson, A. (2017). A mixed methods survey of social anxiety, anxiety, depression and wig use in alopecia. *BMJ open*, *7*(4)..

Moon, H. S., Mizara, A., & McBride, S. R. (2013). Psoriasis and psycho-dermatology. *Dermatology and therapy*, *3*(2), 117-130.

Muller, S. A., & Winkelmann, R. K. (1963). Alopecia areata: an evaluation of 736 patients. *Archives of Dermatology*, *88*(3), 290-297.

Nelson, P. A. (2015). Getting under the skin: qualitative methods in dermatology research. *British Journal of Dermatology*, *172*(4), 841-843.

Nelson, P. A., Magin, P. & Thompson, A.R. (2017). Six of the best: how excellent qualitative research can contribute to practice, *British Journal of Dermatology*, 177 (3), (603-605)..

Nelson, P. A., Magin, P., & Thompson, A. R. (2019). Take 10: ten qualitative studies on under-researched groups and hard-to-reach issues in dermatology. *British Journal of Dermatology*, *180*(6), 1271-1273.

NHS Choices, *Hair Loss – Treatment*, retrieved from http://www.nhs.uk/Conditions/Hair-loss/Pages/Treatment.aspx

NHS England (2016). Five year forward view for mental health. Retrieved 19 July 2019 from https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

NICE (2014) *Alopecia areata*, retrieved from http://cks.nice.org.uk/alopecia-areata#!topicsummaryhttps://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-4-Holistic-support-physical-and-psychological, last updated 2017, accessed 20/7/2019

Nightingale, D., & Cromby, J. (1999). *Social constructionist psychology: A critical analysis of theory and practice*. Open University Press.

Obeyesekere, G. (2014). *Medusa's hair: An essay on personal symbols and religious experience*. University of Chicago Press.

Okhovat, J. P., Marks, D. H., Manatis-Lornell, A., Hagigeorges, D., Locascio, J. J., & Senna, M. M. (2019). Association Between Alopecia Areata, Anxiety, and Depression: A Systematic Review and Meta-analysis. *Journal of the American Academy of Dermatology*.

Opperman, E., Braun, V., Clarke, V., & Rogers, C. (2014). “It Feels So Good It Almost Hurts”: Young Adults' Experiences of Orgasm and Sexual Pleasure. *The Journal of Sex Research*, *51*(5), 503-515.

Orbach, S. (2009). *Bodies*. Profile Books.

Padesky, C. A. (1996). *Guided discovery using socratic dialogue*. New Harbinger Publications.

Papadopoulos, L., & Walker, C. (2003). *Understanding skin problems: acne, eczema, psoriasis and related conditions*. John Wiley & Sons.

Parker, I. (Ed.). (1999). *Deconstructing psychotherapy*. Sage.

Parker, I. (2005) *Qualitative Psychology: Introducing Radical Research.* Buckingham: Open University Press.

Parker, I. (2014). Deconstruction and psychotherapy. In *Psychology After Deconstruction* (pp. 68-79). Routledge.
Parker, I., Georgaca, E., Harper, D., McLaughlin, T., & Stowell-Smith, M. (1995). *Deconstructing psychopathology*. Sage.

Parker, I., & Shotter, J. (Eds.). (2015). *Deconstructing social psychology*. Psychology Press.
Peel, E. (2009). Pregnancy loss in lesbian and bisexual women: an online survey of experiences. *Human Reproduction, 25*(3), 721-727.Persson, M. (2012). Using Retrospective Approaches in the Study of Disfigurement. In: N. Rumsey & D. Harcourt (Eds.) *Oxford Handbook of the Psychology of Appearance.* OUP.

Picardi, A., Pasquini, P., Cattaruzza, M. S., Gaetano, P., Baliva, G., Melchi, C. F., ... & Biondi, M. (2003). Psychosomatic factors in first-onset alopecia areata. *Psychosomatics*, *44*(5), 374-381.

Polkinghorne, D. E. (1992). Postmodern epistemology of practice. In Kvale, S. (Ed.). (1992). *Psychology and postmodernism* (Vol. 9). Sage.

Prickitt, J., McMichael, A. J., Gallagher, L., Kalabokes, V., & Boeck, C. (2004). Helping patients cope with chronic alopecia areata. *Dermatology Nursing*, *16*(3), 237-242.
Rafalin, D. (2010). Counselling psychology and research: Revisiting the relationship in the light of our ‘mission’. In: M. Milton (Ed.) *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*, (pp. 41-55) Wiley-Blackwell.

Rafique, R., & Hunt, N. (2015). Experiences and coping behaviours of adolescents in Pakistan with alopecia areata: An interpretative phenomenological analysis. *International journal of qualitative studies on health and well-being*, *10*(1), 26039Randall, V. A. (2001). Is alopecia areata an autoimmune disease?. *The Lancet*, *358*(9297), 1922-1924.

Randle, B. A. (2015). I am not my hair: African American women and their struggles with embracing natural hair!. *Race, Gender & Class*, *22*(1-2), 114-121.
Reid, E. E., Haley, A. C., Borovicka, J. H., Rademaker, A., West, D. P., Colavincenzo, M., & Wickless, H. (2012). Clinical severity does not reliably predict quality of life in women with alopecia areata, telogen effluvium, or androgenic alopecia. *Journal of the American Academy of Dermatology*, *66*(3), e97-e102.

Rencz, F., Gulácsi, L., Péntek, M., Wikonkál, N., Baji, P., & Brodszky, V. (2016). Alopecia areata and health-related quality of life: a systematic review and meta-analysis. *British Journal of Dermatology*, *175*(3), 561-571.

Ricciardelli, R., Clow, K. A., & White, P. (2010). Investigating hegemonic masculinity: Portrayals of masculinity in men's lifestyle magazines. *Sex Roles*, *63*(1-2), 64-78.

Rizq (2010) Psychodynamic Approaches In: R. Woolfe, S. Strawbridge, B. Douglas & W.Dryden (Eds.), *Handbook of counselling psychology*, (3rd Edition, pp.85-104).

Rosiek, J. L. (2013). Pragmatism and post-qualitative futures. *International Journal of Qualitative Studies in Education*, *26*(6), 692-705.

Robinson, C. L. (2011). Hair as race: Why "good hair" may be bad for Black females. *Howard Journal of Communications*, *22*(4), 358-376.

Robinson-Moore, C. L. (2008). Beauty Standards Reflect Eurocentric Paradigms--So What? Skin Color, Identity, and Black Female Beauty. *Journal of Race & Policy*, *4*(1).

Rumsey, N., & Harcourt, D. (2005). *The psychology of appearance*. McGraw-Hill Education (UK).

Rumsey, N., & Harcourt, D. (2012). *Oxford handbook of the psychology of appearance*. Oxford University Press.

Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data*. Sage.

Statista, *Value of the hair loss treatment market worldwide in 2010 and 2017 (in billion U.S. dollars)* retrieved http://www.statista.com/statistics/489025/value-of-the-global-hair-loss-treatment-market/

Safavi, K. H., Muller, S. A., Suman, V. J., Moshell, A. N., & Melton, L. J. (1995). Incidence of alopecia areata in Olmsted County, Minnesota, 1975 through 1989. In *Mayo Clinic Proceedings* (Vol. 70, No. 7, pp. 628-633). Elsevier.

Sellami, R., Masmoudi, J., Ouali, U., Mnif, L., Amouri, M., Turki, H., & Jaoua, A. (2014). The relationship between alopecia areata and alexithymia, anxiety and depression: a case-control study. *Indian journal of dermatology*, *59*(4), 421.

Shah, R. B. (2018). Impact of collaboration between psychologists and dermatologists: UK hospital system example. *International journal of women's dermatology*, *4*(1), 8-11.

Shah-Beckley, I.S. (2017), *Therapists' and non-therapists' constructions of heterosex: A story completion study*. Unpublished thesis

Sharratt, N. D., Jenkinson, E., Moss, T., Clarke, A., & Rumsey, N. (2018). Understandings and experiences of visible difference and romantic relationships: A qualitative exploration. *Body image*, *27*, 32-42.

Sherrow, V. (2006). *Encyclopedia of hair: a cultural history*. Greenwood Publishing Group.

Shifman, L., & Lemish, D. (2010). Blondejokes. com: The new generation. *Society*, *47*(1), 19-22.

Simakou, T., Butcher, J. P., Reid, S., & Henriquez, F. L. (2019). Alopecia areata: A multifactorial autoimmune condition. *Journal of autoimmunity*, *98*, 74-85.

Simms, J. (2017). Assessment and formulation in counselling psychology. In V. Galbraith (Ed.) *Counselling Psychology* (pp. 33-49). Routledge.

Speer, S. A., & Potter, J. (2002). From performatives to practices Judith Butler, discursive psychology and. *Talking gender and sexuality, 94,* 151.Stenn, K. (2016). *Hair: A human history*. Pegasus Books.

St. Pierre, E. A. (2019). Post qualitative inquiry in an ontology of immanence. *Qualitative Inquiry*, *25*(1), 3-16.

Strawbridge, S., & Woolfe, R. (2010). Counselling psychology: Origins, developments and challenges. In: R. Woolfe, S. Strawbridge, B. Douglas & W.Dryden, *Handbook of counselling psychology*, (3rd Edition,pp. 3-22). Sage.

Strazzulla, L. C., Wang, E. H. C., Avila, L., Sicco, K. L., Brinster, N., Christiano, A. M., & Shapiro, J. (2018). Alopecia areata: Disease characteristics, clinical evaluation, and new perspectives on pathogenesis. *Journal of the American Academy of Dermatology, 78*(1), 1-12.

Synnott, A. (1987). Shame and glory: A sociology of hair. *The British journal of sociology, 38*(3), 381-413.

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological inquiry*, *15*(1), 1-18.

Terry, G., & Braun, V. (2013). To let hair be, or to not let hair be? Gender and body hair removal practices in Aotearoa/New Zealand. *Body Image*, *10*(4), 599-606.

Terry, G., & Braun, V. (2016). "I think gorilla-like back effusions of hair are rather a turn-off":'Excessive hair'and male body hair (removal) discourse. *Body Image, 17*, 14-24.

Terry, G., & Braun, V. (2017). Short but often sweet: The surprising potential of qualitative survey methods. In: V. Braun, v. Clarke &d. Gray (Eds.) *Collecting qualitative data: A* *practical guide to textual, media and virtual techniques*, (pp. 15-44). Cambridge University Press.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In: C. Willig & W. Stainton-Rogers (Eds) *The Sage handbook of qualitative research in psychology*, (2nd Ed., pp. 17-37). Sage.

Thompson, A. (2012). Researching appearance: models, theories and frameworks. In: In: N. Rumsey & D. Harcourt (Eds.)*The Oxford Handbook of The Psychology of Appearance. (pp. 91-109*). Oxford University Press..

Thompson, C. (2009). Black women, beauty, and hair as a matter of being. *Women's Studies*, *38*(8), 831-856.

Tiggemann, M., & Hodgson, S. (2008). The hairlessness norm extended: Reasons for and predictors of women's body hair removal at different body sites. *Sex Roles*, *59*(11-12), 889-897.

Tischner, I. (2013). *Fat lives: A feminist psychological exploration*. Routledge.

Toerien, M., & Wilkinson, S. (2003). Gender and body hair: Constructing the feminine woman. In *Women's Studies International Forum* (Vol. 26, No. 4, pp. 333-344). Pergamon.

Toerien, M., & Wilkinson, S. (2004). Exploring the depilation norm: a qualitative questionnaire study of women's body hair removal. *Qualitative Research in Psychology*, *1*(1), 69-92.

Tribe, R., & Morrissey, J. (Eds.). (2015). *Handbook of professional and ethical practice for psychologists, counsellors, and psychotherapists*. Routledge.

Trusson, D., & Pilnick, A. (2017). The role of hair loss in cancer identity: perceptions of chemotherapy-induced alopecia among women treated for early-stage breast cancer or ductal carcinoma in situ. *Cancer nursing*, *40*(2), E9-E16.

Tucker, P. (2009). Bald is beautiful? The psychosocial impact of alopecia areata. *Journal of health psychology*, *14*(1), 142-151.

Turner, B. S. (2012). Introduction: The turn of the body. In *Routledge Handbook of Body Studies* (pp. 16-32). Routledge.

Ussher, J. M. (Ed.). (1997). *Body Talk: The Material and Discursive Regulation of Sexuality, Madness, and Reproduction*. Psychology Press.

Ussher, J. M. (2011). *The madness of women: Myth and experience*. Routledge.

Van Deurzen, E. (2007). Existential therapy. In: W. Dryden (Ed.) *Dryden's Handbook of Individual Therapy* (5th Ed.), pp. 195-226). Sage.

Vaillant, G. E. (2011). Involuntary coping mechanisms: a psychodynamic perspective. *Dialogues in clinical neuroscience, 13*(3), 366.

Valeri, R. M., Sweazy, N. E., & Borgeson, K. (2017). An analysis of skinhead websites and social networks, a decade later. *Michigan Sociological Review*, *31*, 76-105.

Vojdik, V. K. (2002). Gender Outlaws: Challenging Masculinity in Traditionally Male Instituions. *Berkeley Women's LJ*, *17*, 68.

Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: a model whose time has come. *Clinical Rehabilitation, 31*(8), 995-1004.

Walkerdine, V. (2015). Transmitting class across generations. *Theory & Psychology, 25*(2), 167-183.

Wampold, B. E. (2015). How important are the common factors in psychotherapy? An update. *World Psychiatry*, *14*(3), 270-277.

Wang, E., & McElwee, K. J. (2011). Etiopathogenesis of alopecia areata: Why do our patients get it?. *Dermatologic therapy*, *24*(3), 337-347.

Weedon, C. (1987). Feminist practice and poststructuralist theory. Blackwell.

Weitz, R. (2004). *Rapunzel's daughters: What women's hair tells us about women's lives*. Macmillan.

Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: a qualitative study. *Body Image*, *6*(3), 194-200.

Wetherell, M., & Edley, N. (1999). Negotiating hegemonic masculinity: Imaginary positions and psycho-discursive practices. *Feminism & psychology*, *9*(3), 335-356.

Wiggins, S., Moore-Millar, K., & Thomson, A. (2014). Can you pull it off? Appearance modifying behaviours adopted by wig users with alopecia in social interactions. *Body image*, *11*(2), 156-166.

Willemsen, R., Vanderlinden, J., Roseeuw, D., & Haentjens, P. (2009). Increased history of childhood and lifetime traumatic events among adults with alopecia areata. *Journal of the American Academy of Dermatology,60*(3), 388-393.

Willemsen, R., Haentjens, P., Roseeuw, D., & Vanderlinden, J. (2010). Hypnosis in refractory alopecia areata significantly improves depression, anxiety, and life quality but not hair regrowth. *Journal of the American Academy of Dermatology*, *62*(3), 517-518.

Willemsen, R., Haentjens, P., Roseeuw, D., & Vanderlinden, J. (2011). Hypnosis and alopecia areata: Long-term beneficial effects on psychological well-being. *Acta Dermato-Venereologica*, *91*(1), 35-39.

Williamson, H., Antonelli, P., Bringsén, Å., Davies, G., Dèttore, D., Harcourt, D., ... & Yalçın, A. D. (2018). Supporting patients with body dissatisfaction: A survey of the experiences and training needs of European multi-disciplinary healthcare professionals. *NursingPlus Open*, *4*, 8-13.

Williamson, H., & Rumsey, N. (2017). Perspectives of health professionals on the psychosocial impact of an altered appearance among adolescents treated for cancer and how to improve appearance-related care. *Journal of psychosocial oncology*, *35*(1), 47-60.

Willig, C. (1999). Beyond appearances: A critical realist approach to social constructionism. In: D.J. Nightingale & J. Cromby (Eds.) *Social constructionist psychology: a critical analysis of theory and practice. Social constructionist psychology: A critical analysis of theory and practice*, (pp. 37-51). Open University Press.

Willig, C. (2000). A discourse-dynamic approach to the study of subjectivity in health psychology. *Theory & Psychology*, *10*(4), 547-570.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill education (UK).

Willig, C. (2016). Constructivism and 'The Real World': Can they co-exist?. *QMiP Bulletin*, (21).

Willig, C. (2019). Ontological and epistemological reflexivity: A core skill for therapists. *Counselling and Psychotherapy Research*. *19*(3), 186-194.

Willig, C., & Stainton-Rogers, W. (Eds.). (2017). *The SAGE handbook of qualitative research in psychology*. Sage.

Woolfe, R. (2016). Mapping the world of helping: The place of counselling psychology. In: Douglas, B., Woolfe, R., Strawbridge, S., Kasket, E., & Galbraith, V. (Eds.). (2016). *The handbook of counselling psychology*, (pp. 5-19). Sage

Young, L., & Frosh, S. (2010). And where were your brothers in all this?': A psychosocial approach to texts on 'brothering. *Qualitative Research*, *10*(5), 511-531.

Appendix A

Glossary of Terms

This glossary defines some terms as they are used in the thesis. They are terms that carry potentially multiple, complex or contentious meanings. The definitions provided here are therefore intended only to orientate the reader to the meanings that I have come to through my reading, research and reflections. Where relevant, references are given to texts that have provided the definitions I have used, or that have shaped and informed my understanding.

1. discourse	"a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events" (Burr, 2015, p.74). The discourses available to a person at any given time are dependent on contextual elements such as social class, education, current news stories, built environment, gender, family structure and so on. Discourses therefore constitute the knowledge available to us, represent the power relations operating in society, and operate to regulate us (Foucault, 1979). Their contextuality means that they are fluid constructions and that multiple, potentially contradictory discourses, may operate simultaneously to produce a person's knowledge of the world, others and themselves.
2. dominant discourse	A discourse that is particularly pervasive and/or operates in particularly powerful ways to constitute how the world is understood, and to shape who and how it is possible to be (subjectivity). Gendered discourses offer examples of this kind of dominance, such as the "have/hold" and "male sex drive" discourses defined by Wendy Hollway and which can be seen to powerfully shape the subjectivities available to men and women (Hollway, 1984). The discipline of psychology itself is produced by, and contributes to, the construction of dominant discourses about the source and status of knowledge and what it is to be a person (Henriques et al., 1984).
3. social construction	The way that meaning and knowledge are generated through social processes, including relationships between people (Burr, 2015; Gergen, 2015).
4. The unconscious	"Unconscious" is used in this thesis as an adjective to describe psychical processes that are outside conscious awareness. The meanings attached to this are influenced by Freudian and Lacanian conceptualisations of the unconscious, including: 1) The idea that the unconscious consists of thoughts that are experienced as intolerable and are therefore repressed, yet manifest "quite without the Subject's intentions, in dreams,

	unsuccessful/self-defeating acts, slips of the tongue, and even pathological symptoms." (Bailly, 2009, p.42). 2) An emphasis on the role of language, signification and the symbolic in forming the unconscious, and the difficulties that ensue for a person when language fails – for example, in the analysis of the data presented in this thesis, the words "bald woman" fail to attach to a conceivable idea.
5. Split objects	This expression is used on p.28 of the thesis. The noun "object"(s) refers to *the object of analysis; the thing that is studied*. The preceding adjective "split" references the object relations perspective that healthy relationships with self and other are dependent on the development of a capacity to experience the other as an integrated whole (See Greenberg & Mitchell, 1983 on the development and variety of object relations approaches in psychoanalytic theory). On p.12, I draw attention to the way in which psychology as a discipline frequently splits aspects of subjectivity out from the whole in order to create clearly defined objects of study. My use of the term "split objects" on p.28 is therefore intended to highlight the reductive objectification that results from splitting exploration of subjectivities into either a Foucauldian focus on power/discourse or a psychoanalytic focus on internal psychical processes.
6. unconscious enactment	The manifestation of unconscious processes in actual interactions between people. Specifically, "the very place where the struggle between coercive normative unconscious processes and counter-normative unconscious processes are enacted. And since all identities are relational, these repetitions are stirred up and played out in relation." (Layton, 2008, p.15)
7. critical deployment	This term is used on page 54 of the thesis in an interpretive analysis of a participant's account of her wig use. "Deployment" - "the use of someone or something in an effective way" (Cambridge Dictionary) describes her effective use of a wig to exercise agency in recognising, then both submitting to, and resisting, gendered discourses – a critical process.
8. unconscious defense	The Freudian idea that we defend ourselves against intolerable thoughts through unconscious mechanisms. Vaillant (2011) proposes that there are some unconscious defenses that are effective in regulating distress without significant negative effects on interpersonal relationships or day-to-day functioning. He describes these as adaptive coping mechanisms and defines them as "mature defenses". Use of the term "unconscious defense" in this thesis is specific to observations on pages 59, 60 and 63 that some of these "mature defenses" can be identified in the data and may offer insights into some

	processes through which people with AA develop effective coping strategies.
9. subjective change	This is used to denote changes in the subjectivities available to a person. The positioning of the words is intended to emphasise: 1) That some aspect of what it is to be that person is changed in some way. 2) That any such change is contingent on the meanings available to both observer and subject, i.e. that the questions of a) whether change has happened, and b) what that change might consist of, are subjective matters.
10. subjectification	The process of becoming constituted as a subject. Also referred to in the literature as "subjectivation". In my application of the term I intend it to mean *the dynamic operation of discourses and social interactions in subordinating and productive processes through which a reflective and agentic "self" is constituted.* This meaning is shaped by my reading of Judith Butler's exploration in The Psychic Life of Power (Butler, 1997).

Appendix B

Journal Article

Appendix C

The Living With Alopecia Areata, Totalis and Universalis Online Survey

1. Please tell me about your experience of starting to lose your hair
2. How does having alopecia affect your day to day life?
3. How do you think other people perceive you?
4. In what ways, if any, does having alopecia affect your sense of who you are as a person?
5. In what ways, if any, does having alopecia affect your identity as a woman/man?
6. Has your experience of living with alopecia changed over time?
7. What is your experience of seeking information and help (including pharmaceutical and cosmetic products) around your hair loss?
8. Have you ever been offered counselling or psychological support to help you cope with having alopecia?

If yes:

When was this offered and what kind of support was it?

Can you tell me about the experience, including what, if anything was helpful or unhelpful?

If no:

Is counselling or psychological support something that you would like?

Can you tell me why you would or would not like to be offered counselling or psychological support?

9. What do you think counsellors and psychologists should know about your condition and how it affects you?
10. Is there anything else that you think it is important for me to know about what it is like for you to live with alopecia? Please include anything that feels relevant or significant to you.

Appendix D

Living with Alopecia Areata, Totalis or Universalis – Interview Guide

1. **Could you start by telling me how old you were when you first started losing your hair and what impact it had on you?**
    - How did it affect the way you felt?
    - How did it affect your identity?

2. **Where did you go for help/information and what was this like?**
    - Eg. GP/dermatologist, internet, Alopecia UK, online forums, wig shops
    - Do you have a diagnosis? If so, what is it and who diagnosed you?
    - What was your experience of looking for help?

3. **How did you come to have counselling/psychotherapy/ psychological intervention?**
    - Specifically for alopecia or related to something else
    - Context – NHS/private, GP practice, IAPT, dermatology
    - Offered/requested/recommended/found via internet
    - How were you feeling about yourself at the time? What effect was your hair loss having on your identity?

2. **What kind of therapy/counselling/psychological intervention was it?**
    - Who provided it? (counsellor/psychologist/psychotherapist/psychological wellbeing practitioner)
    - How many sessions did you have?

3. **What was the experience of having this like for you?**
    - Was it helpful or unhelpful?
    - What did you think of your therapist/counsellor/psychologist/psychological wellbeing practitioner?

4. **Did therapy/counselling/psychological intervention help you to live/cope with having alopecia?**
    - If yes, in what ways?
    - If no, do you have thoughts about why not?

5. **Did therapy/counselling/psychological intervention have negative effects on you and the way you live/cope with alopecia?**

6. **Do you think you changed through having therapy/counselling/psychological intervention?**
    - If so how?

7. **Are there things that you wish your therapist/counsellor/psychologist had done differently?**

8. **Is there anything else that you think would have made a helpful difference to your experience of therapy/counselling/psychological intervention and its impact on helping you to cope/live with having alopecia?**
    - Eg. number of sessions, context, cost, timing, type of therapy

9. **Is there any other help or support that you feel would have helped you to cope or adjust to living with alopecia?**
    - Eg. Information from GP, access to funding for wigs or permanent make up, greater public awareness

10. **Is there anything else that you would like to say about your experience of therapy /counselling / psychological intervention or your experience of living with alopecia more generally?**

Appendix E

Orthographic transcription notation system from (from Braun & Clarke, 2013, adapted from Jefferson, 2004)

Feature	**Notation**
Laughing, coughing etc.	((laughs)) ((coughs)) ((general laughter))
Pausing	((pause)) signals a significant pause (.) signals a shorter pause
Inaudible speech	**?**
Cut-off speech and speech sounds	**-**

Appendix F

Survey participant demographics (N= 98)

Diagnosis	Alopecia universalis – 40 Alopecia areata – 35 Alopecia totalis – 17 No formal diagnosis – 6
Source of diagnosis	Dermatologist – 63 GP – 31 No diagnosis - 2 Clinic doctor – 1 Self – 1
Age range	18-79
Range of age at first hair loss	1-69
Range of number of years since first hair loss	1-50
Sex	Female 86 Male 12
Sexuality	Heterosexual – 91 Bisexual – 4 Gay - 2 Lesbian - 1
Racial/ethnic Identity	White – 78 British – 11

	Scottish – 2 British Asian – 2 South Asian – 1 Black British – 1 Middle Eastern – 1 British Welsh – 1 Australian - 1
Disability	Yes - 9 No – 88 No data - 1
Social class	Middle class – 44 Working class – 33 Blank - 7 No class – 8 Other – 4 Lower class – 2
Occupation	Full-time employed -49 Part-time employed – 15 Retired – 8 Unemployed – 7 Self-employed – 6 Full-time student – 5 Part-time student – 5 Carer -5 Unable to work - 2

Current relationship status	Married -46 Single - 26 Partnered – 17 Divorced/civil partnership dissolved – 7 Civil Partnership – 2

Appendix G

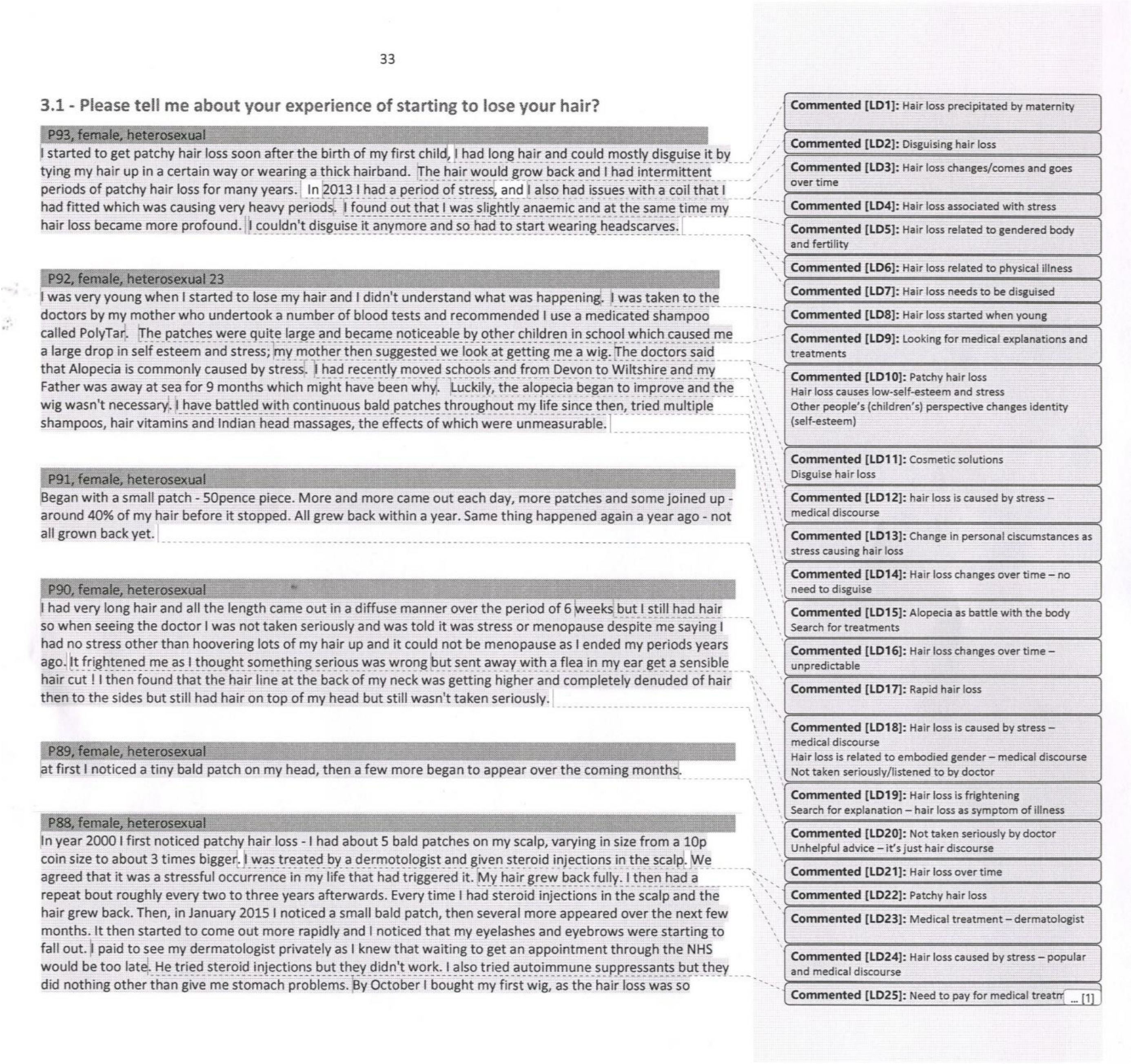
Interview participant demographics

Age range	32-55
Sexuality	Heterosexual – 1
Gender	Female – 5 Male - 1
Ethnicity	White – 2 British -1 Black British – 1 Human – 1
Disability	No – 6
Relationship status	Married – 4 Single – 1 Partnered - 1
Occupation	Full-time employed -3 Carer – 2 Part-time employed -2 Self-employed -1

Appendix H

Evidence of coding

1. Example of initial, primarily inductive coding



33

3.1 - Please tell me about your experience of starting to lose your hair?

P93, female, heterosexual

I started to get patchy hair loss soon after the birth of my first child, I had long hair and could mostly disguise it by tying my hair up in a certain way or wearing a thick hairband. The hair would grow back and I had intermittent periods of patchy hair loss for many years. In 2013 I had a period of stress, and I also had issues with a coil that I had fitted which was causing very heavy periods. I found out that I was slightly anaemic and at the same time my hair loss became more profound. I couldn't disguise it anymore and so had to start wearing headscarves.

P92, female, heterosexual 23

I was very young when I started to lose my hair and I didn't understand what was happening. I was taken to the doctors by my mother who undertook a number of blood tests and recommended I use a medicated shampoo called PolyTar. The patches were quite large and became noticeable by other children in school which caused me a large drop in self esteem and stress; my mother then suggested we look at getting me a wig. The doctors said that Alopecia is commonly caused by stress. I had recently moved schools and from Devon to Wiltshire and my Father was away at sea for 9 months which might have been why. Luckily, the alopecia began to improve and the wig wasn't necessary. I have battled with continuous bald patches throughout my life since then, tried multiple shampoos, hair vitamins and Indian head massages, the effects of which were unmeasurable.

P91, female, heterosexual

Began with a small patch - 50pence piece. More and more came out each day, more patches and some joined up - around 40% of my hair before it stopped. All grew back within a year. Same thing happened again a year ago - not all grown back yet.

P90, female, heterosexual

I had very long hair and all the length came out in a diffuse manner over the period of 6 weeks but I still had hair so when seeing the doctor I was not taken seriously and was told it was stress or menopause despite me saying I had no stress other than hoovering lots of my hair up and it could not be menopause as I ended my periods years ago. It frightened me as I thought something serious was wrong but sent away with a flea in my ear get a sensible hair cut ! I then found that the hair line at the back of my neck was getting higher and completely denuded of hair then to the sides but still had hair on top of my head but still wasn't taken seriously.

P89, female, heterosexual

at first I noticed a tiny bald patch on my head, then a few more began to appear over the coming months.

P88, female, heterosexual

In year 2000 I first noticed patchy hair loss - I had about 5 bald patches on my scalp, varying in size from a 10p coin size to about 3 times bigger. I was treated by a dermotologist and given steroid injections in the scalp. We agreed that it was a stressful occurrence in my life that had triggered it. My hair grew back fully. I then had a repeat bout roughly every two to three years afterwards. Every time I had steroid injections in the scalp and the hair grew back. Then, in January 2015 I noticed a small bald patch, then several more appeared over the next few months. It then started to come out more rapidly and I noticed that my eyelashes and eyebrows were starting to fall out. I paid to see my dermatologist privately as I knew that waiting to get an appointment through the NHS would be too late. He tried steroid injections but they didn't work. I also tried autoimmune suppressants but they did nothing other than give me stomach problems. By October I bought my first wig, as the hair loss was so

Commented [LD1]: Hair loss precipitated by maternity

Commented [LD2]: Disguising hair loss

Commented [LD3]: Hair loss changes/comes and goes over time

Commented [LD4]: Hair loss associated with stress

Commented [LD5]: Hair loss related to gendered body and fertility

Commented [LD6]: Hair loss related to physical illness

Commented [LD7]: Hair loss needs to be disguised

Commented [LD8]: Hair loss started when young

Commented [LD9]: Looking for medical explanations and treatments

Commented [LD10]: Patchy hair loss
Hair loss causes low-self-esteem and stress
Other people's (children's) perspective changes identity (self-esteem)

Commented [LD11]: Cosmetic solutions
Disguise hair loss

Commented [LD12]: hair loss is caused by stress – medical discourse

Commented [LD13]: Change in personal ciscumstances as stress causing hair loss

Commented [LD14]: Hair loss changes over time – no need to disguise

Commented [LD15]: Alopecia as battle with the body
Search for treatments

Commented [LD16]: Hair loss changes over time – unpredictable

Commented [LD17]: Rapid hair loss

Commented [LD18]: Hair loss is caused by stress – medical discourse
Hair loss is related to embodied gender – medical discourse
Not taken seriously/listened to by doctor

Commented [LD19]: Hair loss is frightening
Search for explanation – hair loss as symptom of illness

Commented [LD20]: Not taken seriously by doctor
Unhelpful advice – it's just hair discourse

Commented [LD21]: Hair loss over time

Commented [LD22]: Patchy hair loss

Commented [LD23]: Medical treatment – dermatologist

Commented [LD24]: Hair loss caused by stress – popular and medical discourse

Commented [LD25]: Need to pay for medical treatm ... [1]

2. Example of deductive coding for “shame (restricted subject)”

I am ashamed of my body for failing me. I'm ashamed that I am balding and have to attempt to wear my hair in a particular style, which isn't very flattering, in an attempt to hide it. This is to help stop people in general, from asking, pointing it out and staring at me. I have no confidence in myself, I want to hide away, I'm embarrassed for my kids	P74, Female, heterosexual
it's affected my confidence. Illogically I also feel ashamed of having no hair and of wearing a wig.	P53, Female, heterosexual
Was absolutely devastating and shocking. Last all my hair very quickly and became very depressed and low. I also felt ashamed and felt I was loosing my identity and feminism.	P10, Female, heterosexual
Initially it destroyed my self confidence. I felt ugly. I had suicidal thoughts. Once I had a wig and could hide the developing problem, I felt much more confident as I could go out and about and no-one need know my problem.	P56, Female, heterosexual
Most of my hair grew back but I have patches that come and go and they are in places where it is very difficult to hide it. I have got used to my life as a very socially awkward person but every single time a bald patch appears the panic takes hold no matter how much I tell myself i don't care about it.	P29, Female, heterosexual
That is makes me feel unwomanly, I have lost all self esteem in myself. That the real me wants to be here again, not this shy hideaway that I am now.	P 74, Female, heterosexual
My alopecia now is a lot worse I seldom leave my home and if I have to go shopping I leave early as less people about. I also lost my eyelashes and eyebrows	P65, Male, gay
I have only told my husband and daughters and four close friends. Other people are not aware of my condition. I did not feel able to talk about it/be open to people about it.	P56, female, heterosexual
I am reserved as I do not show my baldness to those I do not know or trust as it's a part of me even I do not like.	P95, female, heterosexual
I have only told my husband and daughters and four close friends. Other people are not aware of my condition. I did not feel able to talk about it/be open to people about it.	P56, female, heterosexual
I fear pity which is why I wear a wig. I know most won't care / judge but it's the feeling of being normal that I crave.	P75, female, heterosexual
I felt humiliated by the experience initially, I refused to wear a wig as I felt that they were seen as a comedy item although I have started to now.	P93, female, heterosexual
It used to make me feel like I was different to everyone else. Because I was bullied so much, I felt so isolated and worthless. I hated myself for the way I looked and because I had no friends because no one wanted to be friends with the girl with no hair; I felt embarrassed about the way I looked. It made me feel like I didn't want to live any more.	P2, female, heterosexual
It affects me everyday but my confidence is what is affected the most. Having to look like this everyday has been a struggle, I lost my identity to those who know me and because of this I have had to deal with verbal abuse, humiliation and anxiety.	P87, Male, heterosexual
My self esteem and confidence has dropped enourmosly, I sometimes don't want to leave my house due to my hair loss	P13, female, heterosexual
It changed me from being a quiet and reserved person to almost a total recluse. I struggle with social gatherings and will avoid as far as is possible. I have no social life and no confidence and very very low self esteem.	P29, female, heterosexual

Appendix I

Ethics Approval Letter

Appendix J

Thematic Map

Appendix K

Living with Alopecia Areata, Totalis or Universalis

Participant Information Sheet

The researcher and the study

My name is Louise Davey. I am a trainee counselling psychologist at the University of the West of England. For my doctoral study I am researching how ideas, attitudes and practices to do with hair and hair loss affect people with alopecia areata, totalis and universalis. I am interested in this because someone dear to me lives with alopecia universalis. As a trainee counselling psychologist I hope the study will help to increase understanding around what it is like to live with hair loss resulting from this condition.

I have already collected information using an online questionnaire. This allowed me to read answers provided by lots of different people about living with alopecia areata, totalis and universalis. I am now meeting individually with a small number of people who have these forms of hair loss and have accessed some form of counselling or psychological intervention. This will allow me to develop a deeper understanding around what it is like to live with alopecia areata, totalis and universalis, as well as whether and how counselling or psychological intervention can influence experience and identity for people in relation to this form of hair loss.

Contact details

Researcher – Louise Davey louise2.davey@live.uwe.ac.uk.

Research Supervisor: Dr Victoria Clarke, Associate Professor of Qualitative and Critical Psychology, University of the West of England, Victoria.clarke@uwe.ac.uk.

Questions you may have

Who can take part in the study?

If you are aged 18 or over, first noticed hair loss at least 1 year ago, believe that it is caused by alopecia areata, totalis or universalis and have since accessed some form of counselling or psychological intervention then I would like to hear about your experiences. It is not necessary to have a diagnosis from a doctor.

How long will the interview take?

The interview is likely to last for around 1 hour. The aim is to explore in detail your experience of living with alopecia areata, totalis or universalis and of accessing counselling or psychological intervention in relation to your hair loss so it is possible that it will take longer. If you know that you have a limited amount of time available for our meeting, just let me know and I will make sure that we finish when you need us to.

Where will the interview take place?
We will agree a place to meet that feels comfortable to you. Potential places include a quiet room at the University of the West of England campus, your home, or a quiet café.

Will I be identifiable?
I will audio-record the interview and store it securely as an encrypted file. I will then transcribe it, anonymising your information (I will remove or change any details that can identify you). This will include changing your name. The audio-recording will be destroyed once the research is complete. It is possible that I will use anonymous quotations from your interview in my doctoral thesis, in presentations at conferences, in publications, or in training resources.

How will my data be used?
The information collected for the study will be analysed using qualitative methods. I will look to see what patterns there are in the information that you and others have shared about what it is like to live with alopecia areata, totalis and universalis. The themes and meanings that are found will be discussed in my doctoral thesis and may be presented at conferences, in publications, or in training resources.

What benefits and risks are there in taking part?
In the interview I will ask you to think about and describe your past and current experiences in living with alopecia areata, totalis or universalis and of accessing counselling or psychological intervention. You may find it helpful to share these but it may also bring up some difficult thoughts, feelings or memories for you.

If you find that you feel distressed then support is available from the following organisations:

Alopecia UK (www.alopeciaonline.org.uk) – a charity that offers an online forum and local **support groups for people with hair loss.**

Changing Faces (www.changingfaces.org.uk) – a charity that offers a helpline (0300 012 0275), online resources and face to face support for people with visible difference.

Will I be able to change my mind?
If you decide that you no longer want your answers to be included in the study you will be able to withdraw by emailing me at louise2.davey@live.uwe.ac.uk. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within a month of participation if you wish to withdraw your data.

Consent

Before we start the interview I will invite you to sign a consent form. This is to ensure that you have read the information about the study and that you agree to participating in it.