PSYCHOSOCIAL INTERVENTIONS FOR YOUNG PEOPLE WITH BURN INJURIES AND THEIR FAMILIES

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ABSTRACT

Burn injuries can be one of the most traumatic experiences of a family's life and may cause a number of psychosocial difficulties (including depression, anxiety, social difficulties, and appearance-related concerns). However, little research has explored interventions to facilitate healthy psychosocial adjustment after a burn injury, with most studies focusing on burn camps for young people. The studies in this thesis aimed to address this gap in knowledge by exploring a range of interventions for both young people and their families, considering interventions of different intensities as represented by the Centre for Appearance Research pyramid framework of appearance-related interventions.

This thesis employed a mixed methods approach across four studies. Study 1A utilised photo-elicitation techniques to explore seven families' (n=21 participants) experiences of attending a family burn camp, revealing that camp was a place where families could share new experiences, have fun without feeling different, and receive support from others who understood their feelings. Study 1B aimed to further research into young people's burn camps, by addressing a number of methodological limitations identified in previous research. Standardised outcome measures and open-ended questions were used to evaluate young people's (n=23) and their parents' (n=22) expectations and experiences of camp. Both the qualitative and quantitative findings suggested that camp improved feelings towards appearance and social situations.

A feasibility study of a newly-developed online support programme was then undertaken with three young people, one guardian and ten clinical psychologists. Results indicated that the programme can be used flexibly to meet individual needs, and improved psychosocial outcomes for the participants in the study. The final study was exploratory in nature, and involved qualitative interviews with fourteen clinical psychologists working within paediatric burns, to consider their current practices when providing face-to-face support to children and young people with burn injuries and their families.

The studies in the thesis support the need for flexibility within psychosocial interventions proposed by the Centre for Appearance pyramid framework. However, it was felt that revising the framework may better represent the way in which young people and their families can move fluidly between different levels of interventions according to their changing needs. The pyramid framework was thus reworked into a wheel framework. The overall findings from this thesis emphasize important implications for researchers, health professionals and policy makers, considering ways of improving burns services and translating research into practice.

CHAPTER 1. INTRODUCTION

1.1 INTRODUCTION TO THE THESIS

While most burn survivors adjust well, a minority continue to experience wide-ranging psychosocial difficulties (Patterson, Everett, Bombadier, et al, 1993). Bakker et al (2013) suggested that future research should investigate a number of concepts relevant to burn injuries, including body image, self-esteem, anxiety, depression and social issues such as bullying or social comfort. Research in this area is critical to further our understanding of the different levels of psychosocial needs experienced by those burn injuries and the hope offered by suitable interventions (Fauerbach, Pruzinsky & Saxe, 2007). Therefore, the overall aim of this thesis was to evaluate interventions to promote healthy psychosocial adjustment to burn injuries, considering a range of interventions providing different levels of support.

The thesis begins by introducing the impact that a burn injury can have on both an individual and their family, before considering psychosocial adjustment to a burn injury, discussing models of adjustment to a visible difference and psychosocial interventions currently available. It then outlines the methodology used throughout the studies, including a consideration of mixed methods research and relevant ethical concerns. It presents four studies that explore a range of interventions, beginning with a qualitative study using photo-elicitation to explore the experiences of families attending a family burn camp. This is followed by a mixed methods study examining the impact of burn camp on children and young people (CYP's) social concerns and body image (as evaluated by CYP themselves) and behaviour (as evaluated by their parents). A feasibility study then examines the use of YP Face IT (an online support intervention for CYP affected by appearance-related concerns) by CYP with burn injuries being treated within secondary care. This is followed by a qualitative exploration of the experiences of psychosocial specialists working within paediatric burns, considering both face-to-face support and viable alternatives. The thesis ends with a general discussion of these four studies and their place in the burns literature, followed by recommendations for future research and care provision.

1.2 INTRODUCTION TO BURN INJURIES

A burn is an injury to the skin tissue encompassing scalds, thermal, chemical or electrical injuries (World Health Organization, 2016). It is estimated that around 130,000 people of any age visit emergency departments with burn injuries each year, (NHS England, 2013). A review of the international Burn Injury Database (iBID) of burn injuries in England and Wales between 2003-

2011 by Stylianou, Buchan and Dunn (2014) revealed that 63% of patients treated in burns services were male and 37% were female, while the median age was 21 years. The severity of a burn injury can be determined by the Total Body Surface Area (TBSA) burned, which can be classed as a complex injury in CYP under 16 years of age if TBSA is larger than 5% (National Burn Care Review; NBCR, 2001). Stylianou et al's review reported that the median TBSA was 1.5%. The most common cause of burn injury was scald in 38% of cases, followed by contact burns and then flame burns. While hospital admission is not usually necessary, around 3,750 CYP under the age of 15 are admitted to hospital with burn and scald injuries each year (The Child Accident Prevention Trust, 2012), and most burn injuries happen to children under the age of three (Pope, Solomons, Done et al, 2007). Burn injuries are more common in households with a lower socioeconomic status (SES) (Park, Do Shin, Kim et al, 2009), which can be defined by a number of factors such as ethnicity, large families and single parents, low income and unemployment, illiteracy or low levels of education, or not owning a home or telephone (Edelman, 2007).

The British Burn Association asked the National Burn Care Review Committee to conduct a review of UK burns services in response to a growing body of evidence that burn care was insufficient from the perspective of patients. The committee published the National Burn Care Review (NBCR) in 2001 which examined the delivery and organisation of UK burn services, aiming to propose improvements to the service in its entirety, including national guidelines to be used by all services, the development of rehabilitation services to be integrated within acute services and a research and development programme to develop the evidence base within burn care. Although mortality rates from burn injuries as a whole have significantly decreased from 7.2% in the 1980s to just 2.3% since 2000 (Roberts, Lloyd, Parker et al, 2012), there are still around 300 deaths every year resulting from burn injuries, particularly in those aged under 1 or over 56 years of age (NBCR, 2001). However, this overall decrease in mortality means that more individuals with severe burns are faced with a long and challenging recovery process (Wisely & Gaskell, 2012), comprising seven stages according to the NBCR (2001).

The first two stages involve "rescue" and "resuscitation", with support commonly required for the cardio-respiratory and renal systems. Around 1,000 patients a year suffer from burns so severe that they require fluid resuscitation (Hettiaratchy & Dziewulski, 2004). Patients, particularly CYP, may then need to be "retrieved" from their initial assessment in the emergency department, to a specialist burn unit or team. This may help to relieve the burden on A&E staff, but it is also important to ensure that the individual receives the appropriate level of care. The fourth stage is "resurface" as the physical injuries to the skin need to be treated and repaired, either by dressings or actual skin replacement techniques which can be extremely painful and distressing for CYP

(Atchison, Osgood, Carr & Szyfelbein 1991). Debridement (removal of dead or damaged skin) has been described by CYP as the most painful aspect of treatment (Landolt, Marti, Widmer & Meuli, 2002) and may have to continue on an outpatient basis for patients with severe burns (Wiechman & Patterson, 2004). This is an unpleasant phase of treatment for both CYP and their caregivers.

Once the patient stabilises, he or she must next be "rehabilitated". This process begins at admission and aims to facilitate the individual's return to society with minimal changes to appearance, abilities and functioning. It can take the form of physical therapy, psychological support (which will be discussed in more detail throughout the thesis) or scar management. One of the most common physical complications after a burn injury is the tightening of the skin known as contractures, which can restrict movement and cause deformities to the joints and face, and are usually caused by keloid or hypertrophic scarring (Esselman, 2007). Keloids and hypertrophic scars are fibrous growths that occur as an abnormal reaction to a wound or trauma (English & Shenefelt, 1999). The main difference between the two is that keloids often grow beyond the boundaries of the original wound whereas hypertrophic scars are usually confined to the original wound area (Edgar & Brereton, 2004). Many burn survivors wear pressure garments for up to two years after the injury in an attempt to minimize keloid and hypertrophic scarring (Bombaro, Engrav, Carrougher et al, 2003). A stretching programme can be implemented to try and improve motion in those who have developed contractures (Godleski, Oeffling, Bruflat et al, 2013), and patients may be prescribed a programme of exercise or activities to continue at home (Edgar & Brereton, 2004).

The sixth stage is "reconstruction", as further surgery may be needed in both the short and long term. This may involve further skin grafting, or the removal of unstable areas of skin. In the long term, the patient will be regularly "reviewed". For CYP this follow up usually continues well into adulthood, and they may then be referred to an adult burn service, as both the physical and psychological effects of a burn can persist into adulthood (Goodhew, Van Hooff, Sparnon et al, 2014). Williams, Doctor and Patterson (2003) suggested that although the majority of burn survivors will experience good physical recovery, psychological complaints are far more prevalent than physical issues.

The National Burn Care Review (2001) examined the provision of burn injury care in the UK and found insufficient psychosocial care for patients with burn injuries. The review stated a pressing need for a national strategy providing clear standards of burn care. The National Burn Care Standards (National Network for Burn Care, 2013) were developed based on the original objectives of the National Burn Care Review, and state that burns services must provide

psychological care to burn patients and their families/carers. Different levels of psychological support should be available, based on a tiered approach to assessment and care depending on the needs of patients and their families/carers. A systematic review carried out by Bakker et al (2013) identified emotional, social and behavioural outcomes of both CYP with burns and their families and found a range of problems such as appearance concerns, anxiety, depression and social difficulties, particularly in the first few months following the burn injury. However, some CYP and families were also found to suffer from these psychosocial problems in the long-term. It is likely that CYP with burns will be required to continually adjust as they pass through different developmental stages (Sawyer, Minde & Zuker, 1983).

For example, Smolak (2012) suggests that while babies as young as four months can distinguish themselves from other infants, a clear sense of self does not emerge until around the two year mark, indicating that children who are burned before this age may be less concerned about the changes to their appearance as a result of the injury. Children are able to draw comparisons between themselves and others at around five years (Neaum, 2013), so this may be the age where they start to notice more acutely if their appearance differs from that of their peers. It is thought that while babies experience basic emotions such as joy or anger at around eight months, more complex emotions such as shame, guilt, pride or embarrassment do not emerge until around 18-24 months, since these rely on the children having some sense of self (Kail, 2004). Therefore, while a common reaction to a burn injury relates to shame about one's appearance (see section 2.1.1) it is possible that feelings of shame will not occur before these ages. Another emotion which can differ depending on the child's age is fear, as typical childhood fears (such as imaginary monsters) tend to lessen during primary school as they are replaced by fears such as those relating to school or health (Kail, 2004). A burn injury could tap into either of these fears as CYP worry about its impact on school, or their physical recovery.

A significant developmental stage in a CYP's life occurs as they approach adolescence, as puberty generates changes to the body and new feelings emerge, which can cause a disruption to a CYP's sense of self (Robinson, 2008). This is also a time when CYP transition from primary to secondary school, and are could therefore be exposed to an entirely new social group. During adolescence, CYP also begin to show an interest in romantic relationships, which can lead to worries about intimacy (Robinson, 2008). The increased focus on appearance, a new school environment and the development of relationships means that this may be a particularly problematic time for those who sustain a burn injury. However, it is also important to consider that how a CYP may react to their burn at the time of injury may continue to change and develop over time. The emergence of

feelings and psychological difficulties at different stages of the burn injury is discussed in more detail in study 3.

Blakeney, Herndon, Desai et al (1988) found that whilst the majority of adolescents and young adult burn patients aged 14 and over adjusted well to their injuries, some individuals demonstrated significant signs of psychological disturbance. This chapter now examines some of these implications in more detail, with the aim of demonstrating the importance of psychosocial support for the burns population. It focuses on the psychosocial effects of a burn injury, specifically depression and anxiety, body image, self-esteem, post-traumatic stress disorder (PTSD) and acute stress disorder (ASD), social challenges, and effects on the family. It ends with a discussion of screening and will then lead on to a consideration of specific models of adjustment to a visible difference in chapter 2.

1.3 THE EFFECT ON THE INDIVIDUAL

There are a great number of reasons to conduct a literature review (Hart, 1998), however the literature reviews in this thesis review aimed to establish the context of the topic, discover variables relating to the area of research and consider the main methodologies and techniques used in burns research to date. The goal of the literature review presented throughout this chapter was to gain a comprehensive understanding of the effects a burn can have on both the young person with the injury, and other members of their family, i.e. research outcomes (Cooper, 1988).

Before conducting the literature review, the "Finding Information" section on the UWE library pages was consulted (UWE, 2017a), which provides guidance on identifying the key concepts of the topic, techniques for keyword searching, and effective use of literature databases. Key concepts relate to the topic of investigation, in this case the psychosocial effects of a burn injury on young people and their families. Keywords were extracted from this topic, e.g. "psychosocial", "burn injury", "young people" and "families" and expanded using synonyms, broader and narrower terms, e.g. "burns", "family members" or "psychological and social". Boolean operators such as "AND" or "OR" were then used to focus the search further.

The principles of conducting a structure search proposed by Webster and Watson (2002) were then followed. First, combinations of the keywords listed above were entered into Google Scholar (Google, 2017) and the UWE library search (UWE, 2017b), as well as more subject specific resources such as PsychInfo (American Psychological Association, 2017) and PsychBOOKS (EBSCO

Industries, 2017). Once saturation (the point where no new relevant articles emerge; Randolph, 2009) was reached, a backward search was employed by reviewing the citations for the literature identified, and a forwards search was conducted by using Google Scholar to identify sources citing the original literature identified. The literature review in this chapter was all-encompassing – in other words it included all literature examining the psychological and/or social effects of a burn injury, to formulate a clear picture of the range of potential difficulties experienced by young people and their families.

A concept-centric approach (focusing on the key concepts within studies; Webster and Watson, 2002) was used to organise the literature and the literature is presented below using a narrative review. In contrast to a meta-analysis which adapts the results of numerous studies into one collective measure, narrative reviews can integrate studies using a range of different methods (Baumeister, 2013), thought to be appropriate for the current search due to the extremely varied nature of burns research identified. Baumeister (2013) suggests that this 'methodological convergence' strengthens conclusions as it reduces potential bias within studies using the same techniques, however notes the importance of discussing the methodological diversity within identified literature. This is considered throughout the literature review and detailed within the relevant sections.

1.3.1 Depression and anxiety

Research into levels of depression and anxiety in CYP has produced ambiguous results. Rimmer, Bay, Alam et al (2014) found that almost half of 197 CYP with burn injuries demonstrated separation anxiety and 28% school avoidance disorder. Conversely, Robert, Meyer & Bishop et al (1999) failed to find a significant difference in levels of anxiety or depression between CYP with a burn injury and a control group; however the characteristics of the control group in this study are not reported, so it is unclear whether it is an appropriate comparison. Stoddard, Stroud & Murphy (1992) suggest that while CYP with burn injuries present a risk for depression, this may go unrecognized as the primary focus tends to be survival and then healing. Stoddard et al conducted face-to-face interviews with 30 CYP who had severe burns at a mean of 9 years post-injury. Only one CYP had symptoms of severe depression at the time of interview, but 8 had a lifetime history of major depression and thirteen had suicidal thoughts, of which their parents were usually unaware. Most CYP reported causes other than the burn injury for their depression, such as social or family problems, echoing a suggestion by Patterson, Finch, Wiechman et al (2003) that a burn injury can sometimes act as a sign that there may be problems in a patient's life that extend past the injury itself.

More positive findings emerged from a study conducted by Pope, Solomons, Done et al (2007). Contrary to their hypotheses, 36 CYP aged 11-19 with a burn injury had no significant differences in mood when compared to 41 age-matched controls, although females were found to report lower levels of mood across both groups. Although this study had a small sample size, it makes an important contribution to burns research as it shows that CYP with a burn injury do have the potential to cope and function well. However, it is worth noting that three times as many participants were recruited for this study through a children's burns club as through general hospital admission records. There is a link between depression and avoidance of social situations (NHS Choices, 2016) so it is possible that the children who participate in the social opportunities provided by the club were less likely to be suffering from depression.

Although the aforementioned studies are thought-provoking, interpretation of the results should be undertaken with caution. Methods of assessment varied from interviews (Stoddard et al, 1992) to a battery of standardised outcome measures (Pope et al, 2007), and it is thought that the method of data collection used can influence the outcome of a study (Palmieri, Przkora, Meyer & Carrougher, 2014). The range of different methods of assessment may be partly due to a lack of measures suitable for research in the burns population. A systematic review by Griffiths, Armstrong-James, White, et al (2015) identified 32 patient reported outcome measures (PROMs) used in paediatric burns research and found that only three of the PROMs had psychometric evidence relevant to the young burns population. Furthermore, none of these three PROMs were based on patient interviews, a method which is considered important to ensure that the items accurately reflect the experience of the targeted population (Brédart, Marrel, Abetz-Webb, et al, 2014).

1.3.2 Body image

Body image can be defined as "a person's perceptions, thoughts and feelings about his or her body" (Grogan, 2008, p3) and has been found to be the strongest predictor of long-term psychosocial adjustment to a burn injury (Thombs, Notes, Lawrence et al, 2008). Burn injuries can force the patient to adapt to alterations in physical appearance (Van Loey & Van Son, 2003) which can have a detrimental effect on body image (Pellard, 2006) and may also lead to worries about the reactions of others (Partridge & Robinson, 1995). Research into the body image of CYP with burns is fairly limited (Corry et al, 2009) and has produced equivocal results. Although Abdullah, Blakeney, Hunt et al (1994) found a correlation between the number of visible scars and dissatisfaction with physical appearance, other research has found that CYP with burns actually

felt slightly more positive about their general appearance than a control group (Pope et al, 2007; Lawrence et al, 2007).

As discussed in section 1.3.1 above, it is possible that these conflicting results were due to the different measures used. However, it is noteworthy that the mean time since burn injury in Lawrence et al's (2007) study was 7.8 years, compared with almost 12 years in Pope et al's (2007) study. Partridge (2006) suggested that there are three stages involved in adjusting to a burn injury: the first stage (up to six months) focuses on survival; the second stage (6 months – 2 years) focuses on trying to overcome feelings such as anger and shame about appearance; and the third stage (2+ years) involves an acceptance of the body. According to this notion, the CYP in Pope et al and Lawrence et al's studies may have already adjusted to their injuries some time ago by developing appropriate coping mechanisms. Furthermore, although the mean age at injury in Lawrence et al's (2007) study was 6.9 years, almost three quarters of the participants in Pope et al's (2007) study had been burned at the age of three years. As discussed previously, children are thought to start acquiring a sense of self during the second year of life (Smolak, 2012), so it is possible that some of the CYP in the latter study were burned before their body image began to develop. The study by Pope et al (2007) found a weak relationship between age at burn and negative body image.

Lawrence et al's (2007) study revealed a moderate relationship between body image, and social comfort and perceived stigmatization, indicating that CYP who felt happier in social situations felt better about their bodies or vice versa. A striking finding from Pope et al's (2007) study was that the burn survivors evaluated other people's opinions of their appearance as significantly more positive than the control group, which may have been a contributing factor to their overall body image. Nevertheless, body image remains a key concern in the general population and improving understanding of the specific effects of a burn injury is an important priority in future research in CYP. The relationship between body image and reactions from others is discussed in more detail throughout section 2.1.

1.3.3. Self-esteem

Self-esteem relates to an individual's evaluation of their own worth (Hofland, van Loey & Faber, 2009) and is essential for general wellbeing (Robert, Meyer, Bishop et al, 1999). The changes to a person's self-image following a burn injury can have a detrimental effect on self-esteem, particularly if the burn survivor experiences negative reactions from other people (Hurren, 1995). However, CYP with burn injuries have also been found to demonstrate positive self-esteem

comparable to their peers, which seems to improve with time following the injury (Blakeney, Meyer, Moore, et al, 1993a). While the majority of burn survivors appear to adjust well to their injuries, it is important to consider those whose self-esteem is adversely impacted as a result of the injury. Low self-esteem can lead to depression, hopelessness, feelings of scholastic incompetence and even suicidal ideation (Harter, 1993).

An interesting relationship between appearance and self-esteem was proposed by Harter (1999) who found that teenagers who felt that their appearance characterised their self-worth tended to have lower self-esteem than those who felt that their self-worth influenced their feelings about appearance. Robert et al (1999) found a correlation between competence and importance, meaning that adolescents rated the domains in which they felt they were competent as important, and the domains in which they felt they were less competent as unimportant. CYP's response of placing a lower value on aspects in which they are less competent has been put forward as a coping mechanism, as they choose to place a lower value on aspects of themselves they cannot change such as impairments to physical function (LeDoux, Meyer, Blakeney & Herndon, 1996). Therefore, helping a CYP to identify and focus on their individual strengths may be a useful strategy in ensuring their psychological wellbeing (Robert et al, 1999) and should be supported by the burn care team during the adjustment process (Le Doux et al, 1996).

1.3.4. Behavioural problems

In contrast to the internalizing behaviours described above (i.e. depression and anxiety), externalizing behaviours are those which are directed outwards, such as anger, aggression or hostility. Research has indicated that such problematic conduct may be found in CYP following a burn injury, with parents and teachers reporting a higher number of externalising problems in CYP with burn injuries compared to their peers (Andersson, Sandberg, Rydell & Gerdin, 2003). However, this study failed to provide an explanation of the reasons behind these problems. The authors investigated factors such as gender, TBSA and location of burn and found no significant differences. It is possible that psychosocial, rather than demographic, factors influence a CYP's behavioural adjustment after an injury, such as coping styles, personality, or family functioning, which have been examined in subsequent research.

For example, Liber, Faber, Treffers & Van Loey (2008) suggested a link between adjustment and both coping styles and personality. A passive coping style occurs when a person attempts to reduce negative emotions using strategies such as wishful thinking or mental disengagement, whereas active coping involves a conscious attempt to address discomfort using techniques such

as problem management (Smith, Lumley & Longo, 2002). Lower emotional stability and agreeableness were found to predict behavioural difficulties, as was a passive coping style (Liber et al, 2008). This research suggests that an assessment of personality could be used to predict which individuals are at the greatest risk of poor adjustment to their injuries, while strategies to encourage more active coping styles could improve outcomes.

Family functioning is also thought to contribute to behavioural adjustment, with parental ratings of family cohesiveness, expressiveness and less family conflict promoting the most positive behavioural adjustment (Landolt, Grubenmann & Meuli, 2002). Self-report measures have also indicated a strong relationship between family conflict and poor behavioural adjustment, highlighting the importance of the family to adjustment, even several years after the injury (Rosenberg, Blakeney, Thomas et al, 2007).

1.3.5. Post-traumatic stress disorder (PTSD) and acute stress disorder (ASD)

The Diagnostic and Statistical Manual for Mental Disorders – Fifth Edition (DSM-V; American Psychiatric Association, 2013) defines PTSD as consisting of specific psychological symptoms persisting for a minimum of one month including flashbacks, loss of interest in significant activities and sleep disturbances. The DSM-V also includes Acute Stress Disorder (ASD), which presents with similar symptoms. However, in contrast with PTSD, a diagnosis of ASD requires symptoms to be present for between 2 days and 4 weeks, within 4 weeks of the traumatic incident. Research has indicated that the symptoms of ASD are predictive of the development of PTSD (Difede & Barocas, 1999; Difede, Ptacek, Roberts, et al, 2002) so it has been suggested that patients who present symptoms of ASD be closely monitored, to ensure their symptoms do not progress into long-lasting PTSD (Difede, Cukor, Lee & Yurt, 2009).

While preschool children are considered a particularly high-risk group for burn injury, it is sometimes thought that young children are unlikely to be affected by trauma, which has led to a dearth of research into PTSD in this population (De Young, Kenardy, Cobham & Kimble, 2012). However, it is now recognised that children who are exposed to traumatic events such as a burn injury can develop PTSD symptoms in the same way as adults (Kaminer, Seedat & Stein, 2005). While psychological trauma is a very relevant aspect of a burn injury, it is a huge and complex topic (Ringel & Brandell, 2012). Symptoms of PTSD can vary greatly and the onset of symptoms can be delayed in some people, sometimes for years after the event (Flannery, 1994). Children at different developmental stages may experience varying symptoms of PTSD (Yule, 1999), which can depend on a number of neurobiological, cognitive and other factors. It can sometimes be

difficult to differentiate PTSD from other, often related, psychiatric disorders such as anxiety or depressive disorders (Peterson, Prout & Schwartz, 1991).

1.3.6 Social challenges

Social challenges may be particularly prevalent when the CYP is first trying to adjust back to 'normal' life. Reintegration into everyday life can be a significant challenge for burn survivors; indeed, Partridge and Robinson (1995) compare it to returning to infant school, where children first experience social interaction. Preparing to face the reactions of the general public for the first time since the burn injury can be terrifying for both the CYP with the injury (Blakeney, 1995) and their family members (Rossi, da SC Vila, Zago & Ferreira, 2005). This is consistent with broader literature, which has shown that almost two thirds of people with a visible difference find situations that involve meeting new people or being in the public eye particularly troublesome, and can lead them to avoid these social situations if possible (Robinson, Rumsey & Partridge, 1996). Theories surrounding social avoidance are considered in more detail in section 2.1.

Such social withdrawal can subsequently lead to a reduction in self-confidence (Shakespeare, 1998) and can impair both mental and physical recovery (Pallua, Kunsebeck & Noah, 2003). People may experience feelings of intense loneliness and lead more solitary lifestyles (Taal & Faber, 1998) as social activities such as meeting friends are affected (Shakespeare, 1998), particularly among those with visible burn injuries (Pallua et al, 2003). However, positive community re-entry is an essential part of recovery, predicting quality of life at both 6- and 12-months post-burn (Cromes, Holavanahalli, Kowalske & Helm, 2002), so tackling social problems appears to be instrumental to ensuring successful adjustment to the injury.

While children with burn injuries often experience stigmatizing behaviours, many also experience teasing or outright bullying, which can be defined as "a negative action when someone intentionally inflicts, or attempts to inflict, injury or discomfort upon another" (Olweus, 1994, p1173). Rimmer, Foster, Bay et al (2007) found that almost two-thirds of children with burn injuries reported that bullying was a problem and that a quarter of the children classed this as a 'big problem'. Similar to previous research with adolescents in the general population (e.g. Lovegrove & Rumsey, 2005), many bullied children in Rimmer et al's (2007) study experienced physical effects such as headaches, or reported avoiding school altogether. 68% of those with visible scarring reported that they were experiencing problems with bullying, compared to 54% of those with non-visible scarring; however both of these statistics are worryingly high. It may be useful for burn services to make parents and schools aware that bullying may occur once the child

is discharged from hospital to pre-empt this behaviour (Rimmer et al, 2007). School reintegration programmes are considered in more detail in section 2.2.

1.4 THE IMPACT OF A CHILD'S BURN INJURY ON THE FAMILY

1.4.1 The family as a system

A family can be defined as the members of a household at a given time, although this may be considered fairly restrictive as the members of the family move through the stages of their lives (Jones, 1996). Individuals may feel that they are part of a wider family group than simply the members that live with them. Family systems theory suggests that a family is made up of a number of interacting elements that together contain properties which are greater than the sum of their parts (von Bertalanffy, 1968). The properties of the system become lost when the system is reduced to its individual elements (Nichols, 2013). In other words, the family system involves more than just the individual family members, and may contain complex interactions and organisation within the family. Systemic perspectives focus on the interaction between family members, and their influence on subsequent behaviours within the system (Akamatsu, 1992).

A system also contains different sub-systems, which in the case of a family may be defined by aspects such as generation (parents/children), sex (fathers/sons) or shared interests (Goldenberg & Goldenberg, 2008). Individuals can also be considered systems themselves so a systems approach to interventions therefore includes multiple levels of support, which may involve the patient as an individual, therapy with parents or siblings, or group therapy involving the entire family at the same time (Kazak, 1992). The importance of family support throughout the recovery of a burn patient is well documented (Watkins, Cook, May et al, 1996) but there is limited research on the psychosocial needs of other family members (Thompson, Boyle, Teel et al, 1999). Anything that happens to one family member will affect the others (May, 1992) and family members may experience many of the same psychological symptoms as the patient, and must also adjust to the injury. Therefore, along with examining the level of need for each individual, it is also important to think about which members of the family should be considered within each intervention (see chapter 7). The following sections discuss the effects of a child's burn injury on their parents and siblings.

1.4.2 The impact on parents

The parents of a child with a burn injury often experience uncertainty about the outcomes of treatment and long-term effect of the injury, along with feelings of intense guilt as an immediate reaction (Partridge & Robinson, 1995), particularly if they feel that they could have prevented the injury (Rizzone, Stoddard, Murphy & Kruger, 1994). Parents have also reported worrying about both their child's health and appearance more since the injury, in some cases expressing concern that even their own family were uncomfortable around the injured child (Phillips & Rumsey, 2008). They may also become overly protective and need to know where their child is at all times (Rizzone et al, 1994; McGarry, Elliott, McDonald et al, 2015). Parents may experience adverse psychological reactions to the injury (Kent, King & Cochrane, 2000) such as clinically significant levels of anxiety and depression, at both the inpatient and outpatient stage (Phillips & Rumsey, 2008). This has been found to be more prevalent among parents of children with burn injuries than parents of children hospitalized for other procedures such as hernia repair, tonsillectomies or benign mass excision (Cella, Perry, Poag, Amand & Goodwin, 1988). Depression has been found in around 50% of parents of children with burn injuries (El Hamaoui, Yaalaoui, Chihabeddine, Boukind & Moussaoui, 2006; Kent, King & Cochrane, 2000).

Other aspects of parents' lives may also be affected by the burn injury. For example, Griffiths, Rumsey, Pleat et al (2015) found that the burn had a significant impact on parents' relationship, either directly from increased stress leading to more arguments, or indirectly such as feelings of guilt from those who were present at the event seeking frequent reassurance. Blakeney et al (1993a) found that the concerns most frequently voiced by parents related to disruption to family life, financial difficulties, the amount of time they spent caring for the child with the burn, and the effect of the burn on siblings.

1.4.3 The impact on siblings

Research into the impact of a burn on siblings of the injured child has produced mixed results. Siblings have reported feeling upset, shocked and even repulsed when seeing the burn injury for the first time (Phillips, Fussell & Rumsey, 2007). Although a significant proportion of siblings in Phillips et al's (2007) study did not feel that the injury had affected their daily life, several did report changes. The most difficult aspect of the burn was considered to be the experience of the accident itself, followed by the resulting scarring and teasing of the injured child, and missing their parents at home while they spent time with the injured child in hospital. Siblings have also reported that their parents did too much for the injured child, even to the extent that the child

with the burn injury was considered 'lucky' to get special treatment (Mancuso, Bishop, Blakeney, Robert & Gaa, 2003). This decrease in attention from parents can lead to feelings of anger towards both the parents and the patient (Drotar, 1992), so it is essential to maintain open communication with siblings to ensure their queries or worries are addressed. Siblings have reported that they would have found it helpful to talk to someone about the injury, particularly about how people can feel in similar situations (Phillips, Fussell & Rumsey, 2007).

While some siblings may become less involved in activities at school, others report trying to do better in school to help prevent their parents worrying about them (Mancuso et al, 2003). The effect of the injury on siblings has also been found to alter life perspectives, resulting in a strengthening of the relationship between the siblings and a sense of warmth and closeness (Lehna, 2010). These findings indicate the resilience of family members, despite the challenges of adjusting to a burn injury, and are further highlighted when considering the parents' views on their non-injured children. The majority of parents stated that many changes since the injury were positive, including a change in maturity, increased protectiveness of the injured child and an increased closeness between the children (Mancuso et al, 2003). However, despite these observations it is important to remember that although the burn injury may strengthen the family bond between children this is not always the case, and siblings of the burn-injured child should still be assessed to ensure they have sufficient support, particularly as parents may initially focus on the injured child.

1.4.4 Supporting the family

It is exceptionally stressful for a family to care for a child with a serious health condition. As the child's condition and treatment requirements change over time, so the entire family must learn to adapt (Koocher & MacDonald, 1992). Parents try to balance the needs of the patient with the needs of any healthy siblings, whilst attempting to maintain a 'normal' developmental environment for their children. The entire family is affected by the patient's condition, and should be considered part of the child's care, to ensure the best chance of support and adjustment for the family as a whole (Koocher & MacDonald, 1992).

It has been suggested that there is a need to better understand the family's influence on the patient's recovery from a burn injury (Ogilvie, McCloughlen, Curtis & Foster, 2012). For example, anxious or distressed reactions from family members may promote the same response in the patient (Wiechman & Patterson, 2004), and parental anxiety has been found to significantly affect functional outcome in CYP at 6-month post-burn (Tyack & Ziviani, 2003). It has even been

suggested that parents' behaviours towards their child may be the most significant determining factor of a child's adjustment to their injury (Beard, Herndon & Desai, 1998), particularly when parents use avoidant coping and emotionally distance themselves from problems (Browne, Byrne, Brown et al, 1985).

A supportive family environment has been posited as one of the most important factors for positive psychosocial adjustment following a burn injury (Blakeney et al, 1988). For example, the degree of cohesion within the family, defined as the emotional bonding between family members (Jones, 1996), may have an effect on the family's adjustment and functioning (Koocher & MacDonald, 1992). However, it has been suggested that stronger cohesion within families may be an adaptation to the injury, rather than a characteristic of the family prior to the injury (LeDoux et al, 1998), suggesting that families exhibiting stronger cohesion are able to better adjust to the injury due to their adaptability. Families who encourage autonomy and expression of individual ideas are also more likely to adjust well (Blakeney, Meyer, Robert et al, 1998), promoting self-esteem and social skills in the child (Rumsey & Harcourt, 2007). It is important that the family members are supported to cope with the injury independently, as well as provide a supportive role to the other members (Blakeney et al, 1998; Rizzone et al, 1994), which is considered to be as important as individual therapy for the child with the burn injury (Meyer et al, 1994). Any family members who have been affected by a traumatic injury may benefit from stress management techniques (Blakeney et al, 1998), as well as information on how to deal with uncomfortable social situations (Phillips, Fussell & Rumsey, 2007).

Overall, it is evident that the wellbeing of the patient can be significantly influenced by the wellbeing of the rest of the family (Blakeney, Robert & Meyer, 1998) and the observed benefits of family support has led to the suggestion that a systems model is an ideal approach for working with families affected by a visible difference (Clarke, 1999). Therefore, it is essential to determine the level of psychosocial support required by each family affected by a burn injury and to ensure that other members of the family are included in the patient's treatment (Blakeney et al, 1998). While it has been suggested that family members should be screened and provided with family-centred psychological interventions as necessary (Phillips & Rumsey, 2008), there is currently a dearth of research on the effectiveness of appropriate methods of screening and available support for family members of CYP with burn injuries.

1.5 SCREENING

Psychosocial screening involves an assessment to determine risks factors, identify whether further evaluation is needed, and develop suitable methods of treatment if necessary (Kazak, Brier, Alderfer, et al, 2012). There is little published research on screening within the burns population, although Lawrence, Qadri, Cadogan and Harcourt (2016) conducted a survey to compare the provision of psychosocial care to people with burn injuries in the UK and the US. The results indicated that screening was more common in the UK, however the type of screening used was documented using a three point scale indicating "no screening", "informal screen" or "structured screen". Therefore, it is still unknown specifically how screening is carried out within burns services; however numerous studies have evaluated a range of screening tools aimed at identifying various psychological issues which are also commonly found within the burns population.

Several studies have demonstrated that a modified version of the Child Behaviour Checklist (CBCL-PTSD; Wolfe, Gentile, and Wolfe, 1989) may be used to screen for PTSD in both older (6-16 years; Ruggiero and McLeer, 2000) and younger (1-6 years; Dehon & Sheeringa, 2006) children. Briggs-Gowan, Carter, Irwin et al (2004) discovered that the Brief Infant-Toddler Social and Emotional Assessment (BITSEA) could be used to screen for social-emotional/behavioural problems in toddlers aged 1-3 years, while Simon and Bogels (2009) found the Screen for Child Anxiety Related Emotional Disorders-71 (SCARED-71) to be an effective screening tool for anxiety aged 8-13.

Even these few studies suggest that screening tools could be implemented to identify psychological difficulties in CYP with burn injuries and their families; however the research discussed in sections 1.3 and 1.4 shows that the potential difficulties experienced are wide-ranging. This means that it could be necessary to employ a large battery of measures to ensure that as many potential outcomes as possible are considered, and would be extremely impractical. It is also important to remember that generic measures of mental health may not specifically target the particular issues experienced by CYP with burn injuries and their families (see chapter 5 for more discussion around this). Further discussion on the challenges surrounding screening within the burns population is provided throughout chapter 7 and in section 8.2.1.

While appropriate screening techniques are essential for identifying areas of psychosocial concern, they do not guarantee the provision of appropriate psychosocial support (Braeken et al, 2013). Instead screening should be considered the first stage in a process requiring additional

assessment to determine the level of need and subsequent provision of therapeutic intervention (Carlson et al 2012). A review of interventions aimed at targeting a range of different psychosocial needs in those with a visible difference is provided in section 2.2.

1.6 CONCLUSION

In summary, while the majority of children with burns adjust well to their injuries, the difficulties faced by those who do struggle can have severe consequences, many of which can continue into the long-term. These difficulties may be primarily psychological (such as appearance-related stress or depression), social (such as bullying or social withdrawal), or a combination of both. The effects of a burn injury may stem from an altered appearance (e.g. negative body image), or from the trauma itself (e.g. PTSD). The issue of adjustment to burn injuries is a complex one, for which future research is needed in order to untangle fully. Whilst this chapter has discussed research indicating a range of psychosocial consequences of a burn injury, much of it has produced ambiguous results.

While the specific details contributing to adjustment may not yet be fully understood, this chapter has highlighted the general consensus among psychologists of the need for appropriate psychological interventions. The importance of early, and regular, screening and treatment (if needed) for individuals with a burn injury to maximise the likelihood of successful adjustment to the injury has been emphasized time and time again. The importance of including the entire family in a patient's treatment is also apparent. As outlined above, the family can be considered to be a system, and a systems approach to interventions can include multiple levels of support involving different members of the family, or sometimes the family as a whole. This thesis therefore focuses on interventions to improve the overall adjustment of CYP and their families. The next chapter focuses on different models of adjustment to explore how a deeper understanding of this topic can inform suitable psychosocial interventions for CYP with visible differences and their families, which leads on to the research questions and aims of the thesis.

CHAPTER 2. PSYCHOSOCIAL ADJUSTMENT TO BURN INJURIES

Following on from the review of the effects that a burn injury can have on CYP and their families, this chapter explores models of adjustment to a visible difference, and considers current interventions designed to promote healthy psychosocial adjustment. The literature search in this chapter was conducted using the same search strategy detailed in section 1.3, using keywords such as "intervention", "visible difference", "model", "theory" and "framework". Literature was included in the review if it related to models, theories and frameworks relating to visible difference (section 2.1) or research involving psychosocial interventions within the visible difference population (section 2.2). Literature relating to general or physical health (i.e. did not include a psychological and/or social element) was not included.

2.1 MODELS OF ADJUSTMENT TO A VISIBLE DIFFERENCE

A visible difference (disfigurement) can be acquired (e.g. scars resulting from a burn injury) or congenital (e.g. a cleft lip). While many people with a visible difference do not experience any particular difficulties, others may be greatly impacted (Jaspal, 2012), and this impact may vary according to condition. For example, although scarring from a burn injury may fall under the umbrella term of a "disfiguring condition", there are additional issues faced by both burn survivors and other family members which are not experienced by those with other visible differences, most notably relating to the trauma of the burn itself. As discussed in section 1.3.5, the traumatic circumstances surrounding some burn injuries can lead to symptoms of ASD and PTSD in certain cases, meaning that CYP with burn injuries and their families face a range of potential challenges relating to both a changed appearance and the trauma of the injury. The notion that the majority of concerns experienced by CYP with burn injuries and their families relate to appearance and/or trauma is discussed in more detail in chapter 7.

While there are currently no models of adjustment to a burn injury specifically, there are numerous theories surrounding the area of adjustment to a visible difference. Kent (2000) stated that there are four main approaches, and suggested that an integrated approach of these different approaches may be useful to understand their experiences, involving social stigma, social anxiety and phobia, social skills, and the cognitive-behavioural model of body disturbance. Each of these approaches is now considered in turn, followed by an examination of Kent's integrated approach.

2.1.1 Stigma model

Goffman (1963, p9) defines stigma as "the situation of the individual who is disqualified from full social acceptance". Individuals can be negatively evaluated due to a personal characteristic, which may relate to their physical appearance or behaviour (West & Hardy, 2007). Stigmatizing behaviours are often experienced by those living with a visible difference, such as burn injuries (Lawrence, Rosenberg, Mason et al, 2011), chemotherapy-induced alopecia (Rosman, 2004) or vitiligo (Thompson, Clarke, Newell et al, 2010). Stigma can be 'enacted' (meaning that the individual is treated differently by other people) or 'felt' (meaning that the individual feels ashamed of their particular attribute irrespective of others' reactions) (West & Hardy, 2007). While negative reactions from others can be extremely disabling, it has been suggested that 'felt' stigma can be even more difficult to manage at it can lead to worries about rejection, which can cause people to consciously avoid social interactions (Kent, 1999). This in turn prevents them from ascertaining whether the feared stigmatization in social situations will actually materialise, and can in this way become a self-fulfilling prophecy (Jacoby & Austin, 2007). Fear of negative reactions from others is discussed in more detail in section 2.1.2.

Goffman (1963) distinguished between "discredited" and "discreditable" individuals according to the visibility of the stigmatizing attribute. He suggested that people with a difference that is not immediately obvious to others are discreditable but not yet discredited, as they can choose whether or not to disclose the difference to other people. Individuals with a visible difference may be immediately 'discredited' if their stigmatizing attribute is obvious to other people and often report experiencing stigmatizing behaviours. For example, children with a visible facial difference such as burn scars were found to experience significantly higher levels of stigmatizing behaviours, such as staring or teasing, than a control group of their peers (Masnari, Landolt, Roessler et al, 2012). Some people may attempt to hide their visible difference to avoid stigmatizing behaviours, for example by wearing concealing clothes. This can be a useful coping strategy as long as the person does not become over reliant on it, for example if it generates worries about a situation where they may struggle to keep their difference concealed (Rumsey & Harcourt, 2004), such as PE lessons. Therefore, it is essential to help them find ways of adjusting to their visible difference and avoid the associated effects that may accompany a perception of stigmatization, such as reduced self-esteem and academic achievement.

Stigma can also be experienced by the familes of people with visible differences. Family members of those with facial differences caused by cancer report instances of both felt and enacted stigma, as they describe both adverse reactions from the general public as well as their own negative

feelings about the family member's difference (Bonanno & Esmaeli, 2012). Carnevale (2007) explored the experiences of families of children requiring mechanical ventilation, who may experience a range of visible differences including severe muscle weakness and flat facial expressions. The experiences of parents fit with Goffman's notion of "discredited" individuals, as they felt that they and their children were socially marginalized by the outside world, reporting strong feelings of isolation and a desire to meet other families in a similar situation. It is likely that the facilitation of contact between similar families may increase feelings of inclusion and acceptance, reducing the feelings of negative evaluation experienced by stigmatized individuals. This concept is discussed in more detail in chapter 4.

While it is generally accepted that Goffman provides a clear definition of stigma (Link & Phelan, 2001), it has been suggested that his theory focuses too strongly on the stigmatised features themselves (such as a visible difference) rather than the social experience of discrimination. Furthermore, although stigma can be very debilitating, it is unlikely that it can explain the entire process of adjustment to a visible difference on its own. While Goffman's theory discusses the way in which people may feel ashamed of their appearance, it is very limited in its consideration of other emotional reactions to the difference such as anger or sadness. However, it does provide a fundamental basis for explaining other issues surrounding adjustment, such as social anxiety, as a fear of stigmatizing behaviours can explain why certain people worry about subjecting themselves to social situations.

2.1.2. Social anxiety model

Newell (1999) developed a model of fear avoidance to explain social anxiety, suggesting that people with a visible difference may develop strategies of confrontation or avoidance to address a fear of negative evaluations from other people. Life events, personality and history of changes to body image are all thought to contribute to the adjustment process and social interaction with other people (see Figure 1). While those who adopt confrontation strategies face their fears head on to achieve social integration, social anxiety in people with visible differences may stem from an avoidant response as the fear of negative responses leads to avoidance of social situations. Although negative reactions to a visible difference may be very real, Newell and Marks (2000) stress that it is the *anticipation* of stigmatizing behaviours such as staring or comments which actually prompts people to avoid these situations.
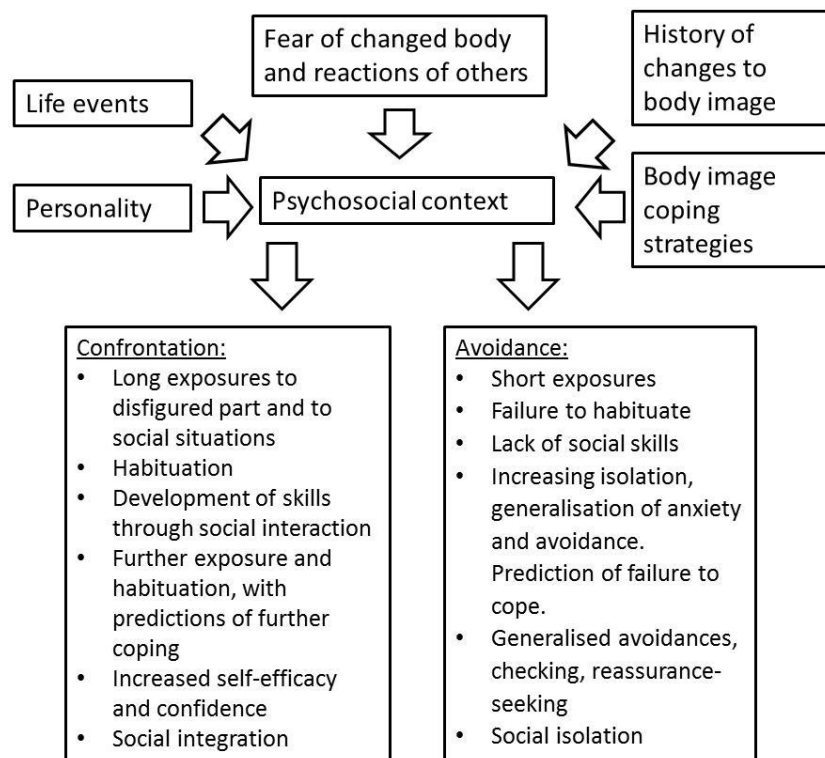
Figure 1 A fear-avoidance model of social anxiety (adapted from Newell, 1999).

Reprinted with permission of the publisher (John Wiley and Sons): Newell, R. J. (1999). Altered body image: a fear-avoidance model of psycho-social difficulties following disfigurement. *Journal of Advanced Nursing, 30(5),* 1230-1238, John Wiley and Sons.

Tagkalakis and Demiri (2009) conducted a review to examine Newell's fear-avoidance model in the context of those with facial burns, examining how strategies of confrontation and avoidance are employed to manage the challenges of a burn injury. They concluded that while these strategies are likely to be key in determining the extent to which people with burns and their families come to terms with the injury, further research is needed to explore their use in more detail. It may be particularly important to target social anxiety in children and CYP, due to the significant impact it can have on social and academic development (Morris, 2004). People who avoid social situations based on a fear of negative evaluations may also become trapped in a vicious circle as social withdrawal may subsequently reduce self-confidence even further and reinforce the avoidant behaviour (Shakespeare, 1998). Kent and Keohane (2001) suggest that interventions comprising cognitive-behavioural therapy and social skills interaction training may be effective in targeting social anxiety among those with a visible difference. Interventions that employ these approaches are considered in more detail in section 2.2.

The stigma model and the social anxiety model provide a clear explanation of how a fear of negative reactions from others can lead to anxiety in social situations. However, the focus within

both theories is other people's (real or imagined) negative reactions to the visible difference. In contrast, the social skills model posits that an individual's behaviour in social situations can actually be detrimental to their overall adjustment.

2.1.3 Social Skills Model

Argyle (1994) suggested that social interaction involves organisation and skill analogous to motor skills such as driving a car. The model focuses on a person's goals, the social behaviour used, and the perceptions of, and reactions to, feedback from the social encounter (Figure 2). Argyle (1994) gives an example of how the model may be applied to social skills, starting with a goal (finding out information about someone), followed by a skilled move (asking basic questions), perceiving the effect of this (receives short answers) and taking corrective action (asks more detailed questions). Unlike the stigma model, which hypothesizes that people experience negative reactions as a direct response to their appearance, the social skills model of adjustment to a visible difference theorizes that people's preoccupation with their appearance can cause them to display poor social skills, and that it is actually this lack of social skills which leads to uncomfortable interactions with other people.
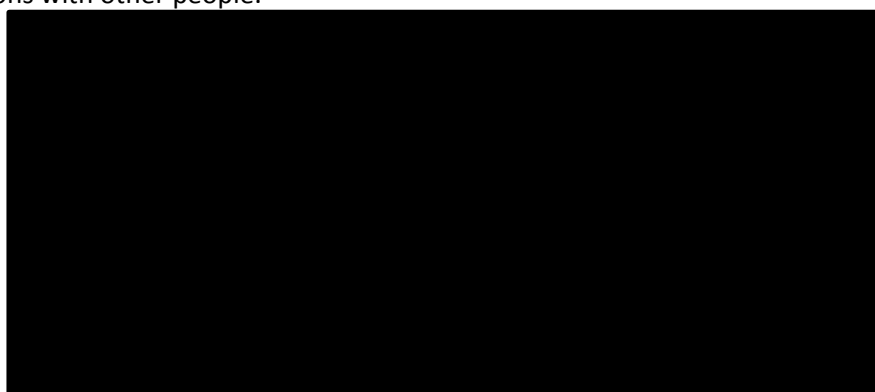
Figure 2 Argyle's motor skill model (adapted from Argyle, 1994)

For example, Rumsey, Bull and Gahagan (1986) conducted a study where an actor was trained to carry out six interviews where he appeared to have a large facial port wine stain, and six where he had no visible difference. In half of the interviews in each condition he presented strong social skills (such as positive body language and eye contact) and in the other half he presented poor social skills (lacks of eye contact and monotonic tone of voice). Twelve 20-30 year olds rated the interviews, and it was found that the interviews employing the strong social skills were rated far more favourably, regardless of the presence of the visible difference. While this study included only one particular type of visible difference, it was indicative of the possibility that improved social skills could lead to a more positive experience within social encounters. Kish and Lansdown (2000) discuss therapeutic sessions run by Changing Faces (a charity which provides support to

people with a visible difference) to help families manage the impact of a child's visible difference, and found that these family-based sessions resulted in reduced awkwardness and uncertainty from others as the family's own social skills improved.

Although the social skills model has a different focus to the stigma model, it is important to remember that one does not discredit the other, simply that one model alone may not be sufficient. While positive social skills may indeed improve social encounters for CYP with a visible difference, that is not to say that stigmatizing behaviours do not occur (e.g. Blakeney, Partridge & Rumsey, 2007; Rahzani, Taleghani & Nikbakht Nasrabadi, 2009). However, a range of other factors can affect how people feel about their appearance, considered in more detail in the cognitive-behavioural model of body disturbance.

2.1.4 Cognitive-behavioural models of body disturbance

Cash (2012) claimed that a cognitive-behavioural approach towards body image comprises of a range of both cognitive and behavioural concepts and processes, rather than relying on a single theory. Cash (2012) proposed a cognitive-behavioural model of the dimensions, determinants and processes of body image, which was divided into either historical or proximal/concurrent factors (see Figure 3). He describes historical factors as the past events and experiences which define how a person thinks, feels and acts in relation to their body, while proximal/concurrent factors relate to the current events which maintain body image, such as information processing or internal dialogues. He described body image evaluation as an individual's satisfaction with their body, while body image investment relates to the importance placed on the body.

Historical influences:

Cultural Socialization

Interpersonal experiences (e.g. modelling, feedback, appearance teasing).

Physical characteristics and changes

Personality (e.g. traits of risk and resilience)

Body image attitudes (Evaluation and investment)

Proximal influences:

Activating situations and events

Appearance schematic processing

Cognitive processing and internal dialogues (e.g. thoughts, social comparisons, interpretations and conclusions)

Body image emotions

Coping and self-regulatory strategies and behaviours

Figure 3 Cash's cognitive-behavioural model of body image dimensions, determinants and processes (adapted from Cash, 2012)

Reprinted with permission of Guildford Press: Cash, T. F. (2012). 'Cognitive-behavioural Perspectives on Body Image'. In Cash, T. and Smolak, L (Ed). *Body Image: A Handbook of Science, Practice and Prevention (2nd ed).* New York: The Guilford Press.

Moss and Rosser (2012) propose that past experiences may influence a person's subsequent perceptions and interpretations in order to fit in with their expectations, and that these cognitive processing biases may reinforce appearance-related concerns. For example, Moss and Carr (2004) suggested that a person with a visible difference will use their self-aspects to interpret social encounters with other people, such as attributing a stranger's gaze to a judgement of their own appearance, which reinforces the notion that they are stared at by others. Similarly, Altabe, Wood, Herbozo and Thompson (2004) found that female students were more likely to interpret appearance-related comments from other people negatively if they had high levels of body dissatisfaction, once again reinforcing their negative thought processes. Moss and Carr (2004) suggested that these findings help to explain why techniques such as cognitive-behavioural therapy (CBT) or social interaction skills training (SIST) may improve adjustment to a visible difference. SIST helps people to apply learned behaviours to manage negative social encounters, which may reduce the number of activating events which reinforce self-schemas (the thoughts and beliefs that individuals hold about themselves resulting from past experiences, which enables them to process information relating to the self). It has been suggested that CBT aimed at tackling negative thought processes may promote healthy adjustment among individuals with a visible difference (Newell & Clarke, 2000), aiming to help clients accept themselves and promote healthy relationships (Lawrence, Fauerbach & Thombs, 2006).

One strength of a cognitive model within the context of burn injuries specifically is that unlike the first three models of adjustment to appearance-altering conditions, it can also be used to explain symptoms of trauma. Similarly to Cash's model of body disturbance, the cognitive model of PTSD also includes the influence of past events (the traumatic incident itself), emotional responses, individual characteristics and personal beliefs, and cognitive processing styles such as maladaptive behavioural strategies (Ehlers & Clark, 2000). This lends support to the notion of using CBT for those affected by a burn injury (discussed in more detail in chapter 7).

2.1.5 Integrated approach

While all of these models provide a useful insight into the challenges faced by those living with a visible difference it has been suggested that, due to the complex nature of this topic, using one theory alone is simply insufficient (Thompson, 2012). As mentioned above, the range of challenges faced by individuals with a burn injury can be very diverse. Furthermore, individuals with a burn injury may experience any combination of different challenges, so it is important to use an approach that includes various considerations. Kent (2000) suggested the aforementioned models could be combined to provide a richer understanding of the experience of a visible difference. Kent's (2000) model (Figure 4) proposed that a triggering event (such as negative reactions from other people) leads to a development of body image disturbance relating to concerns about rejection or exclusion. This is followed by impression management techniques, such as concealment of the visible difference or avoidant behaviour.
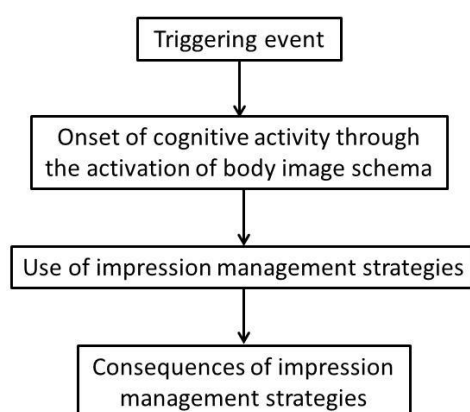
Figure 4 Kent's integrated model (adapted from Kent, 2000)

Reprinted by permission of the publisher (Taylor & Francis Ltd, http://www.tandfonluine.com): Kent, G. (2000). Understanding experiences of people with disfigurement: an integration of four models of social and psychological functioning. *Psychology, Health and Medicine*, 5, 117–129, Taylor & Francis Online.

Kent (2002) tested his model with a sample of 32 adult participants who had attended a skin camouflage service to cover up various conditions including scarring and vitiligo. Results indicated that the participants placed a high importance on their appearance prior to using the service (activation of body image schema), which Kent suggested may have resulted from arranging an appointment with the service (triggering event). Attending the appointment (impression management strategy) then produced various consequences, some of which were found to be more positive than others. For example, while the camouflage service resulted in increased confidence and a reduction in avoidant behaviour, it did not improve concerns relating to negative social encounters.

Kent (2002) considered how his model could be used to influence the development of psychosocial interventions, and concluded that a combination of approaches (i.e. CBT to address negative schemas and SIST to promote more positive coping strategies) may be the most effective method to target the various components of his model. Therefore, a multifaceted approach including a toolbox of strategies from which the CYP can draw may also be the most appropriate method to address the wide range of issues experienced after a burn injury as described in the previous chapter. This notion was furthered by Bessell, Dures, Semple and Jackson (2012), who suggested that a range of therapeutic strategies should be tailored to a person's level of individual psychosocial need using a tiered approach (discussed in more detail in section 2.2).

Kent's integrated approach aimed to encompass the four aforementioned approaches, but overall produced a rather simplistic account of the way in which individuals adjust to a visible difference. While the model recognises the directional process in which a triggering event generates cognitive activity and results in impression management strategies, it fails to take into account any of the predisposing factors which can influence adjustment, or the specific outcomes which may result from a visible difference. This shortcoming was addressed by the Appearance Research Collaboration in their model of adjustment to disfiguring conditions.

2.1.6 The ARC Framework of adjustment to disfiguring conditions

The Appearance Research Collaboration (ARC) created a framework of adjustment to disfiguring conditions, to encompass predisposing factors, intervening cognitive processing and psychosocial outcomes (discussed in Thompson, 2012, see Figure 5). The model proposes that predisposing factors can affect adjustment to a visible difference, which has been supported in the research literature. For example, while research into the impact of the age at which a burn was acquired is equivocal (e.g. Abdullah et al, 1994; Tyack & Zivani, 2003), the current age of the child may be of greater significance, as appearance concerns may become particularly salient during adolescence (Rumsey & Harcourt, 2007), indicating that even those who were burned as young children can start exhibiting worries at any age. As discussed in section 1.4.4, parental influences can have a significant impact on CYP's adjustment to a disfiguring condition. Influences from parents can take the form of direct (such as a specific comment about a child's appearance), or indirect messages (from observing parents' attitudes or behaviours) (Bellew, 2012).
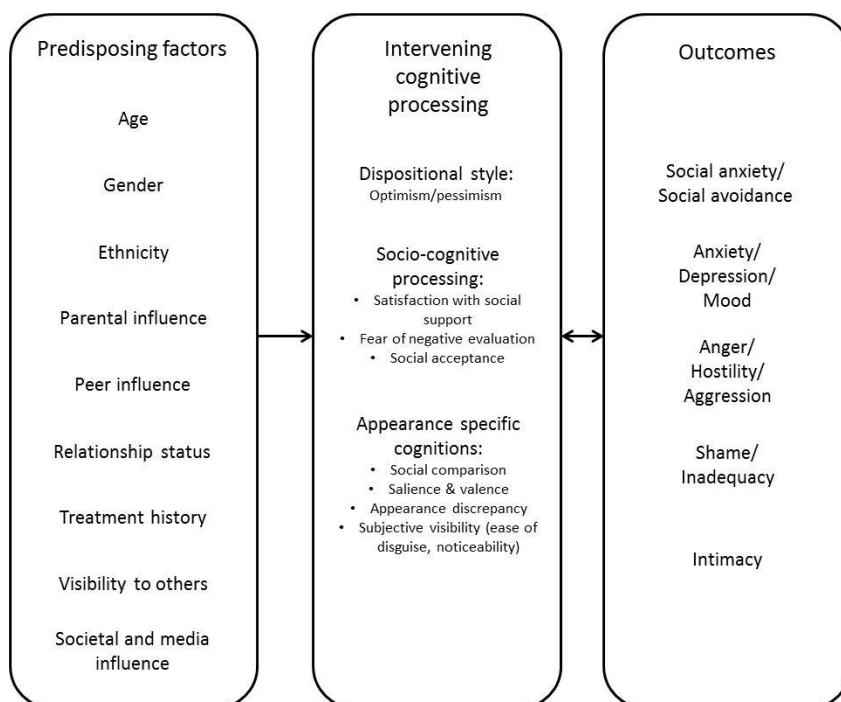
Figure 5. The ARC Framework of adjustment to disfiguring conditions (adapted from Thompson, 2012)

Reprinted by permission of the publisher (Oxford University Press): Thompson, A. R. (2012). 'Researching appearance: models, theories and frameworks'. In Rumsey, N. and Harcourt, D. (Eds). *Oxford Handbook of the Psychology of Appearance*. Oxford: Oxford University Press.

According to the ARC framework, these predisposing factors lead to intervening cognitive processes, which are in turn related to psychosocial outcomes such as those discussed in chapter 1. For example, socio-cognitive processing may involve satisfaction with social support, fear of negative evaluation and social acceptance. Research has indicated that social support can promote adjustment among CYP in a number of ways such as improving self-worth and body image and reducing depression (Barnum, Snyder, Rapoff et al, 1998). Peer support from other people with burns is thought to be particularly powerful, as they have first-hand experience of sustaining a burn injury (Badger & Royse, 2010a). The role that fear of negative evaluation can play in social anxiety and social avoidance is discussed in section 2.1.2 above.

The ARC framework produces the most comprehensive overview of the complex factors surrounding adjustment to a visible difference, and the study in which the model was used has the largest sample to date (n=1,265). The model provides a useful context for this thesis, as it demonstrated that a complex range of individual factors can determine the extent to which someone may adjust positively to a visible difference. It is, however, difficult to encompass the wide range of appearance-altering conditions using a 'one size fits all' approach. For example, as discussed in section 2.1, CYP with burn injuries may experience additional challenges to those with other conditions, such as trauma relating to the circumstances of the burn injury itself.

Overall, there is a lack of models of the psychosocial impact of burns on CYP. The ARC model and the other models outlined in this chapter were designed for adults and there is a lack of information about their applicability to CYP. Although it has been suggested that CYP may react to burn injuries similarly to adults (Scheeringa, 2008), it is cautioned against relying too heavily on these models alone. While consideration of the different factors affecting adjustment within the ARC model may help health professionals to identify risk factors and provide a better understanding of the causes behind their patients' psychosocial responses to the injury, further information is necessary to decide upon the most appropriate way to provide the support required to meet any particular individual's needs.

2.2 THE CAR FRAMEWORK OF APPEARANCE-RELATED INTERVENTIONS

It has been suggested that the variability in the ways that people adjust to a visible difference leads to the difficulties health professionals face when trying to meet patients' needs, and the challenges involved when designing suitable screening methods and psychological support strategies (Rumsey, Clarke, White et al, 2004). It should be noted that not all individuals with a visible difference will want, or need, psychosocial support. Some may cope very well, however

those who are negatively affected by psychosocial issues may benefit from an appropriate intervention targeted towards these issues (Harcourt & Rumsey, 2012). There is little research into interventions for CYP with burn injuries, however Jenkinson, Williamson, Byron-Daniel and Moss (2015) conducted a systematic review of psychosocial interventions for CYP with visible differences in general. They identified twelve studies (encompassing 606 participants in total), seven of which included CYP with burns. Five of the seven studies focusing on burns evaluated residential camp programmes, one intervention combined exercise and counselling and one involved residential social interaction skills training (SIST). Interventions for participants with a range of other conditions included one instance of group SIST, one combined individual CBT and SIST, one group behavioural therapy (BT), one individual SIST, and a residential camp for CYP with cranio-facial conditions. These interventions will be discussed throughout this section.

Bessell, Dures, Semple and Jackson (2012) suggest that a tiered approach should be used to address distress, to ascertain both the level and type of intervention that is most suitable for each individual. Stepped care models (involving treatments of different intensities) are commonly used within psychological therapy services in areas such as depression or eating disorders (Bower & Gilbody, 2005). One such model is the stepped care model proposed by the National Institute of Clinical Excellence (NICE; 2011), which includes four steps. The steps range from common mental health disorders at step one, through to mild-moderate levels of disorders including depression, panic disorder or obsessive compulsive disorder at step two, to moderate-severe levels of depression, panic disorder or obsessive compulsive disorder at step three, and ending at level four with severe presentations which have not responded to lower-level interventions. The model proposes specific treatments for different disorders at different steps, such as psychoeducation or referral for further assessment at level one, individual-facilitated self-help at level two, individual or group-based counselling at level three, and highly-specialised treatment such as complex drug treatment or electroconvulsive therapy at level four. NICE (2011) guidelines propose that an individual starts at the lowest step possible and progresses through each step sequentially if they do not respond.

The NICE model was initially considered for the current research; however the model relates to generic mental health difficulties experienced by the general population as a whole. While there is currently no model exclusively relating to support for those with burn injuries, it was felt that a model incorporating difficulties more specific to those with burn injuries would be better suited to evaluated interventions designed for this population. For example, CYP with burn injuries may experience a wide range of appearance-related concerns (discussed in more detail in chapters 1 and 7), which are not considered by the NICE stepped care model. The Centre for Appearance

Research has created a stepped model of care for different levels of appearance-related interventions aiming to reflect the need of those receiving the intervention (Rumsey & Harcourt, 2012 – see Figure 6). The numbers needing the intervention reduce as the intensity of the intervention increases. It ranges from level 0 (general population and societal campaigns) to level 5 (complex, specialist-led counselling/therapy for individuals/families).

The CAR framework has similarities with the NICE stepped care model, i.e. anyone not benefitting from a particular intervention may be better suited to a different level of intervention. However, unlike the NICE model which proposes that individuals begin at step one and move sequentially through steps two, three and four, the CAR framework suggests that people may begin at any level on the pyramid and move fluidly through the other levels as required. This framework is a useful starting point as it considers the differing needs of individuals with appearance concerns. Each level of the framework will now be discussed in the context of the visible difference literature.
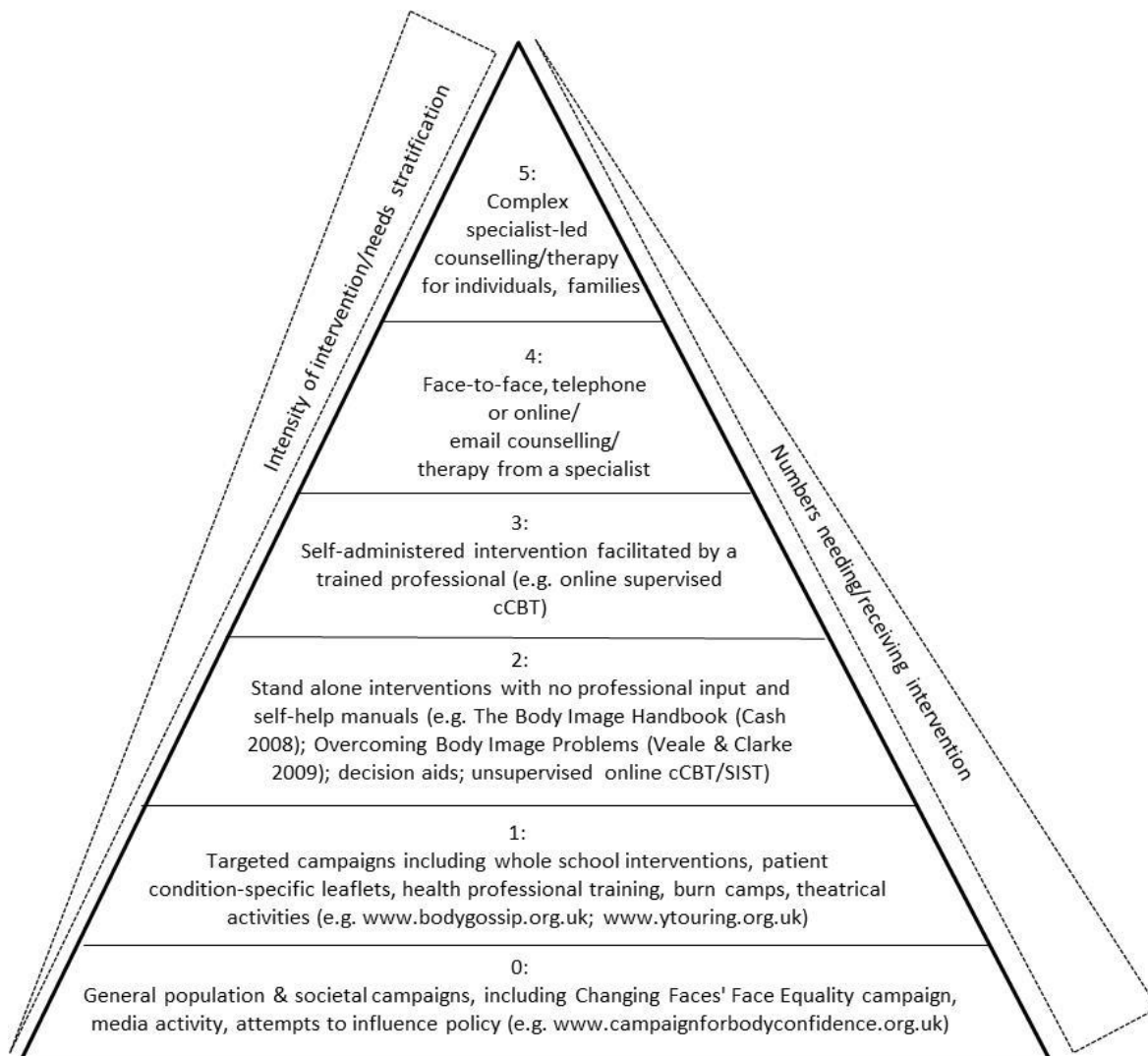
Figure 6. The CAR framework of appearance-related interventions (adapted from Rumsey and Harcourt, 2012)

Reprinted by permission of the publisher (Oxford University Press): Rumsey, N. and Harcourt, D. (2012). 'The Psychology of Appearance: The Future'. In Rumsey, N. and Harcourt, D. (Eds). *Oxford Handbook of the Psychology of Appearance*. Oxford: Oxford University Press.

Level 0

Level 0 interventions may include general population and societal campaigns or media activity. Wardle and Boyce (2009) conducted research into the way in which visible differences were represented on television, including focus groups with 85 people (both with and without a visible difference) to explore audience views about these portrayals. Results indicated that the most common visible differences shown on TV were scarring, burns and limb loss, which were often presented as 'problems' to be solved with solutions such as technology or medicine. Visible differences were also commonly portrayed as having negative connotations, e.g. evil, bitter or reclusive characters. Similarly, a YouGov survey of 1,741 adults commissioned by the charity

Changing Faces in 2012 found that almost half of participants felt that people with appearance-altering conditions tended to play evil characters (Changing Faces, 2012). Leading on from this research, Changing Faces' 'Face Equality' campaign aims to work with the media to try to inform the public about, and change negative attitudes towards, people with a visible difference (Changing Faces, 2016a). While this campaign has not yet been formally evaluated, it is hoped that changing how the media portrays the subject will alter the public's views and attitudes towards those with a visible difference, which may subsequently reduce stigmatizing behaviours.

Level 1

Level 1 interventions are targeted campaigns such as patient condition-specific leaflets or theatrical activities. It is suggested that this level of support should be offered to all individuals with a visible difference who have consulted with healthcare professionals. Another example of a level 1 intervention is school interventions which may be used to facilitate a child's return to school after a burn injury (Rosenberg, Rosenberg, Perez et al, 2006). Wilson, Gaskell and Murray (2014) and Arshad, Gaskell, Baker et al (2015) conducted two studies to evaluate a school reintegration programme run in the UK. The study by Wilson et al (2014) explored the experiences of four primary school teachers who had been involved in a school reintegration programme after a child in their class had sustained a burn injury. Teachers felt that the intervention helped them to answer questions from the other students about the burn injury, which they felt helped them to normalise the situation. They appreciated the collaborative effort with the burn care team, indicating that they would have felt unprepared to facilitate the child's return to school on their own. The study by Arshad et al (2015) found that the time taken to return to school after a burn was reduced from 53 to 20 days after implementation of the reintegration programme. Furthermore, teachers, parents and the children themselves reported a number of positive outcomes from the programme, such as increasing awareness of burn injuries and helping the child to feel supported. These studies included small sample sizes, however the results are indicative of the wide range of potential benefits school reintegration programmes can have on CYP, their parents and teachers.

Findings from studies such as these could be used to inform a more standardised school-based intervention to promote successful reintegration, which could then be subject to more rigorous evaluation. However, it is important to recognise that there may also be disadvantages to this type of intervention. Depending on how the intervention is delivered, it is possible that it could have the unintentional effect of singling out the CYP and emphasizing their visible difference. While the aforementioned studies have been facilitated by psychologists, teachers may not have

the knowledge or confidence to deliver a burn-related school intervention. The Changing Faces charity's 'Face Equality' campaign has also developed a teaching resource which is designed to help teachers encourage a positive response to visible differences within their school (Changing Faces, 2016b). Rather than focusing on an individual child, the resource helps increase awareness and promotes equality for students with a visible difference. An alternative, and more widely used, intervention at level one are burn camps which, as reported by Jenkinson et al (2015), are the most commonly researched intervention within the burns population. A more thorough discussion of burn camp research is provided in chapters 4 and 5.

Level 2

Level two of the CAR framework includes self-help manuals or unsupervised online therapy. Newell and Clarke (2000) demonstrated that a CBT-based self-help leaflet significantly improved social adjustment and depression in those suffering from appearance-related anxiety. These findings are important as they suggest that even basic self-help information can significantly reduce appearance-related distress in people with visible differences, which may considerably reduce the workload of overburdened health professionals, and ensure that more people can access the care they need. However it is important to remember that, as with other largely unsupervised interventions at this level, patients need to be suitably screened to identify those that need more intensive support and ensure they have access to it.

Online therapy refers to an intervention that is delivered using a computer, and can cover many aspects often found in a more traditional CBT session such as identifying and challenging negative thought patterns, and examining the relationship between thoughts, feelings and behaviour (Stallard et al, 2010). However, a potential concern for both self-help materials and unsupervised online therapy is the loss of a therapeutic relationship between practitioner and client. There is a general consensus that online therapy should be used as an extension of therapy, rather than as a replacement for a therapist (Gega et al, 2004; Newman et al, 1997) and it is therefore important to determine the correct level of professional support to ensure adherence to and benefit from treatment (Farvolden, Denisoff, Selby et al, 2005).

Another self-help intervention relates to the use of cosmetic camouflage, introduced in section 2.1.5. Maskell (2014) examined the use of a cosmetic camouflage called Microskin in CYP aged 8-17 years with burn injuries, who attended a training workshop and were then able to apply the product themselves at home. The study found that the intervention led to improvements in perceived physical appearance, and both social and family functioning and it appears that

Microskin may be a useful tool for CYP who are worried about scarring. However, as discussed in section 2.1.1 there is a chance that concealment strategies such as this may generate additional anxiety as CYP worry about their scarring being revealed. This lends support to the importance of providing a toolbox of management strategies to CYP, rather than relying on one method alone.

Level 3

Level 3 interventions are self-administered interventions facilitated by a trained professional, such as supervised online therapy. A number of studies have investigated the effectiveness of online support in treating a range of mental health problems. Barak et al (2008) conducted a systematic review of 92 studies of online therapy for a variety of problems, and found no statistically significant difference between internet-based or traditional face-to-face therapy. A later meta-review of ten systematic reviews by Foroushani, Schneider and Assareh (2011) also concluded that online therapy is no less effective than face-to-face CBT but highlighted the need for further research as new packages are developed. Online therapy can effectively reduce both depression and anxiety among children and adolescents (Richardson, Stallard & Velleman, 2010), with improvements found to be maintained at 12-months post-treatment (Spence, Holmes, March & Lipp, 2006). Both CYP and their parents have reported high levels of satisfaction with treatment (Richardson et al, 2010).

Several studies have reported high levels of satisfaction from patients completing online therapy treatment (Kalenthaler, Sutcliffe, Parry et al, 2008). Patients have positively reported the convenience of being able to complete an intervention at home, at a time that suits them, and without the need to disclose sensitive information to another person (MacGregor et al, 2009). Finally, the self-improvement in symptoms experienced by patients using online therapy has also been found to be a motivating factor (Gerhards, Abma, Arntz et al, 2011).

There is limited research into online therapy to treat appearance-related concerns; however two programmes have been designed to support adults (Face IT) and CYP (YP Face IT). Both programmes are designed to provide information and support for a number of issues often associated with having a visible difference, such as anxiety, depression and worries about social situations. These programmes provide the basis for study 2 in this thesis and are, therefore, discussed in more detail in chapter 6.

Levels four and five of the pyramid relate to one-to-one/family support provided by a specialist, such as a clinical psychologist or psychotherapist. The levels of support differ according to the individual needs of patients, and therefore while both levels may address some similar issues, it is only those with the most extreme difficulties who will require support from level five of the pyramid. For example, a patient experiencing worries about social situations may find level four to be sufficient, whereas a patient experiencing PTSD may require the more complex support found at level five. Support found at levels four and five may include approaches such as SIST or CBT, both of which have been posited as techniques to promote successful psychosocial adjustment to a burn injury (Blakeney et al, 1998). CBT and SIST can also underpin interventions at lower levels, but when they are delivered by a specialist they become level 4 or 5 interventions. Face-to-face support within the burns population is considered in more detail in section 7.1, but has also been used within a range of other visible differences.

SIST aims to teach an individual the necessary skills for successful social interactions, which may include techniques such as observation, listening and non-verbal communication, implemented through the use of behaviour practice and feedback, role modelling, or homework (Houghton, 2008). Cognitive-behavioural therapists believe that emotions and behaviours are determined by an individual's thoughts, and therefore that negative cognitions can lead to psychological difficulties (Hofmann, 2012). CBT aims to help individuals recognize their own detrimental thinking patterns, and learn how to tackle these to help them deal with situations which they may find difficult or upsetting (Wilding & Milne, 2010).

A systematic review examining psychosocial interventions for adults with a visible difference examined twelve papers encompassing six different styles of intervention, including top-tier interventions such as group and individual CBT (level 4/5 of the CAR framework), self-help materials (level 2), group-based SIST (level 4/5), group-based person-centred therapy (level 4/5), and support group-based interventions (level 1) (Bessell & Moss, 2007). Participants had a range of visible differences, including burns, psoriasis and vitiligo. The authors reported that only limited evidence for the effectiveness of each intervention was determined by the review, as all of the studies suffered from methodological flaws, such as incorrect statistical analyses or inappropriate outcome measures. In addition, it is hard to draw comparisons between the interventions reported as they differ to such an extent in terms of factors such as length, contact with the therapist, and type and severity of condition. An updated version of this review was published in 2015 (Norman & Moss, 2015) which included another four papers. All four studies assessed

individual CBT for a range of conditions including lupus and amputation, and two also included an element of SIST. The review did not contribute any new evidence pertaining to the efficacy of such interventions, and led the authors to adhere to their original recommendations, highlighting a need for additional studies with improved methodological considerations.

Jenkinson et al's (2015) aforementioned review also reported a number of methodological flaws within the studies, most notably relating to the outcome measures used. The majority of the studies used either the Rosenberg (1965) Self-esteem Scale or the Harter (1985) Self-Perception Profile for Children to assess self-esteem, although reported only limited improvements across the interventions. Jenkinson et al (2015) suggest that the multifaceted components of self-esteem in CYP with visible differences might be better assessed by focusing on additional constructs such as satisfaction with appearance or social confidence. Indeed, Corry et al (2009) claimed that two of the biggest challenges to the long-term psychosocial rehabilitation of burns survivors relate to social anxiety and body image.

Although both Norman and Moss's (2015) and Jenkinson et al's (2015) reviews reported a large number of methodological limitations within the studies examined, they do provide tentative support for the use of such interventions for a range of factors such as body image, depression, anxiety and self-esteem among adults and CYP with a visible difference. Bessell and Moss (2007) concluded that further research is needed to more specifically examine the most appropriate interventions for particular disfigurements. It has been theorized that CBT combined with a social skills element may be particularly effective for issues such as body image or social integration for burns survivors (Lawrence & Fauerbach, 2012). For example, the CBT component may aim to break negative patterns such as social isolation or depression, while individuals may also be taught social skills such as making eye contact or projecting confident body language.

While interventions located on the first four levels of the pyramid may address a range of appearance-related concerns, they are unlikely to be sufficient for targeting symptoms of trauma. ASD and PTSD can be extremely complex (see section 1.3.5), so it is likely that these will need to be treated by mental health specialists at the highest level. Trauma-based CBT has been shown to effectively treat symptoms of PTSD in children and adolescents in the general population (e.g. King, Tonge, Mullen et al, 2000; Celano, Hazzard, Webb et al, 1996), and has also produced positive outcomes within families attending sessions as a group (Cohen & Mannarino, 2008). Techniques may involve stress management, muscle relaxation and breathing techniques, thought stopping/replacement, gradual exposure or imaginal flooding (Jensen, Holt, Ormhaug, et al, 2014).

2.3 AIMS OF THE THESIS

The majority of the research discussed in this chapter either focuses on populations other than those with burn injuries, or includes only adult participants. Furthermore, research into support for families of those with burn injuries is very limited. As discussed in section 1.3.1, there is also a lack of appropriate measures for visible difference research. Indeed, Jenkinson et al (2015)'s main conclusion was that the equivocal results from their review necessitate further evaluation of interventions for CYP with visible differences, ensuring that appropriate outcome measures are utilised. They discuss the importance of understanding specifically which interventions work for which individuals, and in what context. For example, given the diverse range of psychosocial needs within the burns population, research may consider factors such as the techniques used, the method of delivery and the setting in which the intervention takes place (Fauerbach et al, 2007). Kleve and Robinson (1999) suggested that psychosocial support should include the provision of individual, group and family interventions. While the authors were referring to visible differences generally, the same points apply to burns.

The wide range of difficulties experienced by CYP with burn injuries and their families described in chapter 1 suggests a need for support targeted towards a variety of psychosocial challenges. Based on the tiered approach to support outlined above, this thesis therefore considers a range of interventions relating to different levels of the CAR framework, aiming to provide a comprehensive consideration of interventions suitable for people affected by burns with varying individual needs. The first study within the thesis (chapters 4 and 5) concerns level one of the CAR framework, which includes targeted campaigns such as theatrical activities or burn camps, and it is suggested that this level of support should be offered to all individuals with a visible difference who have consulted with healthcare professionals. This study focused on burn camps and was split into two parts, the first aiming to explore a new area of research by exploring family burn camps and the second aiming to further existing research into child-only camps by addressing several methodological issues. Therefore, these studies are referred to as 1A and 1B.

The next study (chapter 6) involved a newly-developed online programme of support called YP Face IT, designed for CYP with a visible difference who are experiencing appearance-related concerns. This study aimed to determine the acceptability and feasibility of the programme for CYP with burn injuries being treated within secondary care.

The final study (chapter 7) involved interviews with psychosocial specialists working within paediatric burns, to explore their experiences of providing support to CYP with a burn injury at levels four and five of the pyramid, but also their views on the alternative levels of support. While the National Burn Care Review (2001) stated that all burns services should include a designated psychologist, there is little published research within this area. Therefore, this study was exploratory in nature, as it aimed to explore techniques which are commonly used, but little reported on, within the paediatric burns population.

The research questions for the thesis are:

1. How are the psychosocial needs of CYP with burn injuries and their families assessed?
2. How can these needs be addressed using a range of psychosocial interventions?
3. Can these interventions be represented by the levels of the CAR pyramid framework?

CHAPTER 3. METHODOLOGY

3.1 MIXED METHODS RESEARCH

The previous chapters reviewed the psychosocial impact of burn injuries and the need to conduct research into interventions relating to varying levels of need, so the next stage was a consideration of the methodology to achieve this. This chapter explains why mixed methods was selected as the most appropriate approach to use within the research, beginning with an introduction to mixed methods and the paradigm divide between quantitative and qualitative research. An overview of the types of data analysis used within the thesis is followed by the ethical considerations made prior to conducting any research. The use of patient and public involvement (PPI) is discussed, before moving onto a discussion of the challenges of conducting research within paediatric burns.

3.1.1 Introduction to mixed methods

Mixed methods research has gained popularity in recent years (Dures, 2012). There is some variation surrounding the definition of mixed methods, although there is a general consensus that it combines a mixture of quantitative and qualitative methods within a project to fully explore a research question (Wilson, 2013). Mixed methods research aims to utilise the strengths of both techniques and should not be considered a replacement for either approach (Johnson & Onwuegbuzie, 2004). This thesis can be classed as a "mixed methods programme", defined by Johnson, Onwuegbuzie and Turner (2007, p123) as "mixing within a programme of research…across a closely related set of studies".

3.1.2 Quantitative vs. qualitative paradigms and the introduction of pragmatism

Mixed methods research has been surrounded by a certain amount of controversy relating to the paradigm divide between qualitative and quantitative research. Paradigms have been defined as "basic belief systems based on ontological, epistemological and methodological assumptions" (Guba & Lincoln, 1994, p107). In order to gain a thorough understanding of mixed methods research it is necessary to consider these issues in more detail. The main two paradigms in social science research are the positivist/empiricist approach and the constructivist/phenomenological approach (Teddlie & Tashakkori, 1998), which will now be considered in terms of their epistemological, ontological methodological assumptions.

Ontology refers to a researcher's viewpoint of reality which exists as a continuum ranging from 'realism' to 'relativism' (Braun & Clarke, 2013). Quantitative research adopts the realism approach – that there is a single truth 'out there' which can be measured independently of the researcher using objective measures (Creswell, 1994). Qualitative research usually adopts the relativism approach – that reality is created by the individuals included in the research (Creswell, 1994). However, in between these ends of the continuum exists critical realism which suggests that there is a knowable world which can be discovered through the subjective knowledge accessible to a researcher (Braun & Clarke, 2013). Certain qualitative approaches, such as thematic analysis, adopt this approach.

Epistemology is a theory about the best way to gain knowledge from the world (Yardley & Bishop, 2008) and relates to the relationship between a researcher and the individuals being researched. Quantitative research adopts a positivist epistemology which suggests that knowledge is obtained through objective data collection techniques independent of the researcher (Creswell, 1994). In contrast, qualitative research adopts a constructivist epistemology which suggests that knowledge pertains to particular social and cultural contexts (Braun & Clarke, 2013) involving an interaction between the researcher and the individuals being researched (Creswell, 1994).

Qualitative and quantitative research also differ in terms of methodological assumptions. In the most basic terms, quantitative research is usually a deductive approach to the relationship between theories and research (Bryman, 2004), comprising characteristics such as control, replication and hypothesis testing (Burns, 2000). In contrast, qualitative is usually an inductive approach to the relationship between theories and research, focusing on the way in which individuals interpret their world. Quantitative research uses generalization to predict and explain, whereas qualitative research uses patterns and theories to gain understanding and insight (Creswell, 1994).

In an attempt to settle the debate over the two major paradigms, a number of authors have proposed an alternative paradigm, known as pragmatism (Teddlie & Tashakkori, 1998). Rather than focusing on the differences between research stemming from contrasting perspectives, the pragmatic approach emphasises "shared meanings and joint action" (Morgan, 2007, p67). The focus is on the best method for answering the research question (Johnson & Onwuegbuzie, 2004) aiming to obtain a rich and meaningful understanding (Yardley & Bishop, 2008), rather than being constrained by the philosophical position of the researcher.

Morgan (2007) describes the main differences between pragmatism and the quantitative/qualitative approaches in terms of the methodology used. Whereas quantitative research is deductive and qualitative research usually inductive, the pragmatic approach is abductive, which moves between induction and deduction, for example by using theory to explain observations. Instead of the objectivity and subjectivity respectively associated with quantitative and qualitative research, pragmatism involves intersubjectivity, suggesting that whilst there is indeed a 'real world'; all individuals interpret that world uniquely. Finally, rather than assuming that knowledge is context-bound or generalizable, pragmatism suggests that researchers should consider whether their findings and knowledge can be transferred to new situations.

There appears to be a certain level of agreement among researchers using mixed-methods that a pragmatic rationale should be used (Biesta, 2010). The flexibility of the pragmatic approach allows researchers to select the research method, or methods, which they feel will most effectively address a particular research question. Whilst it seems logical to select a research technique based on its perceived compatibility with a research topic, it is important to consider the implications surrounding the decision. The value of using mixed methods research can be demonstrated through a thorough explanation and justification of the approach within a research project (Dures, 2012). The typologies of mixed methods research will now be examined in more detail, with an explanation of the typology used within this thesis.

3.1.3 Typologies of mixed methods research

Bryman (2006) suggests that there are a number of different aspects to mixed methods research which define the typology used, which can be clarified using the following questions:

1. Is there more than one data strand?
2. What is the function of the integration?
3. Which has priority – the quantitative or qualitative data?
4. Are the quantitative and qualitative data collected simultaneously or sequentially?
5. At what stage in the research process does multi-strategy research occur?

A multi-strand study involves more than one research method and more than one source of data. It is debatable whether a mono-strand study consisting of only one research method and a single source of data can be considered as mixed method research (Bryman, 2006). The current research involves a number of studies, each involving different research methods and sources of data. When considering the function of the integration, it may be helpful to refer to Greene, Caracelli

and Graham (1989), who suggest that there are five main purposes for conducting mixed methods research:

- Triangulation –corroborating results from using different methods to study the same phenomenon.
- Complementarity –clarifying the findings from one method using the other method
- Development – using the findings from one method to develop research using the other method
- Initiation – restructuring research questions based on contradictions between the methods
- Expansion –broadening the scope of research by using different methods for different areas of enquiry

The current research used the principles of triangulation and expansion in an attempt to explore the effects of the interventions considered in this thesis in the broadest and most inclusive way possible. Qualitative and quantitative techniques were employed to uncover different avenues of enquiry, discussed in greater detail within the specifics of each study. Bryman's last three questions can be answered using Leech and Onwuegbuzie's (2009) three-dimensional typology model, which is based on time orientation (concurrent or sequential), level of mixing (partially or fully) and emphasis (equal or dominance). For example, data within a mixed methods project may be collected sequentially (one after the other) or concurrently (not in sequence) (Johnson & Onwuegbuzie, 2004). Leech and Onwuegbuzie (2009) state that mixed method designs may be fully or partially mixed. A fully mixed design may refer to a study that mixes both qualitative and quantitative methods across at least one of the following four components: the research objective, type of data and operations, type of analysis and type of inference. A partially mixed design may involve mixing of data at just one stage, for example during data interpretation.

Johnson, Onwuegbuzie and Turner (2007) claim that there are three main types of mixed methods research located on a continuum. The centre of the continuum attributes equal status to quantitative and qualitative methods, claiming that both methods can add insights to the majority of research questions, which can be symbolised as QUAN + QUAL. At one end of the continuum is qualitative dominant mixed methods design, which is sometimes symbolised as QUAL + quan. This approach describes researchers who aim to incorporate quantitative elements into an otherwise qualitative design. Conversely, the quantitative dominant mixed methods design is located at the other end of the continuum, symbolised as QUAN + qual, involving an incorporation of qualitative elements into an otherwise quantitative design.

Leech and Onwuegbuzie (2009) considered each of these typologies to create eight design types:

1. Partially mixed concurrent equal status designs (e.g. QUAN + QUAL)
2. Partially mixed concurrent dominant status designs (e.g. Quan + QUAL)
3. Partially mixed sequential equal status designs (e.g. QUAL → QUAN)
4. Partially mixed sequential dominant status designs (e.g. Qual → QUAN)
5. Fully mixed concurrent equal status designs (e.g. QUAN + QUAL)
6. Fully mixed concurrent dominant status designs (e.g. Quan + QUAL)
7. Fully mixed sequential equal status designs (e.g. QUAL → QUAN)
8. Fully mixed sequential dominant status designs (e.g. Qual → QUAN)

This thesis can be considered within the second type of design, as qualitative and quantitative techniques are partially mixed concurrently throughout the different stages of the thesis and greater overall status is given to qualitative techniques (Quan + QUAL), according to the research questions under consideration.

3.1.4 Application of mixed methods research within the thesis

Johnson and Onwuegbuzie (2004) suggest that there are a number of advantages to using mixed methods. Mixed methods research is flexible and expansive, and allows the researcher to address a much broader range of research questions without being bound by the constraints of a particular technique. The research strategy used can be tailored to suit each individual research question, to ensure the best chance of exploring the topic under consideration. Corroborating evidence from the two methods can also help to draw a stronger conclusion about a particular research question (Greene & Caracelli, 2003). For example, narrative can be used to add depth to statistical findings from a quantitative study, which can in turn add precision to qualitative findings. Combining the techniques in this way can help to provide a more comprehensive understanding of a topic, which can subsequently provide a more significant contribution to the development of further theory and practice (Yardley & Bishop, 2008).

It has been suggested that mixed methods research may have useful applications within health psychology research (Yardley & Bishop, 2015). Bishop (2015) considers several existing studies, to illustrate how mixed methods may be applicable within a health psychology research setting. Two such designs relate to the use of quantitative techniques to investigate ideas originating from qualitative work, and the use of qualitative methods to clarify quantitative findings. Bishop states that the first design could include qualitative techniques to explore a poorly understood phenomenon, which could generate hypotheses to be tested with a subsequent quantitative

design. Conversely, the second design may employ qualitative techniques alongside quantitative methods, to contextualise results and explain any unexpected findings.

Johnson and Onwuegbuzie (2004) also emphasize that there are a number of limitations when using mixed methods research. For example, it can be more expensive or time consuming, particularly for a single researcher, so time and resources were carefully considered when planning each study. Secondly, Johnson and Onwuegbuzie (2004) draw attention to the position held by methodological purists, who argue that researchers should adopt either a qualitative or a quantitative paradigm. However, this view is rejected by a number of researchers (Johnson, Onwuegbuzie and Turner, 2007). Salomon (1991) goes so far as to say that employing a single paradigm can actually limit the validity of a study due to the methodological assumptions required within each approach. Mixed methods can be undertaken in such a wide variety of ways, there is the potential for confusion to arise during a study. It is important for a researcher to be clear about specifically when and how the mixing of the two techniques occurs. Mixing may occur at the data collection, data analysis, or interpretations stage, or at a combination of these stages (Creswell, 2009). The specifics of the current research are discussed below.

Mixed methods were chosen for the current research for a number of reasons. In addition to general advantages, such as uncovering different aspects of a phenomenon or using one method to explain findings from the other (O'Cathain, Murphy & Nicholl, 2007), mixed methods were thought to be particularly suitable for studies of interventions, the core topic within this thesis. For example, while quantitative results might indicate whether an intervention is effective or not, they cannot explain *why* this might be the case. Qualitative techniques can provide additional insight into the reasons behind this outcome (Bradley, Wiles, Kinmonth, et al 1999) and can also explain how an intervention can be used in practice (Parry-Langdon, Bloor, Audrey, et al, 2003), making research more applicable to real-life situations.

As noted in section 3.1.3, the studies in this thesis can be considered to lie within a partially mixed concurrent dominant status design. However, they can be described more specifically as a convergent parallel design (see Figure 7), which involves collecting qualitative and quantitative data concurrently, analysing the datasets separately, and combining the results during interpretation of the data to determine whether there is convergence or divergence between the two (Caruth, 2013). This design is a time-effective method to develop a comprehensive understanding of a phenomenon (Watkins, & Gioia, 2015) while confirming findings from one type of data with another (Stentz, Plano Clark & Matkin, 2012). However, it can also be difficult to compare analyses from different types of data, particularly if the results produce discrepancies

(Creswell, 2009). A more detailed discussion on dealing with data discrepancies can be found in section 8.1.1.

This technique was used within the mixed methods studies in this thesis (studies 1B and 2), as well as for the thesis overall. The qualitative and quantitative data were collected concurrently in studies 1B and 2 and then compared after data analysis to lead to an interpretation of the findings. Bringing the two types of data together for interpretation is known as merging (Watkins, & Gioia, 2015) and it is important to consider at the design stage how the data will be merged for analysis (Fetters, Curry & Creswell, 2013). In the case of the current research this was achieved by implementing quantitative outcome measures with complementary questions to collect qualitative data.

There are a number of different ways to integrate findings at the interpretation level, and in the current research this was achieved using "integration by narrative", or describing the qualitative and quantitative findings in a single report which can use a number of different approaches (Fetters, Curry, & Creswell, 2013). Study 1B employed a "weaving approach" where the qualitative and quantitative findings were presented on a concept-by-concept basis, whereas study 2 employed a "contiguous approach" where the two types of findings are presented in different sections. Results from each of the four studies were subsequently compared to lead to an interpretation of the findings in the context of the overall research questions for the thesis.

Figure 7 Parallel convergent design (adapted from Watkins & Gioia, 2015)

Reprinted by permission of the publisher (Oxford University Press): Watkins, D. C. & Gioia, D. (2015). Mixed Methods Research. Oxford: Oxford University Press.

Within the parallel convergent design, a number of different methods were used throughout the thesis, detailed below in Table 1, justified in more detail within each study chapter. The chronology, research questions and links between studies are represented in Figure 8. Study 1A focused on burn camps, but rather than the children's only camps examined in previous literature, it explored the previously un-researched setting of family camps. As this novel intervention had not been examined within the literature before, it was decided that a solely

qualitative design should be employed to gain a deeper understanding of the camp, with the view that the results could be used to generate hypotheses for further research aimed at measuring and quantifying specific effects.

Study 1B focused on a child-only burn camp which has been investigated in previous research using a variety of both methods; however discrepancies have emerged between the results of the previous quantitative studies and qualitative studies. To explore this further, Gaskell (2007) conducted a mixed methods study into CYP's experiences of attending a burn camp over a 5-year period and consistently found that, although CYP's qualitative responses described a wide range of benefits from attending the camp, these findings were not replicated using standardised outcome measures. These discrepancy between qualitative and quantitative findings exist elsewhere in the burns literature, as a study by Blakeney, Meyer, Moore, et al (1993a) into social and behavioural difficulties following a burn injury refers to a 19-year old man who spoke of his life five years after the burn as a "nightmare", but scored within normal limits on standardized tests. This discrepancy between qualitative and quantiative findings led to the decision to employ mixed methods in study 1B, with quantitative techniques to measure effects and qualitative techniques to explore experiences. A more detailed discussion of the potential conflict between standardized outcome measures and qualitative methods within burns research is provided in section 5.1.

Study 2 was a feasibility study of a newly-designed intervention (YP Face IT: YPF) within a particular setting (paediatric burns patients treated within secondary care). Bradbury, Dennison, Little and Yardley (2015) employed a mixed methods technique to explore the feasibility of a new online weight intervention, which included nurse logs to record the level of support provided by patients, measures of weight loss, and patient interviews to explore their experiences of the intervention. Study 2 employed similar techniques, asking health professionals to complete a record of supervision, using outcome measures to compare wellbeing scores before and after the intervention, and interviews with patients, their parents, and the health professionals to explore their experiences of the intervention.

Study 3 was exploratory research as it aimed to understand the experiences of health professionals working in paediatric burns, an area that had not previously been explored within the literature. Therefore, similarly to study 1A, this study employed solely qualitative techniques to gain a fundamental understanding of face-to-face support provided by a specialist, to determine whether results could lead to the development of future research and provide a more

comprehensive understanding of the complex nature of psychosocial support within the paediatric burns population.

Study number		Type of research	Analyses used
Study 1A	Family burn camp	Qualitative (photo-elicitation family interviews)	Thematic analysis
Study 1B	Child-only burn camp	Mixed methods (questionnaire booklets with outcome measures and open ended questions).	Content analysis (qualitative responses) Wilcoxon signed ranks test (quantitative responses)
Study 2	YP Face IT	Mixed methods (online outcome measures and interviews, and feasibility data)	Thematic analysis and case studies
Study 3	One-to-one support	Qualitative (telephone/face-to-face interviews)	Thematic analysis

Table 1 Types of research methods and analyses from the different studies within the thesis

STUDY 1A
(Burn camp photography)
Data collection:
November 2013-January 2014
Data analysis:
February 2014-August 2014

Research Question:
What are families experiences of attending a family burn camp?

Key findings:
Families experienced a number of benefits relating to sharing new experiences, having fun without feeling different, and support from those who understand. The main limitation of this study was that it is not known how well-adjusted families were before the camp. This generated a need for a study involving a pre-post design, to explore whether outcomes changed from baseline to end of camp, and at a 3-mont follow-up.

STUDY 1B
(Burn camp questionnaire)
Data Collection:
August 2014-November 2014
Data analysis:
November 2014-June 2015

Research Questions:
1. Does burn camp have an impact on CYP's social concerns? If so, how?
2. Does burn camp have an impact on CYP's satisfaction with appearance? If so, how?
3. Does burn camp have an impact on CYP's behaviour? If so, how?
4. Does burn camp have any additional benefits for the CYP that attend?

Key findings:
While the study demonstrated consistency between qualitative and quantitative findings, suggesting that camp led to improvements in appearance satisfaction and social concerns, it was acknowledged that burn camps do not offer targeted psychosocial techniques. It was decided that more research was needed to evaluate interventions for those with a higher level of psychosocial need.

STUDY 2
(YP Face IT)
Data collection:
June 2015 – February 2016
Data Analysis:
February 2016-May 2016

Research Questions:
1. How feasible is it to conduct a study of the effectiveness of YPF in secondary burns care?
2. How acceptable is YPF to YP with burns?
3. What are parents' views on their children using YPF?
4. How acceptable is the therapeutic content and mode of delivery YPF to clinicians?
5. How would clinicians incorporate YPF in practice?

Key findings:
While recruitment rates were low, findings indicated that the participants in the study found the intervention beneficial. However, several participants declined to take part as they expressed a preference for face-to-face therapy, while participants demonstrating symptoms of PTSD were excluded. This highlighted a need to explore face-to-face support for those with the highest levels of psychosocial need.

STUDY 3
(Interviews with psychologists)
Data collection:
January 2015-March 2015
Data analysis:
April 2015-January 2016

Research Question:
How do mental health specialists assess and treat CYP with burn injuries and families with the highest levels of psychosocial needs?

Key findings:
The study indicated that psychologists need to work flexibly to identify and meet psychosocial needs using a combination of different psychosocial techniques. A need for a comprehensive and consistent screening process was revealed.

Figure 8 The chronology, research questions and links between studies

3.2 ETHICAL CONSIDERATIONS

The British Psychological Society (BPS) publishes a code of ethics to which all psychology researchers are expected to adhere, which is based on four main principles: respect for the autonomy, privacy and dignity of individuals and communities; scientific integrity; social responsibility; maximising benefit and minimising harm (British Psychological Society, 2014). These relate to a number of ethical considerations such as confidentiality and anonymity, informed consent, and the right to withdraw. The research in this thesis adhered to the general ethical principles outlined by the BPS, but also took into account the specific ethical issues surrounding research with CYP. Additional considerations were made for studies 1A and 2, as these included photo-elicitation interviews and online research respectively.

The Nuffield Council on Bioethics (Nuffield, 2015) have published a report outlining the ethical issues involved in children and clinical research. They highlight that children differ from adults in the way that they develop, in terms of their abilities, understanding and feelings. They also recognise that while children are individuals, they are also part of families who are involved in their care and decision making. It is important for researchers and parents to work together to ensure that CYP are not vulnerable in research.

One important issue relates to informed consent, which is based on the premise that a participant's agreement to take part in a study should be informed by knowledge about the research (Barrett, 2000). A researcher must ensure that all aspects of the research which may influence the participant's decision are revealed, and it is essential that any information/consent materials are appropriate to the level of the CYP's understanding (UWE, 2014). All participant materials in the current research were checked using the Flesch-Kincaid readability test to ensure that they were age-appropriate. CYP over 16 and parents were asked to provide consent for themselves to take part in the studies while, in line with BPS (2014) guidelines, parents of participants under 16 were also asked to provide consent on their children's behalf. Although CYP may legally take part in research with only a parent's consent, it is best practice not to include CYP in a study against their wishes (Nuffield, 2015). CYP under the age of 16 were asked to provide assent to take part in the research, to ensure their right to refuse participation was respected (Gibson & Twycross, 2007).

3.2.1 Additional ethical considerations for research involving photo-elicitation interviews

Study 1A required additional consideration relating to ethics specific to the use of photography. Allen (2012) outlines five ethical issues specific to research involving participant photography. The first relates to informed consent to take part in the research, and was addressed in the current study by ensuring all participants provided fully informed consent (plus assent for those under 16). The next refers to an individual's right to privacy and states that while it may not be illegal to photograph someone in public, it may be considered unethical. Therefore, participants were reminded not to take pictures of the general public or the family who had not consented to be in the study. Thirdly, Allen discusses safeguarding issues relating to the possible embarrassment of those photographed, a notion which is furthered by Kaplan, Miles and Howes (2011) as they reflect on the potential for photographs to reveal aspects of people's lives which they would prefer to keep hidden. For this study in particular it was considered essential to be sensitive to the possibility that CYP may feel self-conscious if they were experiencing appearance concerns. This issue was addressed by sending a copy of the photographs taken by each family to that family prior to the interviews and asking whether there were any photographs they did not want to include in the research.

Allen (2012) suggests that participants should own the photographs that they produce. Participants were given one set of photographs per family to keep in the current study. Allen's final consideration is that researchers may unintentionally influence the images produced by participants by the directions they provide, discussed in the context of previous research in section 4.1. The researcher in the current study suggested that the families pretend they were taking photographs to post on Facebook in order to show their friends what happened during their time at camp (an approach used by Smith et al, 2012).

Additionally, participants were informed that the photographs they took would be used for academic purposes only and not used publicly for any other purposes. However, they were given the option for their pictures to be used solely for analysis and not disseminated any further. It is also possible to cloak or blur faces in photographs (Prosser & Burke, 2011). While it is acknowledged that other aspects of photographs (e.g. clothing) can identify participants, it has been suggested that this can be addressed by using a tiered consent form outlining the different styles of images which may be used (Jordan, 2014). The consent form allowed participants in study 1A to select whether they provided consent for the images to be used in their original format, to be used in a pixelated format, or not to be used in any format. Anything in the text of

the interview that could identify a participant was also changed. Further ethical issues relating to photo-elicitation are discussed in section 4.2.1.

Before beginning each interview, the researcher explained to the family what it would entail and ensured that they were aware of their right to withdraw. Although the ethical principles provided by the BPS (2014) are intended to provide participants with every opportunity to decline participation, it is possible that the "influence, prestige and power of the investigator" (Coolican, 2014, p287) may make it difficult for some participants, especially children, to refuse consent. Therefore, in addition to verbally confirming that each family member was happy to take part, the researcher also remained vigilant and observed each participant throughout the interview for signs that they were uncomfortable continuing. In addition to remaining enthusiastic and engaged throughout the interview, participants also demonstrated positive body language (such as eye contact and smiling). If any concerns had arisen during the interview, the researcher would have had an ethical obligation to terminate it immediately (UWE, 2015). Advice would be sought from the supervisory team, one of whom is a clinical psychologist working in paediatric burns.

3.2.2 Additional ethical considerations for online research

As study 2 (the feasibility of YP Face IT) involved online research additional ethical considerations were made, based on the British Psychological Society's (BPS; 2017) specific ethical guidance for internet mediated research (IMR). In addition to ensuring general ethical principals were adhered to, this study also considered respect for the autonomy, privacy and dignity of individuals and communities; the effect of levels of control on scientific integrity; social responsibility; and maximising benefits and minimising harm. This study involved a closed-access website which could only be accessed through a login and password unique for each participant, which participants were asked to keep private. This ensured that only the participant could log on to their account within the website, whilst verifying that the participant is indeed the one taking part. IMR means that the researcher and participant were not in the same physical location when the research was taking place so verification of participants was important, which is essential to ensure genuine informed consent (BPS, 2017).

The BPS (2017) states that IMR may result in a loss of control over four factors:
1. Who has access to participate
2. The environmental conditions under which participants are responding (e.g., are they watching television at the same time)

3. Variations in the research procedure due to different hardware and software configurations.
4. Participants' feelings, reactions, responses to the research process

The use of personalised logins and passwords increased the level of control over who had access to participate in the current research. While the second and third factor may influence research, they were inescapable due to the nature of the research, which considered an online intervention completed in the participants' own homes or psychologist's office using technology with varying hardware/software configurations. Therefore, it was recognised that environmental factors and distractions would inevitably occur throughout completion of the programme. Participants' feelings, motivation and responses to the research process were considered in the interviews completed by participants after completing the programme. Participants were also provided with advice on who to contact if needed during and after each session.

Social responsibility relates to maintaining respect for and avoidance of disrupting social structures, and carefully considering consequences and outcomes of a piece of research (BPS, 2017). The first point relates to research which makes use of existing online social groups such as social networking sites as "intrusions from researchers into spaces considered private by their users may be invasive, unwelcome and socially irresponsible" (BPS, 2017, p16). However, participants in study 2 were invited to use a new website which was not one of their existing online social groups, and were told before consenting that the researcher and their psychologist would be able to access their data. The second point relates to the potential widespread access of information gathered within IMR, for example if a researcher was to use a publicly-accessible online blog to make field notes. In study 2 the researcher stored all information on either a password-protected computer or in a locked filing cabinet, and ensured that all identifying information about participants was removed prior to any dissemination. No information was made publically accessible at any stage.

The BPS (2017) states that maximising benefits and minimising harm can be ensured by taking steps such as gaining valid consent, ensuring anonymity and confidentiality (to minimise harm) and maintaining appropriate levels of control over the research process (to help maximise benefits and minimise harm). In addition to the aforementioned considerations of informed consent, the unique login provided to participants ensured that only the participant, researcher and health professional could view the participants' data. The potential lack of control means that extra monitoring precautions may be needed within online research since it is not possible to evaluate participants' concerns remotely. Therefore, the programme was supervised by a clinical

psychologist who judged whether the programme was having any negative effects on the participant, and would have terminated the sessions if they were felt to be causing the participant harm.

3.3 PATIENT AND PUBLIC INVOLVEMENT (PPI)

The INVOLVE website (2015) defines PPI as "public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them". Individuals involved in PPI may contribute towards definition of research priorities or the development of research materials. Brett, Staniszewska, Mockford et al (2014) conducted a systematic review into the effects of PPI in health research and identified both a number of benefits and challenges. Benefits relate to ensuring relevant topics are investigated and identifying suitable outcome measures, as well as improving access to the research community. However, Brett et al (2014) also refer to the practicalities of recruiting individuals for PPI groups, which can be costly and time-consuming. Similar to recruitment for the research itself, it can be particularly difficult to recruit from hard-to-reach groups, and a lack of attendance to planning meetings can also present problems. Despite these potential difficulties, PPI was considered to be important in the present research, to further ensure that suitable and relevant outcomes were being examined. It also ensured that the design of the studies was not over-burdensome or consisted of inappropriate timing or methods of data collection. The relevant parties, such as the burn camp organisers, were asked to provide feedback before ethics approval had been sought. This ensured that the finalised research design was suitable before being subjected to ethical approval.

While PPI with CYP and parents was considered for the burn camp studies, it was not pursued for several reasons. First, the organisers of the burn camps were unwilling to provide contact details for any of the CYP or their families before they had consented to take part in the study. As with the views of camp organizers in research involving cancer camps (e.g., Epstein et al, 2006), they felt that the CYP at camp were frequently asked to take part in research, and while they fully supported the current study they did not create any more 'work' for the participants than was strictly necessary. The burn camp staff act as gatekeepers to the families and in this case exhibited a degree of 'gatekeeper bias' (Groger, Mayberry & Straker, 1999) by choosing not to facilitate contact between the researcher and CYP during the initial stages of the study. While the researcher initially sought to involve CYP and their families throughout the study, the research was dependent on the support of the organisers and so certain compromises had to be made. For example, another compromise was reached regarding the outcome measures used in the study, as the organisers originally wanted to adapt the questions, although after it was explained that

these were standardised measures the organisers accepted their use in their current format. The researcher considered asking CYP who were not involved with the burn camps to take part in PPI; however it was decided that this group would not be representative of the study population and would therefore not be in a position to offer guidance on issues relating to the research.

Study 1A involved photo-elicitation (using photographs as prompts within interviews) and it has been suggested that institutional support is essential for conducting studies using this technique (Clark-Ibanez, 2004). Therefore, during this study the researcher was also in discussion with organizers of the burn camp (Frenchay After Burns club) throughout the planning of the study to make sure that the study was relevant and did not interfere with the structure of the camp. Similarly to the study above, a presentation outlining the research was made to the FAB club committee, which allowed a thorough discussion of the proposed research and allowed the committee to ask questions and make suggestions. Additionally, the researcher attended the camp again in an attempt to establish rapport before requesting interviews. The perceived effect of participation at the camp is discussed in more detail in Appendix 2.

In study 1B the researcher worked collaboratively with the organisers of Burns Camps UK, who run the National Burn Camp, throughout the entire planning and implementation of the study. This ensured that the research was considered appropriate and valid, whilst not disrupting the running of the camp. The researcher volunteered at a burn camp before starting the study, to gain a better understanding of how camps are run and decide on the most suitable way to carry out the research whilst at the National Camp. The researcher also made a presentation to the British Burn Association Burn Camp Special Interest Group, comprised of burn club leaders from around the country, which outlined the proposed design of the study and the measures to be used. This presentation was then followed by a group discussion, to allow the members to ask questions about the research and make suggestions. For example, it was during this meeting that the decision on how to collect data while at camp was made. Finally, the researcher attended the whole of National Camp as a volunteer, in order to get to know the children and build rapport. This was considered to be an essential part of the study, so that the children would not feel they were being asked to participate in research by a stranger (the implications of this are discussed further in the reflexive section, Appendix 2). It also allowed the children to discuss the study with the researcher prior to data collection on the final day. Many of the children were initially reluctant to complete the questionnaires while at camp, but once the purpose of the study was explained to them they became more willing to take part.

For study 2, PPI work was conducted with the clinical psychologists who would be taking part in the study. The researcher attended the British Burn Association Psychosocial Special Interest Group meeting to present the proposed research, which was followed by a discussion. The psychologists were also given the opportunity to try out the online YP Face IT programme, and the most appropriate methods for supervising patients and collecting data were agreed upon. PPI was not conducted with CYP and their families as previous research (Williamson, Griffiths, Harcourt & Cadogan (2015) has conducted a full examination of the acceptability of the programme to CYP with other types of visible difference (non-burns), their parents and health professionals (discussed in more detail in section 6.1).

Study 3 involved interviews with health professionals. Before any research took place, the researcher attended the British Burn Association Psychosocial Special Interest Group to discuss the proposed study and gauge interest from the group. An outline of the programme was given, followed by a discussion of the aims and proposed methods of the study. The health professionals confirmed that they felt there was a dire need for the research to be undertaken, and agreed that they would like to be given the choice to take part in the research either face-to-face or over the telephone. This meeting allowed the health professionals to voice their concerns, which mainly related to issues of confidentiality and anonymity as they are a close-knit group. Therefore, several health professionals expressed worries about being able to talk about their experiences candidly. The researcher was able to reassure the health professionals of the measures that would be taken to ensure confidentiality and anonymity, which the group said increased their willingness to take part.

3.4 CHALLENGES OF CONDUCTING PSYCHOSOCIAL RESEARCH WITHIN PAEDIATRIC BURNS

The National Children's Bureau (Shaw, Brady & Davey, 2011) makes a number of general recommendations about suitable methodology for research with children. For example, researchers should try to ensure an informal atmosphere and inform the child that the data collection process is not a test. There are also specific issues to consider when conducting quantitative or qualitative research with children. For example, Shaw et al (2011) suggest that children under 12 do not complete self-report questionnaires unless appropriate support is available in case a child struggles. It is also important to consider the age range and individual circumstances of participants when deciding upon outcome measures appropriate for specific research questions.

While the above guidelines should apply to all research with CYP, there are also special considerations that should be made when conducting research with children from hard to reach or vulnerable groups. These are now considered in relation to the current research. Doherty, Stott and Kinder (2004, p4) define hard-to-reach groups as "minority groups", those who are "service resistant" or those "slipping through the net". According to the Hospital Episode Statistics around 3,750 CYP under the age of 15 are admitted to hospital with burn and scald injuries each year (The Child Accident Prevention Trust, 2012). CYP with burn injuries may therefore be regarded as a hard-to-reach group as they make up a minority of the population, meaning that the potential pool of participants is much smaller than research with larger populations. However, it appears that burns research is often further impeded by particularly high nonparticipation or attrition rates (Dyster-Aas, Kildal & Willebrand, 2007). Research has indicated non-participation and attrition rates of up to 20% and 80% respectively (McQuaid & Barton, 2003).

Burn injuries are more common in households with a lower socioeconomic (SES) status (Park, Do Shin, Kim et al, 2009), which can be defined by a number of factors such as ethnicity, large families and single parents, low income and unemployment, illiteracy or low levels of education, or not owning a home or telephone (Edelman, 2007). These factors can make it more challenging to involve CYP and their families in research. Clark (2008) reports that a common reason for non-participation relates to practical considerations such as the time and cost involved in participating, and single parents or parents of large families in particular may simply not have the time or resources to permit their children to take part. Illiteracy and low levels of education may hamper or influence parents' understanding of research and its perceived importance, while a lack of a permanent address or telephone makes it much harder for researchers to contact parents (McQuaid, Barton & Campbell, 2003). As CYP's participation is usually dependent on their parents, both to provide informed consent and for practical reasons (Broome & Richards, 2003), this may mean that a large number of potential participants are being overlooked.

One suggestion for conducting research with hard-to-reach groups is to employ web-based interventions and utilise online methods of data collection. While online research requires researchers to possess the necessary technical skills to use online data collection tools, it can also improve access to hard-to-reach groups, particularly those who are geographically diverse (Wilkerson, Iantaffi, Grey, et al, 2014). Web-based research has also been found to improve participation in research from ethnic minorities (Joseph, Ownby, Havstad, et al, 2013). While paper-based surveys often produce poor response rates, particularly in hard-to-reach populations, several strategies may improve uptake rates, such as personal engagement with researchers, utilising surveys with colourful covers and sending introductory letters (Mutrie,

Foster, Estabrooks, et al, 2010). All of these strategies were implemented in study 1B which involved the completion of paper-based measures by young people attending a burn camp.

Another strategy for increasing participation in research across hard to reach groups involves the use of 'snowball' or 'chain referral' sampling. Snowball sampling refers to a technique where existing participants are asked to identify further participants through their social network, who are also then asked to identify further participants (Atkinson & Flint, 2001). Chain referral sampling builds on this technique by focusing on multiple social networks simultaneously (Penrod, Preston, Cain & Starks, 2003). This may be an effective method for research with CYP with burns, as networks may be generated through meeting staff and other burns survivors through burn camp and club programmes (British Burn Association, 2016a), and was used in studies 1A and 1B. Respondent driven sampling (RDS) builds on snowball sampling as it also involves participants actively recruiting other participants to the study. However unlike snowball sampling RDS uses a coupon management system, whereby participants are provided with a number of coupons to recruit others. These coupons are tracked by the research team who pay the participant for each new recruit, who is then provided with coupons of their own (Marpsat & Razafindratsima, 2010). While this method may increase recruitment through personal networking, recruitment can be time-consuming (Semaan, 2010).

An alternative sampling method is time-location sampling (Marpsat & Razafindratsima, 2010) which involves the use of locations which are not often used by those other than the target population, such as services providing accommodation to the homeless. This method can help to increase the sample of participants meeting inclusion criteria and generalise findings to the relevant population (Semaan, 2010). This method may be applicable within the burns population, as burn camps and clubs do not tend to be used by those other than young people with burn injuries. The importance of utilising existing relationships with organizations related to the specific demographic has been also been noted, thought to improve participants' perceptions of research as more credible and acceptable (Altpeter, Houenou, Martin, et al, 2011). Relationships with burn club leaders were utilised within study 1B.

It is, however, important to recognise that time-location sampling may limit participants to those who are more visible or active. This is acknowledged within the discussion section of study 1B, which utilised burn clubs around the country to recruit participants. It is important to remember that the factors which influence participation in research could also influence the likelihood of attending a burn camp or club. Alternative strategies need to be employed to recruit participants

who do not attend clubs or camps, such as liaising with health professionals in burns services to review lists of past patients, used in study 2.

There are a number of issues to be considered when implementing snowball or chain referral sampling methods such as the non-random nature of the sampling method resulting in limitations to the validity of the research (Cohen & Arieli, 2011). 'Gatekeeper bias' can occur when a participant chooses not to facilitate contact between the researcher and certain other individuals who may have been suitable for the research (Groger, Mayberry & Straker, 1999). McQuaid et al (2003) suggest that parents may refuse participation for a number of reasons. For example, if parents feel that their child is coping well then they may not appreciate the benefit of taking part, while if they feel their child is not coping well it could deter them from wanting to take part. Snowball sampling also runs the risk of participants' personal information being disclosed to others (Sadler, Lee, Lim & Fullerton, 2010), so researchers must assure participants that their data will be protected. This can be achieved by following the ethical guidelines outlined above in section 3.2 and 3.3.

Gatekeepers are another important element to consider when conducting research with CYP. A gatekeeper refers to an adult who can control or limit a researcher's access to the participants, and can help to ensure that participants are not subjected to any potentially harmful research (Coyne, 2010). Although gatekeepers are important for keeping young participants safe, they are also often able to help researchers with recruitment. Gatekeepers with specific knowledge of the study population may be able to suggest potential participants or at least pass on research information to those who they feel may be interested. Gatekeepers in burns research may be hospital staff or parents, or may be involved with burns patients in other ways, such as through camp or club programmes. Patel, Doku and Tennakoon (2003) highlight the contribution that health professionals can make as gatekeepers, particularly when research takes place in a clinical setting. Health professionals may also be willing to provide the participant with information about a study and take consent, which prevents the researcher from accessing contact details of participants who do not wish to take part, and ensures their privacy is protected.

Although gatekeepers can be an invaluable resource within research, it is important to remember that the ultimate decision for children to participate in research lies with their parents/carers which, as discussed above, may act as a barrier to participation. Alternatively, they may actively encourage participation. The studies in this thesis involved two sets of gatekeepers, as the researcher had to first liaise with burn camp staff (studies 1A and 1B) and clinical psychologists (study 2) to identify eligible participants for the research. Therefore, these contacts could be

considered gatekeepers to parents/carers, who then acted as gatekeepers for their children. This strategy meant that strong communication was imperative, to ensure that information was conveyed through burn camp staff/clinical psychologists, to parents/carers, and ultimately to CYP with burn injuries.

Even when participants are successfully recruited into studies, there are additional issues to consider around future research. Once researchers identify participants who are willing to take part, it may be tempting to approach the same participants for any additional research. However, this can lead to the danger of 'research fatigue' which occurs when individuals who have been 'over-researched' become unwilling to take part in further studies (Clark, 2008). Research fatigue may be of particular consequence within hard-to-reach or limited groups as they are approached for participation more often than other groups (Pagano-Therrien, 2013). Although there is a lack of research into research fatigue within the burns population, it has been suggested that the concept of research fatigue in general may relate to factors that can be broken down into subjective interest in the research topic and mistrust of the researcher (Way, 2013).

Clark (2010), for example, suggested that some of the factors which facilitate research engagement are subjective interest, curiosity or enjoyment. One strategy for piquing the interest and curiosity of participants, or aiming to involve participants in a research project which they find enjoyable, may be to use novel and innovative methods. Rather than relying solely on methods such as interviews or standardised measures, research could incorporate technology-based methods such as blogs or text messages, or visual methods such as photography, drama or scrapbooking (Harcourt, 2012). In addition to considering a range of research methods to achieve the best possible outcomes, children may actually feel more comfortable using visual methods than language-based methods (Prosser & Burke, 2011). Adolescents have reported a greater willingness to take part in research involving photography because they thought it sounded "fun" (Smith, Gidlow & Steel, 2012) while McCarthy and Sebaugh (2011) found that the main reason children chose to return to a therapeutic scrapbooking class was that they enjoyed the classes. While methods such as photo-elicitation can still involve interviews, they may help to divert the perceived scrutiny of face-to-face techniques for CYP with burns who are very self-conscious about their appearance.

Finally, participants may be suspicious of the true purposes of the research and the researcher's intentions (Sukarieh & Tannock, 2013). For example, McQuaid et al (2003) found that parents of burn-injured children suspected an alliance between researchers and social services, and were far less willing to allow their children to participate in research if they had had previous contact with

mental health or social services. Furthermore, Clark (2008) suggested that a lack of understanding about the research methods used may promote indifference or resistance in participants, reporting responses from participants such as "why are you asking me this, I don't know" (p962). This demonstrates how important it is for researchers to remain transparent throughout the research process, to ensure that participants can appreciate the true purpose of the research and understand why the research is being conducted in the way that it is.

Modi et al (2014) raised the issue of conducting research with particularly vulnerable children. CYP with burn injuries may be considered a vulnerable group due to the traumatic nature of burn injuries. Van Loey and Van Son (2003, p247) describe a burn injury as "among the most extensive and frightening injuries" in existence. It is therefore essential that researchers consider any potentially harmful implications of asking participants to recollect traumatic experiences (Johnson & Benight, 2003).

Research with young burn patients can be particularly sensitive due to the risk of non-accidental injury/neglect (NBCR, 2001). Victims of intentional burns may be children, the elderly, the infirm or those with mental health issues, or individuals held in captivity. Intentional burns on children are usually inflicted by a parent/carer or a sibling (Greenbaum, Donne, Wilson et al 2004). The incidence of non-accidental burn injuries varies between studies. Maguire, Moynihan, Mann et al (2008) conducted a systematic review of the burns literature over a 56-year period, and determined that between 1-35% of children treated for burns in hospital may have been victims of deliberate injury. In addition, severe burns were present in around 10% of children suffering from physical abuse. The USA was found to have the highest incidence of non-accidental injury, and the UK the lowest.

There is a degree of ambiguity surrounding the phrase 'non-accidental injury' relating to burn injuries, as it may incorporate cases of both deliberate injury/abuse, as well as injuries resulting from neglect. A study by Chester, Jose, Aldlyami et al (2006) discovered that although research tends to focus on cases of intentional burn injury, burns caused by neglect are actually far more prevalent. They assessed 440 children who had been hospitalised in the West Midlands with burn injuries over a two-year period and concluded that over 9% had been the result of neglect, compared to less than 1% as a result of abuse.

It may be very difficult to distinguish between a burn which is a result of a genuine accident and one which results from neglect (Greenbaum et al, 2004). There are a number of features which may be indicative of an intentional injury. It is important to consider the history of the child, if

known. Abused children tend to be of pre-school age or younger, and may display signs of apathy or other inappropriate behaviours (Toon et al, 2011). However, it is important to remember that young children who have sustained a burn injury may suffer from symptoms of ASD or PTSD, so traumatized behaviours are not necessarily confirmation of abuse.

While accidental burns, such as spills, tend to display a similar pattern decreasing in severity as it moves down the body (Hornor, 2005), children who have suffered from intentional injuries may be more likely to display burns on both hands or both legs (Andronicus, Oates, Peat et al, 1998). Intentional burn injuries also tend to be far more severe than accidental injuries, and result in longer hospital stays and higher mortality rates (Toon et al, 2011). Risk factors include single parent families, parents who abuse drugs, and at least one previous entry on the child protection register (Chester et al, 2006).

Researchers should also be aware that some burn injuries may also result from deliberate self-harm (DSH). Although it is difficult to know how many CYP self-harm, it is thought that around 13% of CYP aged 11-16 may try to deliberately harm themselves, using methods including cutting or burning (Selfharm, 2016). DSH may also be indicative of other issues in a CYP's life, such as anxiety and depression (Ross & Heath, 2002), disassociation (Zoroglu et al, 2003), negative self-esteem, emotional distress or anger (Laye-Gindhu & Schonert-Reichl, 2005) or undesirable life events (Garrison et al, 1993). However, placing the responsibility of recognising the signs of DSH onto researchers may be unreasonable, and is another instance where collaboration with clinicians is essential.

3.5 CONCLUSION

The first three chapters in this thesis examined the psychosocial impact of a burn injury on CYP and their families, and explored how these effects can be explained using a variety of models. The need for further evaluation of interventions was demonstrated, and consideration was made of the most appropriate methodology to conduct this evaluation, along with relevant ethical issues. The challenges of conducting psychosocial research within paediatric burns were taken into account, and all of these issues were carefully considered when planning and conducting the research. The necessity of employing mixed methods and various research techniques to meet the complex range of needs of CYP with burns are now evident. The following four chapters are dedicated to the evaluation of the aforementioned range of interventions.

CHAPTER 4. STUDY 1A: USING PHOTO-ELICITATION TO EXPLORE THE EXPERIENCES OF YOUNG PEOPLE WITH A BURN INJURY AND THEIR FAMILIES AT A FAMILY BURN CAMP

4.1. INTRODUCTION
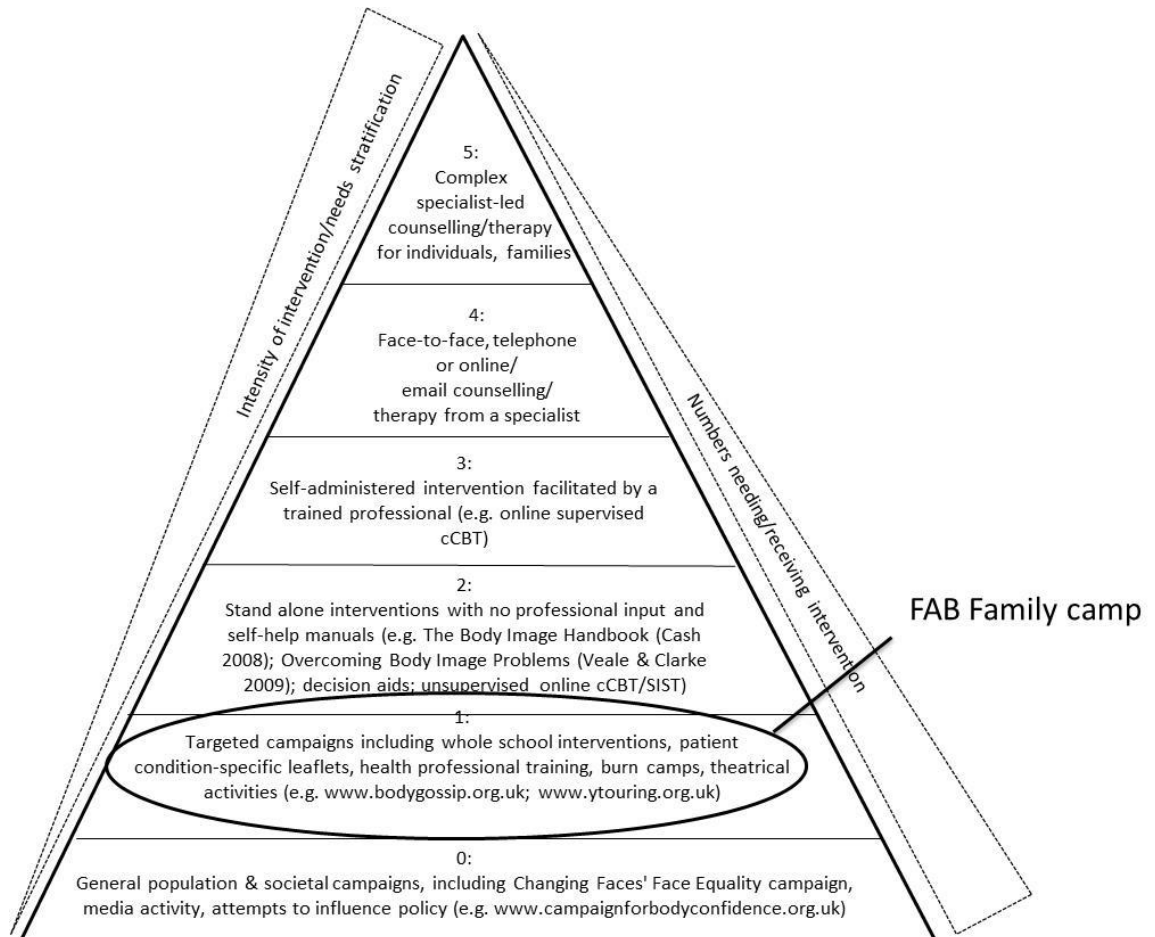
Figure 9 The location of FAB family burn camps on the CAR pyramid of appearance-related interventions

As discussed in section 1.4.2, research has indicated that parents of children with burns also exhibit clinically significant levels of psychosocial distress following the injury (Phillips & Rumsey, 2008). Siblings of burn patients also report feeling upset by the injury, and a number of other difficulties relating to the accident itself, the teasing of their brother or sister by others, and missing their parents while their sibling is in the hospital (Phillips, Fussell & Rumsey, 2007). It has been suggested that it is essential for the entire family to be included in the patient's treatment, as the patient's wellbeing tends to depend on the wellbeing of the family as a whole (Blakeney, Robert & Meyer, 1998). Therefore, the current study explored the entire family's experiences at a specialized family burn camp.

There is a distinct lack of published research into the effects of family camps within the burn population, although this has been investigated in other populations. Cancer camps have similar goals to burn camps, including improving coping skills, emotional adjustment, social skills and self-esteem (Martiniuk, Silva, Amylon & Barr, 2014). While some cancer camps only involve the patient, it has been suggested that camp should be offered as a therapeutic intervention to both patients and their healthy siblings (Hancock, 2011). Peer support camps for siblings of children with cancer have demonstrated a number of psychosocial benefits using pre-post measures including improvements to anxiety, depression, social competence, self-perceptions, and perceived impact of the illness (Sidhu, Passmore & Baker, 2006; Kiernan, Gormley & MacLachlan, 2004). While these studies demonstrated the extent of benefits that may be available to siblings attending camps, the solely quantitative nature of the research prevented further exploration of these effects, so it is unclear specifically what siblings found helpful. However, similar results have been found using alternative methods such as Likert scales and open-ended questions to investigate a camp for both children with cancer and their siblings. Wu, Prout, Roberts et al (2011) suggested that camp provided recreation, respite and peer support. More specifically, campers discussed the opportunity to have a break from their everyday lives, the supportive environment of camp, and a sense of belonging, while parents referred to the level of peer support available, and the increase to confidence and independence that their children experienced.

A more innovative technique was employed by Packman, Mazaheri, Sporri et al (2008) who implemented projective drawing to measure the benefits of camp for siblings of children with cancer, and also explored parents' perceptions of the camp. Siblings and parents were asked to draw both a whole person and a picture of everyone in their family doing something, which were scored to ascertain whether the pictures contained any emotional indicators (EIs) of emotional disturbance. Results indicated that EI scores decreased significantly for both parents and siblings after the camp and the authors recommend such the use of creative techniques within further therapeutic camp research. It is acknowledged that studies with more recognisable designs and large sample sizes may have a greater impact in terms of recognition from governing bodies, but it is also important to conduct research which is engaging to participants.

A research gap when reviewing the cancer camp literature is that although several studies explore parents' perceptions of the camps attended by their children, there is limited research investigating whether parents may also benefit from camp attendance. In fact, a systematic review by Martiniuk et al (2014) found that of 20 studies examining the effects of cancer camps, only one study involved a camp which was actually attended by parents (Barr, Silva, Wong et al, 2010). While Barr et al found that families who chose to attend camp scored significantly better

on measures of coping, family function, social support, and HRQL post-attendance, it is unclear whether families who are better adjusted attend camp, or whether camp attendance had led to the higher scores on the measures. Further research would benefit from a deeper exploration of families' experiences at camps.

Although previous qualitative research has been conducted into burn camps (see section 5.1), these studies have used traditional methods such as focus groups (Cox et al, 2004; Williams et al, 2004) or evaluation forms with open-ended questions (Maertens & Ponjaert-Kristoffersen, 2008). Based on Packman et al's (2008) recommendation regarding the use of novel and creative methods of data collection within therapeutic camp research, a number of data collection methods were considered when planning the current study, including drawing, scrapbooking and photography. Photography was chosen as the most appropriate method as it was thought that it could be incorporated into the families' experiences at camp, rather than detracting any time away from their activities. Furthermore, photo-elicitation has been successfully used to evaluate outdoor activity programmes in a number of previous studies as described below. Photo-elicitation involves the use of photographs as a guide during interviews, thought to elicit rich and meaningful data from participants (Frith & Harcourt, 2007). The aim is to extract the significance of the images to the participant (Prosser & Burke, 2011) and can be used to give a 'voice' to participants (Harding, Harding, Jamieson et al, 2009). Therefore this method may be enlightening when speaking to children or families who may not usually get the chance to express their views.

Photo-elicitation has been employed slightly differently across studies. For example, a study by Epstein et al (2006) presented children at a cancer camp with 13 photographs representing different aspects of the camp, such as the rock wall and the view of the lake, and asked children a set of pre-determined questions about each photograph. They found that allowing the children to take the lead in the interview allowed them to discuss their feelings about the camp in a relaxed and comfortable setting. However, as the researchers themselves took the photos, they speculated on whether they had missed an opportunity to discover what the children themselves would have photographed.

Other studies have provided children with cameras and asked them to take their own photographs at camps for CYP with heart disease (Bultas, Steurer, Balakas et al, 2014), outdoor education experiences (Loeffler, 2004) and residential outdoor programmes (Smith et al, 2012). CYP in these studies reported a wide range of benefits including friendship and inclusion in a peer group, fun, and the safe environment of the camp. The instructions in these studies varied as Bultas et al provided the CYP with cameras and asked them to take pictures to show why the

camp was "special", which may have influenced the type of pictures taken, as children may have felt discouraged from taking pictures of things they did not like. Furthermore, this may have limited children's responses, as Bultas et al reported that their interviews concluded within five minutes and lacked depth. The authors of the other studies provided the children with more open instructions, such as asking them to take pictures to "show what school camp was like" (Smith et al, 2012, p372). Loeffler (2004) stated that student photography during outdoor experiences is essential due to its ability to keep outdoor experiences alive long after they have ended, while Smith et al concluded that the use of cameras and photographs was an effective way to engage CYP in research.

These studies demonstrate that photo-elicitation is an effective method for evaluating outdoor activity experiences, including those relating to therapeutic camps, and was therefore selected as an appropriate technique for the current study. Given the lack of previous research into family camps, the specific research question underpinning this study was:

What are families' experiences of attending a family burn camp?

4.2. METHOD

4.2.1 Design

Bishop (2015) suggests that qualitative techniques may explore a poorly understood phenomenon, which could generate hypotheses to be tested with a subsequent quantitative design. As family camps are a new area of research, a qualitative method was chosen to explore the experiences of the families attending. The study employed photo-elicitation techniques, which was selected for the current study for a number of reasons. It is thought that visual methods such as photography or drawing can facilitate communication between a researcher and participant (Clark-Ibanez, 2004). In particular, photographs can be used as a methodological tool to promote conversations with CYP (Dean, 2007), who may otherwise be reticent to discuss personal feelings with a researcher. The success of an interview may rely on the extent to which a researcher can build rapport with CYP (Coad, Gibson, Horstman et al, 2014), and it is thought that photographs may help to achieve this (Lassetter, Mandleco & Roper, 2007). Harper (2002) reviewed photo-elicitation interviews covering a wide range of topics including explorations of family dynamics, sports, self-concept and technology, and concluded that a photography element led to more information from participants, and that this information was far richer than that obtained from word-only interviews. This lends support to the suggestion that techniques aimed

at capturing children's interest are more likely to generate rich and representative data about their experiences (Darbyshire, MacDougall, & Schiller, 2005).

Focus groups or group interviews can be particularly beneficial in certain circumstances, such as when interaction among participants is required, when participants are co-operative with one another and when participants may be hesitant to provide information in a one-to-one interview (Creswell, 2007). Therefore, conducting the interviews with each family group was considered to be particularly appropriate for the current study for a number of reasons. As the research aimed to investigate the family's collective experience at burn camp the participants were presented with the camera and asked to take pictures of their weekend as a family. Therefore, instead of interviewing individual family members, the family was interviewed as a group, suggested to be the only method to produce comprehensive family data (Åstedt-Kurki, Paavilainen & Lehti, 2001). As some of the participants were as young as eight years old, it was also thought that interviewing the family group as a whole would help reticent participants to feel more confident about speaking to the interviewer.

While family interviews are intended to explore the experiences of the family unit as a whole, it is still important to ensure that individual family members are given a chance to 'have their say' and 'really be heard' (Donalek, 2009) as this can ensure that each family member feels valued. The researcher must take care to treat responses from individual participants with equal importance (Lang, Marvel, Sanders et al, 2002). The researcher gave each participant an equal opportunity to talk, asking for individuals' perspectives on particular issues if necessary to ensure each family member felt as included as possible. However, there were a number of additional considerations to be made surrounding this method.

The families were asked where they would like the interview to take place and all chose for the researcher to interview them in their homes. Therefore, the researcher was aware that multiple interruptions may occur. Irwin and Johnson (2005) suggest that researchers should accept that these interruptions are a natural part of a child's social environment, and that trying to control the environment may actually impede a child's responses. Therefore the researcher remained patient when interruptions did occur and using the photographs as prompts was found to be a useful tool to help get the interviews back on track. An issue which may be far more prevalent when interviewing a family unit than a focus group consisting of strangers is the conflict that may arise between family members (Donalek, 2009). The researcher avoided taking sides or attributing blame (Lang et al, 2002) and acknowledged the differing opinions within the family where necessary, by reminding participants how valuable it was to hear honest and varied opinions.

However, when the conversation started to move off topic, the researchers gently re-directed the conversation to the photographs to get the interviews back on track.

4.2.1.1. Structure of the camp

The family camp in the current study was run by the Frenchay After Burns (FAB) Children's Club, an independent charity which aims to provide support to CYP with burn injuries and their families across the South West of England (Frenchay After Burns Children's Club, 2015). CYP are invited to join FAB club after receiving treatment from the South West Children's Burns Service. FAB's family burn camp aims to bring together families who have been through similar experiences, to help burn-injured children to build confidence and self-esteem and to provide family members with the chance to meet others who have been in similar situations to themselves. The camp that was the focus of the current study has been running annually for five years, and was held over three days at an activity hotel in South West England at which members of the general public also stay.

The camp provided access to the full range of activities offered by the hotel including archery, air pistols, snooker, table tennis, mini golf and ten pin bowling. There was also a craft centre providing a range of activities including card making, candle making, pottery, silk painting and embroidery. A pool complex provided swimming pools, steam rooms, saunas and flume rides, and a hydro spa relaxation pool area with jets, air seats, massagers and scented saunas. There were also areas designed specifically for families, such as the fun house with slides and ball pools, both an indoor and outdoor play area, and a game zone including consoles, air hockey, table football and dance stages.

Timetables and sign-up sheets were provided in the main reception area to allow families to sign up to the organised activities. The structure of the camp was very flexible and allowed each family to decide how they wanted to spend their time. Families arrived at camp on the Friday evening, during which a group activity (bowling) was organised to encourage the families to get to know each other. For the remainder of camp, families could sign up to any activities that they chose and tables were reserved at meal times so that the families and volunteers could all sit together.

A group session for parents/carers was held on the second day, while camp volunteers took the children to the craft centre to paint plaster models, followed by a supervised play session in the funhouse. The parent/carer session, run by an experienced clinical psychologist, aims to provide an opportunity for participants to informally discuss their experiences with others who are in a similar situation, rather than a structured therapeutic session. The psychologist running the

session was there to facilitate the discussion between the parents and provide support if necessary. On the final day of camp the families and volunteers participated in the activities provided by the hotel, tending to break out of the family groups as friendships had been made.

4.2.2 Participants

Eight families were invited to the FAB family camp, and seven attended. All of the families attending camp were eligible to participate in the study, and six of these families (21 family members in total) elected to take part. The ages of the children with burns ranged from 8-13 years and the time since injury ranged from three months to 11 years. The ages of the non-burned siblings attending camp ranged from 2-14 years, however one sibling chose not to take part in the interviews and the two-year old was not involved. Therefore the ages of the siblings who took part in the interviews ranged from 8-11. The family groups are outlined in Table 2. The child with the burn (index child) is listed first, followed by the other family members. All names are pseudonyms.

Name	Family member	Age (if under 18)	Size of burn (TBSA)	Time since burn
Jonathan	Index child	10	4%	1 year
Pete	Father			
Rachel	Mother			
Ethan	Brother	14		
Chloe	Index child	10	0.5%	3 months
Leah	Mother			
Amy	Aunt			
Ollie	Index child	8	5%	6 years
Sarah	Mother			
Jack	Father			
Kieran	Brother	11		
Emily	Index child	11	Unknown	Unknown
Kathy	Mother			
Megan	Index child	12	5%	11 years
Hannah	Mother			
Nathan	Brother	9		
Lucy	Index child	13	1.5%	1 year
Helen	Mother			
George	Father			
Tilly	Sister	8		
Ben	Brother	2		

Table 2 Structure of the families who attended camp and participated in this study

4.2.3 Materials

Each participant group (family) was provided with a disposable camera at the start of camp. It was considered important to provide families with a disposable camera rather than ask them to use phones or digital cameras, as many burn injuries occur in families with a low socio-economic status (see section 3.5). Therefore, this technique was used to reduce any feelings of discomfort if families did not have access to digital cameras, or to prevent comparisons between mobile phones.

Open-ended questions were used to guide the interview process (see Appendix 7). Previous research using photo-elicitation has included questions about each individual image, in an attempt to uncover meaning from the participants. Questions may relate to what is happening in an image and why the picture is of importance to participants (Fleury et al, 2009) or how participants feel in response to the image (Radley & Taylor 2003). The current study asked a number of probing questions about each image to uncover as much detail about each image as possible. Further open-ended questions relating to the purpose of the study were also included as follow-up questions, which may especially help with reticent participants (Mandleco, 2013). Participants were also asked about their experiences of taking part in the photography study. Lassetter, Mandleco and Roper (2007) finished their interviews by asking participants if there were any photographs that they wished they had taken, but did not. Lasseter et al discovered that some of the most meaningful data from the interviews emerged from this question, probably because the researchers had built rapport and trust with the participants by this stage of the interview, encouraging them to be more open and honest. Therefore, the researcher also adopted this approach (see Appendix 7). Feedback on the interview schedule was provided by the supervisory team and camp organisers prior to the interviews taking place.

4.2.4 Recruitment and Data collection

Several pre-camp discussions were held between the researchers, burn camp organisers and FAB club committee (see section 3.4) and University Research Ethics Committee (UREC) approval was obtained for this study. Letters were sent out by FAB to all members of the club (around 150 families) to gauge interest in the family camp. Fourteen families responded with places given to the eight families who had never attended a family camp before. One month prior to camp, the organisers sent information packs and consent forms on the researcher's behalf to each family that had been invited to attend. Once at camp the researcher introduced herself to all of the families to determine which families wanted to take part in the study, and to ensure they

understood the nature of the study and had the opportunity to ask any questions. Consent and assent were then sought from the parents/carers and CYP respectively. All family members from the participating families then signed the consent forms, including the siblings with the exception of the two-year old.   Each family was given a disposable camera with which to photograph their experiences during the weekend. The researcher explained that the camera was for the whole family to use, and that additional cameras could be provided if required. Families were not restricted from using their own cameras as well, but were asked to use the disposable cameras to produce an overall picture of their weekend.

It has been suggested that research involving photographs may create technical challenges if the use of a camera is unfamiliar (Johnson et al, 2012). Although modern-day children are adept with technology to such an extent that most are capable of producing good quality photographs (Prosser & Burke, 2011), time was spent showing each family exactly how to use the camera until they felt confident with the equipment. In addition, the researcher spent the entire weekend at the camp in the role of a volunteer which meant that the families had the opportunity to ask follow up questions or discuss the study further if necessary. While the researcher did not engage in the activities which participants took part in within their family groups, she participated in the group activities such as bowling and the craft centre/funhouse with the children while the parents attended their group session. A reflection on the researcher's attendance at camp is provided in Appendix 2.

On the final day of camp the researcher collected the cameras from each family as they left and had the photographs developed. Examples of the participants' photographs can be found in Appendix 9. In accordance with Fleury, Keller and Perez (2009), two sets of photographs were developed, one set for the researcher to retain as part of the data set and one set for each family as a gesture of appreciation for taking part in the study. Considerations were given to any ethical issues surrounding photographs of people who had not consented to be a part of the study, so the photographs were carefully reviewed by the researcher before being sent out to the families. Dockett and Perry (2005) deleted photographs including people who had not given consent to be in the study. However, this was not necessary in the current study as all of the photographs only showed other families who had consented to be in it.

Photographs were sent out in advance of the interviews, to allow the families to decide whether there were any pictures they particularly wanted to include/exclude during the interviews. It was acknowledged that participants would probably end up with a large number of photos or may take a number of pictures of the same image (Mandleco, 2013). Capello (2005) asked children to

separate pictures that showed "something important" and Loeffler (2004) asked participants to choose 3-5 photographs that best represented the meaning of their experience. As participants were interviewed in their family groups the researcher asked them to select around 10 salient photographs to discuss. The researcher then travelled to the families' homes to conduct the interviews. Photo-elicitation interviews can vary in length, for example Smith et al's (2012) interviews ranged from 23 to 53 minutes, whereas Clark-Ibanez's interviews lasted from 30 minutes to 2 hours. As the interviews in the current study involved the entire family the researcher was flexible about the length of the interviews, to ensure each family member had the opportunity to express their views.

4.2.5 Data analysis

Photographs on their own cannot be considered to be data until their meaning is extracted and decoded (Cruickshank & Mason, 2003). This may occur through interviews with participants (e.g. Harding et al, 2009), through analysis of the content within the photographs themselves (e.g. Sharples, Davison, Thomas & Rudman, 2003), or using a combination of both methods (Fleury et al, 2009). It has been suggested that analysing the content of the pictures alone is restrictive as it effectively separates the participant from the objects in the photograph (Radley & Taylor, 2003). The true meaning of photographs within research is thought to stem from the joint interpretations of them by the researcher and participant together.

While analysis of both the photographs and the interview data was considered, this was rejected for several reasons. Although the current study involved the use of photographs, photo-elicitation does not traditionally involve a content analysis. Harding et al (2009) advised that even when photographs are not analysed in a systematic way, they can be effective tools within interviews, as they allow researchers to understand the views of participants and engage CYP in research. The majority of the aforementioned studies of outdoor activity programmes did not involve a content analysis of the photographs themselves, instead focusing on the meanings within the images. Loffler et al (2004) did conduct a content analysis which grouped the photographs into four categories: scenic natural beauty, pictures of friends/group members, pictures of self, and significant personal moments. However, the content of the photographs is not mentioned by the authors again, as the majority of the paper focuses on participants' subjective interpretations. It is thus difficult to see what the analysis brought to the study. Smith et al (2012) specifically referred to the apparently mundane nature of the photographs in their study before they were discussed in the interview. Therefore, as with the aforementioned studies exploring the experiences of

camp programmes, the focus in the current study was based on not what the participants photographed but what the photographs meant to them.

Photo-elicitation studies involving families may take a number of different forms. Previous family photo-elicitation interviews have involved separate interviews with young people and their parents (e.g. Lachal, Speranza, Taieb, et al, 2012), a parent responding on behalf of the entire family (e.g. Johnson, Sharkey, McIntosh, et al, 2010), or using photographs taken by one family member and then asking the others to take part in interviews (e.g. Gram, 2005) or complete questionnaires (e.g. Binn & Harris, 1991). These studies therefore lacked a comprehensive family perspective, something which the current research aimed to address by ensuring all family members were involved throughout both the photograph and interview stages of data collection.

The main aim of the current study aimed to gain a whole family perspective of camp; however, as discussed in section 1.4.1, the family should be considered as a system made up of a number of different elements, and sub-systems such as generation or gender. It was therefore considered important to consider individual perspectives within each family interview. This approach was also adopted by Schanzel (2010), who conducted whole family photo-elicitation interviews to explore family holiday experiences in New Zealand, including the three perspectives of generation (parent/child), gender (male/female) and group (whole family) during the analysis. Schazel's analysis led to two overarching themes (family time and own time), and was presented according to these different perspectives. The consideration of these three perspectives in the current study also led to themes concerning both individual and group experiences, presented in more detail in section 4.3.

When deciding upon a suitable method of analysis for the interview data, the researcher conducted a review of the literature which revealed four main techniques: discourse analysis (DA), grounded theory (GT), interpretative phenomenological analysis (IPA) and thematic analysis (TA). Although thematic analysis (TA) has traditionally been viewed as a "poorly demarcated, yet widely-used" technique (Braun & Clarke, 2006, p77), it is now gaining recognition as an effective technique, of equal standing to established qualitative methods such as DA or GT (Braun & Clarke, 2012). However unlike DA, which focuses on the language itself rather than on the people using the language (Langdridge, 2004), the researcher was aiming to gain a deeper understanding of participants' experiences from their responses, specifically uncovering personal meanings, rather than focusing on the ways in which participants constructed their experiences through language. Similarly, GT is more suitable for research questions relating to understanding and perceptions or influencing factors, rather than experiences (Braun & Clarke, 2013).

Braun and Clarke (2013) discuss the different types of data collection and methods of analysis for a range of research questions. They suggest that research exploring participants' experiences should be analysed using TA or IPA, so both TA and IPA were considered for the current research. The main difference between TA and IPA is that IPA provides an entire framework for conducting research. The dual focus within IPA on individual accounts, and the themes within these accounts, means that analysis can lack the depth and richness achieved with other methods such as TA and GT (Braun & Clarke, 2013). Unlike IPA, which focuses on identifying meaning within a single data item (Larkin & Thompson, 2012), TA aims to identify a rich and comprehensive account of an entire data set, to determine collective values throughout a participant group (Joffe, 2012). The current research focused on the participant group as a whole, rather than examining the experiences of individuals. Therefore, TA was used to gain a comprehensive and meaningful understanding of the overall dataset.

While TA may be viewed by some as an 'easy' technique, it is actually just as challenging as any other form of qualitative analysis, demonstrated by Braun and Clarke's guidance for ensuring an "exacting and sophisticated" analysis (Howitt & Cramer, 2008). TA aims to identify and interpret themes within a data set, which are patterns of meaning that are significant and relevant to the research topic under investigation. Themes are not necessarily quantified to determine their importance, but evaluated according to the contribution they make to the research question (Braun & Clarke, 2006). TA is extremely flexible as it is a method of data analysis, rather than an entire methodology, and can be used within a range of theoretical frameworks (Joffe, 2012). Unlike other methods of qualitative analysis such as IPA, which is bound by a pre-existing theoretical framework, the flexibility of TA means that the researcher can address the data in a variety of different ways (Willig, 2013). However, it is essential that the theoretical position of TA is explicitly stated within the research (Braun & Clarke, 2006).

In the case of the current research the analysis was approached from an inductive, experiential and essentialist perspective. More specifically, the type of analysis used was considered in the context of the specific research questions within the thesis, which aimed to explore participants' experiences of different interventions aimed at improving psychosocial adjustment to their burn injuries (inductive). The focus was explicitly on the participants' own perspectives and interpretations of the interventions, using the data to create meanings relevant to the specific research questions (experiential). The data were taken at face value to describe participants' experiences, which were then interpreted by the researcher to evaluate their significance in relation to past literature (essentialist).

Braun and Clarke (2006) describe a six-phase process for undertaking thematic analysis (TA). The six phases are:

1. Familiarisation with data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

The process involved in completing the first five phases in order to produce the current report will now be described in more detail.

1. Familiarisation with data

The first phase of TA is a thorough familiarisation with the data, beginning with a transcription of the data. The researcher transcribed the interviews verbatim which is the usual method for TA, rather than using a specific technique such as a Jefferson transcription (Howitt & Cramer, 2008). The researcher then read through the entire data set several times in an 'active' way (e.g. being aware of potential patterns of data). Whilst reading through the data the researcher made notes about the data for consideration when generating initial themes. Note taking is considered to be a useful technique for reading the data in a critical and analytical way, rather than simply reading the words (Braun & Clarke, 2012).

2. Generating initial codes

The second phase involves producing initial codes from the data. The researcher worked carefully through the data set to identify features of the data that were considered interesting in the context of the research question. All potentially relevant information was coded as it was considered preferable to disregard codes at a later stage than to miss out information at this early stage. In accordance with Schanzel (2010) the perspective of all data was considered, i.e. whether the response could be considered as fitting with a gender, generation, or group standpoint. Coding took place using Microsoft Word by marking codes next to each relevant section of the data. This allowed the data to be easily cut and pasted so that all data relating to each code could be grouped together. This allowed the researcher to identify whether each code was adequately represented by data and whether some codes could be combined.

3. Searching for themes

Once the list of codes and data extracts had been finalised, the researcher began searching for themes within the data. This phase involved sorting and collating the codes into relevant themes. The relationships between codes and potential themes were considered and six initial codes were generated:

1.   Camp in general

2.   Activities

3.   Family

4.   Other people

5.   Group session

6.   Burn injury scars

The data extracts for each theme were grouped together in order to review the themes more fully.

4. Reviewing themes

The next phase involves two levels, the first of which involves reviewing the themes at the level of the coded data extracts. The researcher carefully read all of the extracts that had been grouped for each theme, to ensure that they contain a clear and coherent pattern. At this stage, it became evident that some of the codes did not fit within their initial themes, or were not adequately represented by the data extracts. A through consideration of the data extracts also distinguished between main themes and sub-themes. The themes were reworked into three main themes: the effect on the family as a whole (new activities and experiences); the effect on the child (having fun without feeling different) and the effect on the adult (support from those who understand). The second level of this phase involves reviewing themes at the level of the entire data set. The researcher carefully read through the entire data set to ensure that the themes accurately represented meanings in the data set as a whole, and fit with the initial interpretations of each response as fitting a gender, generation or group perspective. Reading back through the data with the themes in mind also allowed for additional data items to be coded that were considered relevant to the newest themes. This stage is essential to ensure that the themes are distinct and relevant, whilst fitting together to answer the research question and 'tell a story' about the data set as a whole.

5. Defining and naming themes

Finally, once the themes had been reviewed to the researcher's satisfaction, the themes were defined and named in much greater detail in order to produce the report. A detailed analysis was conducted on each individual theme, as well as a consideration of the relationship between each

theme (reported in the results section). Each theme was then verified by a member of the supervisory team. A worked example of thematic analysis is provided in Appendix 8.

4.3 RESULTS

This section provides a discussion of the themes identified from the interviews and includes quotes from participants (all names are pseudonyms). A thematic map to visually represent the themes is provided below in Figure 10. The three themes are colour-coded as follows:

- The effect on the family as a whole (new activities and experiences) – green
- The effect on the child (having fun without feeling different) – blue
- The effect on the adult (support from those who understand) – purple

The themes are presented in the circular boxes and sub-themes found within each theme are presented in the rectangular boxes. Relationships between sub-themes are indicated by the dotted lines.

Key

Theme: 1. NEW ACTIVITIES AND EXPERIENCES

Sub-theme: A positive from a negative

Relationship between themes and sub-themes

Relationship between sub-themes across different themes
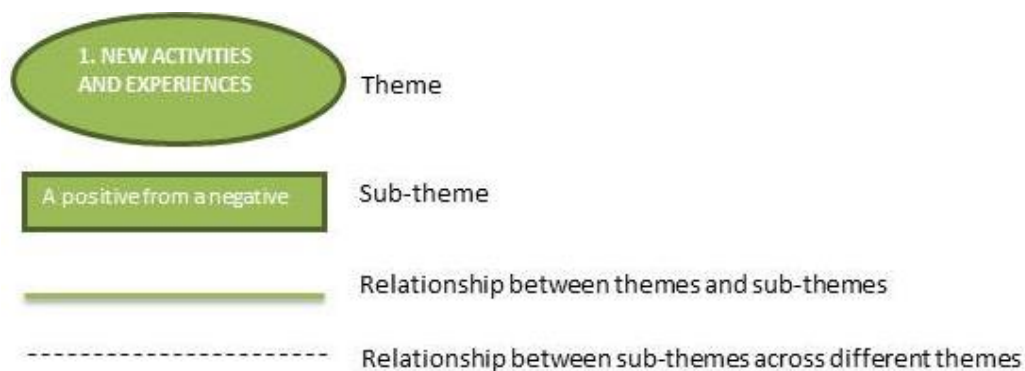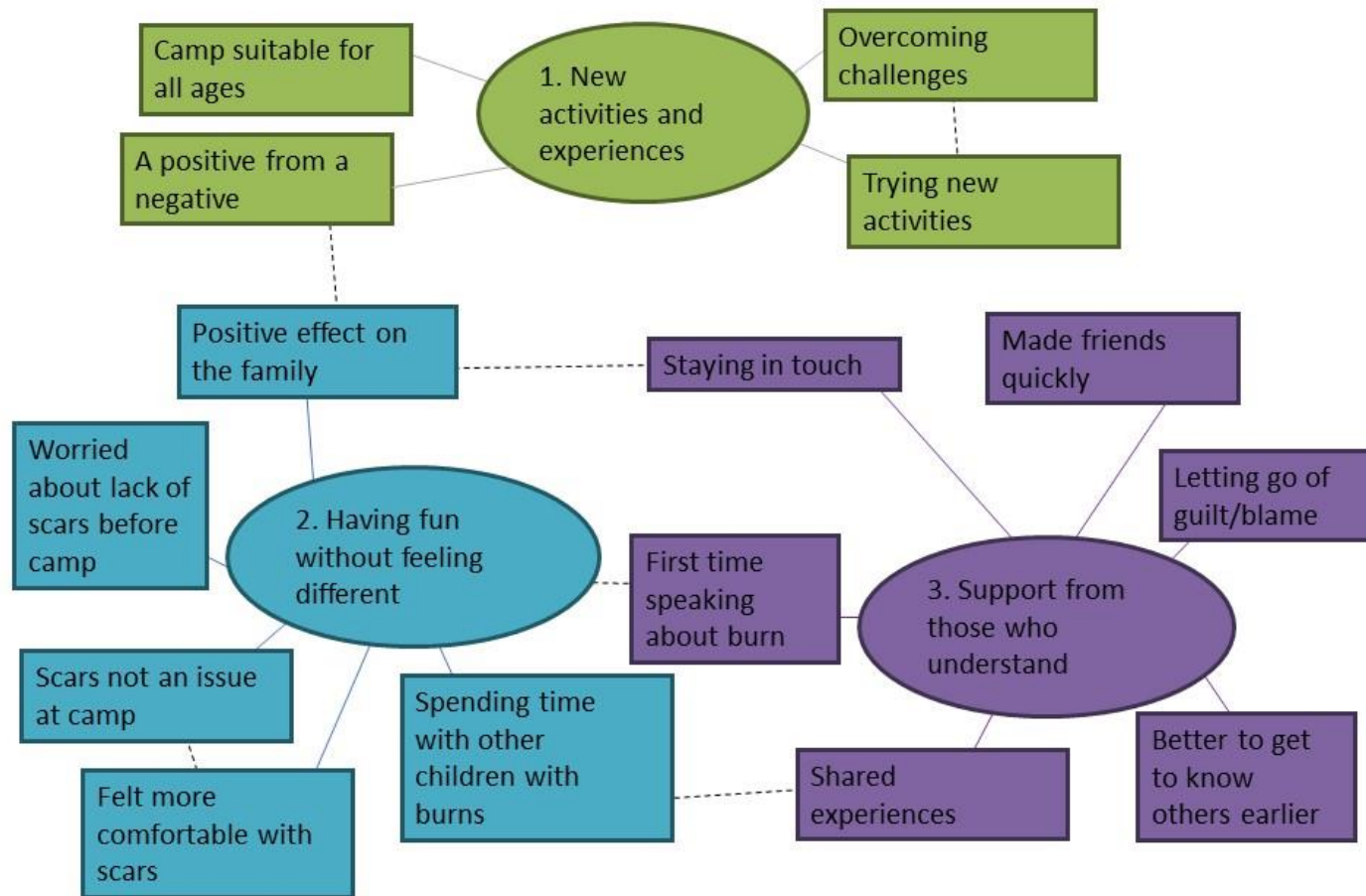
Figure 10 Study 1A Thematic Map

4.3.1 Benefits for the family as a whole - new activities and experiences

While some members of a family may sometimes be overlooked when a burn injury occurs (Brodland & Andreasen, 1974), this camp provided an inclusive environment for the family as a whole. One mother admitted that they had understandably given a lot more attention to their burn-injured child over the previous year which the other siblings had noticed.

Helen (mother):   "We've given a lot of attention to Lucy in the last year, and they obviously don't have as much, and Ben has obviously noticed."

Several participants described how the camp helped families to make a positive out of a negative, suggesting that camp can provide participants with happier memories in place of their traumatic memories about the injury. One family in particular felt much happier together since leaving camp. Therefore, it seems that the benefits of the new activities and experiences of camp may extend into the future, in the context of altering participants' previous behaviours and attitudes.

Leah (mother):   "Do you think as well that it puts a nice touch on something that was actually a horrible experience…to actually have something really nice come out of it?"

Chloe (child):   "Yeah… I think it's going to put a better view of what can happen to children and adults and it can also bring a good thing, not only sad memories."

Leah (mother):   "Honestly, it's changed the way we've been for the last few weeks. Things have been a lot different, we've been a lot happier, a lot nicer, we talk about it all the time"

One of the mothers also felt that her daughter had previously been struggling at school due to the timing of the burn injury, which occurred at the beginning of secondary school. As Lucy was in hospital for some time, Helen felt that she has missed out on the opportunity afforded to the other children to make friends at the same time. Although she had since returned to school, Helen felt that it was much more difficult for her to make friends, and enjoyed seeing Lucy make a new friend so easily at camp. Helen hoped that this friendship could be maintained after the camp.

Helen (mother):   "I like that one, because that shows that Lucy's been able to make a positive out of a negative, and that she's gained a friend, which would be great for them to sort of chat and hopefully meet up"

An interesting point that emerged from one of the interviews was that one child had been too nervous about meeting new people to go to child-only camps in the past, but felt more comfortable about the idea of attending the family camp, which in turn gave him the confidence to try a children's only camp. Family camp may therefore be particularly appealing to children who would like to experience the activities available at burn camp, but are not yet ready to attend a burn camp alone.

Rachel (mother):   "I think we really appreciated that it was the whole family as obviously in other camps they are for just the children and Jonathan didn't really want to participate until then."
Int: "What do you think now Jonathan; would you like to go to camp with the other children?"
Jonathan: "Yeah!"

One family referred specifically to the effect of camp on their eldest son Ethan (the brother of the burn-injured child). Parents Pete and Rachel felt that their relationship with Ethan had been very tempestuous in recent months as he had been diagnosed with a condition which led to problems with communication and social interaction. They felt that the opportunity provided by the camp to interact with other CYP, such as the supervised play session in the fun house while the parents attended the group meeting, had helped him to practise his social skills in a safe environment. This suggests that camp may provide social benefits unrelated to the burn injury, such as strengthening cohesion within the patient's family.

Rachel (mother):   He normally is just with people he knows really well and shies away from people he doesn't know… he's beginning to understand how in these situations to behave…very often we experienced very inappropriate behaviour in public and we were all embarrassed by it, but it was really nice and I felt so relieved that everything was going so well.

Furthermore, Pete and Rachel reported that enjoying the activities at camp had inspired Ethan to spend more time with the rest of his family. This indicates that camp has led to a positive, longer-lasting impact involving the whole family, rather than affecting solely the burn-injured child. This

finding is specific to the family camp, as Ethan would not have been able to attend the child-only camp and so would have missed out on these benefits.

Rachel (mother):	"But then also it's something Ethan (brother, 14) enjoyed, it's more like a grown up activity."
Pete (father):	"Because if that's what he wants to do, and that's an opportunity to kind of just keep it going…while Jonathan's swimming I could take Ethan off to a gym or something, sit in the steam room."

The photographs provided a visual demonstration of the time spent together as a family. Interestingly, while many of the children reported that the activities were their favourite part of the weekend, two picked out photographs showing their family together when asked to select their favourite picture. This lends support to claims that photographs are a useful tool when interviewing children, particularly as means to help them articulate their feelings. Although the chance to spend time together as a family was evidently significant to these children, this point was not immediately evident from the conversation alone, suggesting that the pictures helped them identify and express these feelings.

Interviewer:	"Why do you like that one the best?"
Jonathan (child):	"Because we're all together"

Many of the participants talked about the opportunity to try activities which they had never done before, some of which they found quite challenging. However, once the children had practised the activities and had the chance to improve they reported enjoying themselves more. This suggests that family camp provides the opportunity for the families to challenge themselves and improve their skills, which has been reported as one of the aims of camp.

Chloe (child):	"And then afterwards you got to examine everyone and then you had a few different turns at it, and then you got to see how everyone made improvements."
Leah (mother):	"Yeah, you got some practice and then they told you where you was going wrong didn't they? And then we got to do it again as a competition."

Consistent with previous literature (e.g. Shakespeare, 1998; Ptacek et al, 2002) the families acknowledged that the size of the burn did not necessarily contribute to the psychological wellbeing of the family, and felt that individual circumstances influenced the level of adjustment to the injury. Camp provided a chance for families who had experienced burn injuries of varying severity to meet each other and share experiences. It may have also helped children who thought their burns were too insignificant to attend camp to realise that any burn, no matter what size, can be exceedingly traumatic. This in turn may have helped them feel that their reactions to the injury were completely 'normal' and justified, which may have helped them come to terms with their feelings.

Leah (mother):   "It's the psychological stuff that goes with it, we were really worried about this actually, about coming on the holiday because Chloe's burn is so small, it was more the psychological issues of the whole event that's traumatised us, rather than the injury itself."

Kathy (mother):   "And I said, it's actually not what or where, it's how the person's reacted, and they could have had a tiny one but reacted the same as a big one."

Most of the families said that it was the first time they had experienced anything like camp, and stated that they would not have had the chance to do anything similar themselves. The finding was significant because it highlighted how much the families enjoyed camp and that it provides an opportunity that may not otherwise be available.

Helen (mother):   "Because I think, you know, not everyone can afford to go off for a little weekend doing all of these lovely things, so just having the opportunity, we're very lucky."

4.3.2 Benefits for the child - having fun without feeling different

A common response from the children with burn injuries in the study related to having fun with other children who had been through similar experiences, without worrying about feeling or looking different.

Jonathan (child):   "I thought we were all the same"

The children also discussed the opportunity provided by camp to talk to other people who had been through the same thing. Several children said they did not speak to their usual friends about their burns, but could open up to the other children at camp because they could relate to each other.

Lucy (child):   "It was nice, to meet them…people who had burns and stuff, so I could like chat to them and stuff…my friends at school don't really chat about my burns and I don't really chat to them about it and I could like chat to those people…."

Although the majority of the children did not report feeling self-conscious about their scars before camp, some of them did say that they worried about them in certain situations such as swimming, where they were visible to the general public. This is in keeping with the previous suggestion that people with usually non-visible scars may worry about the scars being revealed to other people (Coughlan & Clarke, 2000). This highlights that spending time with other children with burn injuries helps children to feel more comfortable and encourages them to participate in activities which they may have previously been unwilling to do.

Helen (mother):   "She used to do a lot more but because of her burn she refuses to go swimming most of the time now"
Lucy (child):   "When I went with my friends, people were like staring at me and I didn't like that….people had burns there, and I felt more, I'm not sure what the word is…"
Helen: "A bit more comfortable"
Lucy   "yes"

There was not any obvious effect of age or gender between those who worried about their scars, and those who did not, although the sample size in this study was too small to generalise to the general population. Two participants who mentioned feeling self-conscious about their scars were both adolescent girls aged 11 and 13. CYP tend to become more conscious of their appearance during adolescence (Rumsey & Harcourt, 2007); one of the other female adolescents did not report a concern regarding her appearance. Children with an older burn, however, did seem to be less concerned with their scars. Two of the children had sustained their injury during the first two years of their life and neither of these children reported feeling self-conscious about their appearance. One father commented on the differences between children who had been burned as babies and children who had been injured more recently.

George (father):   "There were ones very new to it, you know the recent burn on the child, and then the one where it's all they've ever known, with the child growing up and having to deal with this…so that was interesting to see those children, the ones that were burnt from birth and the ones that have been recently…"

Three of the participants had been burned within the previous year. One female participant felt very self-conscious about her scars, while another male participant was not worried about people seeing them. It is unclear what caused this difference, but may have due to the importance placed upon appearance by the participants, which can significantly affect one's own feelings towards the burn (Lawrence, Fauerbach & Thombs, 2006). Interestingly, some children were worried about going to camp because they did not have any scars, or did not think they were severe enough to warrant their attendance at camp. One participant, Jonathan, also worried about his brother Ethan attending as Ethan did not have any burn scars.

Rachel (mother):   **"**Jonathan (child, 10) had worries "oh he doesn't have any scars, how would he look compared to the others" and should he even be there at camp, because he didn't have scars and he thought other children might have scars"

However, scarring (or the lack of it) was not such an issue once they had arrived at camp as the children said that they felt like they could relate to each other because they had all been through the same thing. CYP with burn injuries have reported being stigmatized by non-burned individuals (Lawrence, Rosenberg, Mason & Fauerbach 2011), whereas at camp they did not have to worry that they might be judged on their injuries.

Emily (child):   "When I went there I didn't see people as in their burns, I saw them as the person they were."

The children particularly enjoyed the non-organised activities, such as the funhouse where they could simply have fun together without adult supervision. Parents/carers of burn-injured children can become very protective (Rizzone, Stoddard, Murphy & Kruger, 1994) so this may have been an opportunity for the children to experience independence. Both the burn-injured children and their siblings played together in the funhouse, suggesting that the camp produced an inclusive environment for all CYP.

Chloe (child):   "That was quite fun as well because it was like a space where we weren't around like adults and it was sort of a place for like kids only, whereas a lot of the other things you had to be with the adults."

CYP felt that the funhouse provided a special place just for them, but this is not to say that they did not also want to spend time with their family. As discussed in section 4.3.1, when asked to pick out photographs showing the best part of the weekend, two selected pictures showing their whole family together.

While the burn injured children did refer to the chance to meeting other CYP with scars, siblings mainly focused on the chance to have fun and try out activities which they would not normally have the chance to do.

Kieran (brother, 11):   "Yeah because here we wouldn't normally play around…because it's not like a funhouse, and there's not a bar here, there's not a swimming pool here"

4.3.3 Benefits for the adult - support from those who understand

The most common response among the adults related to the value of being able to speak to others who could understand their feelings associated with having a burn-injured child. They referred to the parents'/carers' meeting which allowed them to discuss their experiences in a safe environment. For most, even those whose child had sustained their burns several years previously, this was the first time they had spoken to other parents/carers who had been through a similar experience:

George (father):   "It's been very much on Helen, so it's nice for her to share at last with another mother, and you know someone else really, with a similar experience. Because it was a year of you very much on your own, wasn't it?"

Speaking to the other families also helped participants realise they were not alone, creating a bond that encouraged them to share their experiences and feelings more freely.

Kathy (mother):   "Oh yeah, absolutely, we were all strangers with the same thing in common, so we weren't strangers at the end. After the parents' meeting we weren't strangers."

It became evident that parents were able to address their feelings more easily when speaking to other parents who had the experience of the burn injury in common. Even though the circumstances of the injury were different for each family, parents may experience similar emotional reactions. Realising that their reaction to the injury was 'normal' and experienced by other people seemed to help them to be more accepting of their feelings.

Helen (mother):   "Every child is different and every child goes through a different experience so your experience is obviously different to their…but it's how you deal with your experience…it's quite nice to hear from other people how they're dealing with it."

All of the families found the camp to be beneficial in some way, irrespective of whether their child's injury had occurred recently or some time ago. Some parents/carers talked about feelings (including a sense of blame for their child's injury) which they had suppressed for a long time and described how talking to other families had helped them to let go of these feelings. This is very important as parents of burn-injured children can experience intense feelings of guilt and blame, which can be very difficult to change (Partridge & Robinson, 1995).

Jack (father):   "I mean people like changed their way of thinking, like blaming themselves when to put it simply it's just not their fault. It's just wrong place, wrong time."

Although parents may have been told that they were not to blame for the burn, it emerged that hearing this from the other families was extremely powerful.

Pete (father):   "It provides the opportunity for people to share that experience, to get some support and understanding from people who've been there…and maybe help to remove some of those guilt complexes that some of those folks are carrying with them."

Rachel (mother):   "If you hear that from somebody else who felt that way then I think it's quite different."

It was suggested that camp would be more beneficial to families that had experienced the burn more recently, as families may no longer experience difficulties relating to a burn injury which occurred several years previously

Hannah (mother):   "Yeah. I think I would have found it helpful if it had happened a year after her injury, I think in the time that it's been it's not a massive part of our life now, but back then I think that probably would have been helpful."

However, speaking to families for whom the burn was no longer a significant issue was still extremely valuable to families in the early stages, which would indicate that it is beneficial to invite families to camp who are at different stages of life since the injury. New issues might arise over time so it is hard to judge at which stage of life camp may be most beneficial. Those for whom their child's injury was still quite recent gained a sense of hope from those whose children had been burned some time ago.

Hannah (mother):   "To see people at different stages…for some people it was still quite new, quite fresh and emotions were quite raw. And others it's been a longer time period and I think that's quite nice for the children to see, other people who have not necessarily just gone through it."

Parents felt it would be helpful to speak to other families on a regular basis, to share experiences with supportive individuals, and had discussed staying in touch with the others and meeting up again in order to continue newly-built friendship. This highlights how helpful the parents found the group session to be, and suggests that regular support groups might be helpful for some. Interestingly, none of the families were keen on the idea of the group before attending, as they did not know what to expect. Although the group was voluntary, the parents were encouraged to attend by the camp staff. Had it not been for this, they might not have entered into a situation where they could discuss their experiences with other parents, indicating that introduction to this experience was another benefit of the camp:

Helen (mother):   "I think if you'd had longer with them then you could have opened up even more and chatted even more. So if that group had been able to continue as maybe once a month."

Some of the families had stayed in touch since camp and already discussed meeting up and staying with each other. Although the families came from all over the South West, they had discussed the possibility of meeting up somewhere central, perhaps at another activity centre to repeat the experience of camp. This demonstrated how positive the experience of meeting other families had been. The fact that families living geographically quite far from each other had already arranged to stay in touch and travel to see each other highlighted their desire to keep in contact. This showed that further to the positive experience of meeting others at camp, the families actually intended to continue the newly-built friendships. Camp may therefore act as a means to facilitate further contact and support in the future.

4.4. DISCUSSION

This study explored the experiences of those attending a residential camp for families affected by a child's burn. Overall, experiences were positive and attendance had been beneficial to the children, parents/carers and family units as a whole, through opportunities to try new activities, have fun without feeling different, and gain support from other families who could understand what they had been through. One of the aims of burn camps is to provide individuals with positive experiences such as taking part in activities, meeting new friends and learning new skills (Biggs et al, 1997) and these findings indicate that the family camp met these aims. The burn-injured children themselves described how camp had provided them with opportunities to have fun and enjoy activities without feeling different. Their responses were consistent with previous qualitative studies of child-only camps that found meeting others helps CYP to feel normal and accepted (Bakker et al, 2011; Gaskell et al, 2010). Previous studies have revealed that burn camp can lead to an increase in confidence and self-esteem (Williams et al, 2004), as a result of CYP achieving things which they did not realise they were capable of (Maertens & Ponjaert-Kristoffersen, 2008), such as learning new skills and making new friends (Gaskell, 2007).

However, while camp may offer a number of benefits, such as increased confidence and self-esteem, it may not be a suitable intervention to target more complex difficulties experienced by CYP with a burn injury such as trauma symptoms. It is important for interventions to be guided by an individual's level of psychosocial need, and CYP with a greater need may require more intensive treatment, as illustrated in the Centre for Appearance framework of appearance-related interventions (see section 2.2).

Parents/carers in the current study valued the chance to talk to others who had lived through similar experiences, a finding which supports previous research (Gaskell et al, 2010). Although

there is a fairly small body of evidence into the effect of a burn-injury on the child's parents, it has been reported that parents often experience feelings of intense guilt (Partridge et al, 1995), especially if they feel they could have prevented the injury (Rizzone et al, 2004). Parents reported discussing both of these issues within the support group, claiming that the peer support from other parents helped them realise that the injury was an accident, and in some cases, helped them to let go of their feelings of guilt. Providing more of these opportunities for parents may be a service development worth considering within burn care services.

Few studies have investigated interventions (e.g. support groups and peer support) for parents/carers of burn-injured children, but the benefits of such groups for parents/carers of children with disabilities have been reported. Parents/carers who share a similar experience may be 'uniquely qualified' to support one another (Law, King, Stewart & King, 2001); boosting the skills needed to cope with a child with special healthcare needs (Kerr & McIntosh, 2000). The current study suggests that a peer support group for parents/carers of burn-injured children might be helpful to them.

Although camp provided evident benefit to CYP who have had burn injuries and their parents/carers, the findings from the siblings were more limited. Their comments focussed on the chance to try new activities and meet new friends, rather than issues surrounding the burn itself. The importance of including the entire family in a patient's treatment and rehabilitation has been emphasised previously (Bakker et al, 2013; Wiechman & Patterson, 2004) and, in contrast to interventions that focus on the child alone, the camp facilitated this process of allowing all family members to be involved. Although one sibling found camp to be socially beneficial, siblings on the whole did not report any psychosocial benefits, so it is possible that family camp simply provided them with an enjoyable break rather than addressing issues relating to their brother or sister's injury. However, although the siblings were forthcoming about the fun they experienced at camp, they became more reticent when asked questions relating to their brother or sister's burn injury. Research into the experiences of siblings of burn-injured children is limited, but research into the experiences of siblings of children affected by cancer has demonstrated that siblings use avoidance as a coping strategy, even going as far as pretending their brother or sister was not sick (Heiney, Goon-Johnson, Ettinger & Ettinger, 1990). Therefore, it is possible that the siblings in this study were engaging in avoidant behaviour towards their brother or sister's burn injury.

Finally, while parents/carers were invited to a session to talk specifically about their feelings towards their child's injury, children did not partake in any activities designed specifically to target psychosocial issues surrounding the injury. Although burn-injured children in the current and

previous research report numerous benefits simply from spending time with other burn-injured children, it is possible that simply the experience of being around other CYP did not produce the same level of benefit among siblings. Siblings who are experiencing psychosocial concerns may require a more structured intervention to target specific concerns.

Photo-elicitation was chosen for the current study in an attempt to engage the participants in the research, which was considered to be successful. Using their photographs as prompts during the interviews worked well with parents/carers and CYP with burn injuries, although these were less effective at eliciting responses from siblings. It has been suggested that it is imperative that research at camp must not detract from the fun and safe environment that children (and their families in the current study) experience whilst at camp (Arnoldo et al, 2006). Therefore, the study was introduced to the families as a 'fun project', and the children became very excited when the cameras were produced. The families reported enjoying using the cameras to create memories of their time at camp.

The use of photographs as prompts during the interviews also worked very well. The interviews took place in the participants' homes so were subject to multiple interruptions, as expected (Irwin & Johnson, 2005). However, the photographs helped to structure the interviews so that when interruptions did occur, it was straightforward to return to the same point in the interview. The use of photographs during the interviews was also an attempt to retain the children's interest in the interviews (Samuels, 2004). This was an effective tool as whenever children appeared to be getting bored or restless, the interviewer directed the focus back to one of the pictures taken by the child, which reengaged them in the topic.

The final aim of using photo-elicitation as a method was to act as a channel of communication between the researcher and the participants (Clark-Ibanez, 2004). The photographs acted as an icebreaker in the interviews, and it was found that once all of the photographs had been discussed the families were speaking much more openly and readily about their feelings and experiences at camp, as well as other feelings relating to the injury itself. Similar to the research conducted in the study by Lassetter, Mandleco and Roper (2007), it is thought that the photographs helped to build rapport and trust between the researcher and the participants, which helped them to feel more comfortable discussing personal issues. Therefore, photo-elicitation was considered to be a very appropriate method for the current study, and should be considered for future research with CYP and their families. Novel methods such as these may help to pique participants' interest in the research and help to keep them engaged throughout the study, whilst also helping to facilitate open and honest discussion.

4.4.1 Limitations and future research

A limitation of the current study was that it only included those up to 14 years of age. It has been suggested that living with a visible difference may become particularly challenging during adolescence (Rumsey & Harcourt, 2004) so it would be useful to investigate the experiences of older adolescents attending a family camp. The FAB family burn camps are for 8-18 year olds and their families (Frenchay After Burns Children's Club, 2016), so future research could aim to include those aged 14-18 at family camp. Similarly to the study by Wu et al (2011), the participants in this study were all Caucasian, so the results from the current study may not be fully generalizable to the larger population of burn patients. As discussed in section 3.5, the majority of burn patients come from ethnic minorities so the participants in the current study are probably not representative of children with burns on the whole.

It is also worth noting that two of the participating families with siblings had experienced the burn between 6-11 years previously, which could suggest that the families had adjusted to the injury over time. One parent reported that while the family enjoyed the camp, it would have been far more psychologically beneficial if the family had attended in the year following the burn injury, over ten years previously. The method of data collection may also have influenced siblings' responses. Although a family interview was used to try and ensure that children felt comfortable talking to the researcher, it is possible that siblings actually found it difficult to speak frankly about their feelings towards the injury in front of their parents and burn-injured sibling. It is not known whether speaking to the siblings in private would have encouraged them to speak more openly, but this is a possibility.

Unlike the study by Bultas et al (2014) and study 1B in this thesis, all of the participants in the current study were first-time campers. Therefore it is not known whether the positive benefits they experienced were due to attending camp for the first time. As many of the parents in the current study reported that the camp was the first time they had ever spoken to other families about the injury, it is possible that they would find the experience to be less powerful during subsequent camps. Conversely, it may be that repeated attendance to camp produces a cumulative effect, although FAB gives priority to families who have not been to camp before. Further research could investigate the differences between first-time and repeat campers, as this could have implications for future selection processes. In addition, this study explored the experiences of families attending camp over a single weekend, so the researcher had no previous knowledge of how they were coping with the injury prior to this.

The cross-sectional nature of this study also meant that longer-term benefits of camp were not considered. This study revealed that the families expressed an interest in staying in touch after the camp, and possibly arranging another activity holiday together privately. Future research could therefore include a follow-up period to investigate whether families do stay in touch after camp, and whether this provides any extra benefits to the various members of the families. Parents' opinions of the support group indicated that they found it a very worthwhile experience, and one suggested that it would be helpful to attend a regular group. Further research could focus on the effects of a support group, as well as considering different mediums of support. For example, research has indicated that internet support groups can provide similar benefits to face-to-face sessions (Baum, 2004). As it may be geographically difficult for families affected by burn injuries to meet in person (mentioned by the participants in the current study) online support networks may offer support to a much wider range of people.

While the chosen families had never attended a camp before, this is not to say that these families were necessarily in need of any psychosocial support. Indeed, one mother said that although she enjoyed the camp, she would have found it to be far more beneficial if she had been invited years previously. A more thorough consideration of families' psychosocial needs before the camp may therefore ensure a more effective method of delivery. While camp organisers may not have the experience to be able to do this, a large proportion of children in FAB club are known to the clinical psychologist associated with the club who may be able to provide information about the families' psychosocial status. However, it is acknowledged that not all families are known to the psychologists, and time constraints are likely to prevent additional psychosocial assessments. Finally, this study took place at a single camp run by FAB club, which may be run differently to other family camps. It has been suggested that the next step in therapeutic camp research is a focus on which particular components of camp programmes produce specific positive outcomes (Martiniuk et al, 2014), which could prove invaluable to camp organizers when planning subsequent camps.

4.5 CONCLUSION

While findings from the CYP with burn injuries were consistent with previous research, parents reported finding camp very helpful. While camp allowed siblings to enjoy the activities and have fun, it is possible that they did not experience the same psychosocial benefits as the rest of their family. Further research should investigate whether burn camp produces similar benefits for families with older adolescents, as well as those attending repeated camps. The results from this

study generate an additional area of research to explore the effects of support services for parents of burn-injured children. Photo-elicitation was found to be a successful method within the current study, both to engage participants in the research and to promote conversation within the interviews. Therefore, it is suggested that this novel method would be an appropriate method to use in research with CYP in the future, particularly when asking them to recollect their thoughts and feelings towards a particular experience or intervention.

This study suggests that family burn camp may be of some benefit to the majority of those attending it. It addresses the overall research questions for the thesis by considering an intervention for both CYP with burn injuries and their families and provides a basis for the other studies in the thesis by considering a lower-level intervention suitable for those with lower psychosocial needs. However, although the results of this study indicate that parents and CYP with burn injuries found family burn camp to be beneficial, a major limitation of the study is that it is not known how well-adjusted family members were before attending camp. The next study in the thesis consisted of a pre-post design at a children-only camp, implementing outcome measures at a number of time points, to investigate whether pre-camp scores changed at the end of camp and at a 3-month follow-up.

CHAPTER 5. STUDY 1B: THE IMPACT OF BURN CAMP ON YOUNG PEOPLE'S SOCIAL CONCERNS, SATISFACTION WITH APPEARANCE, AND BEHAVIOUR

5.1 INTRODUCTION
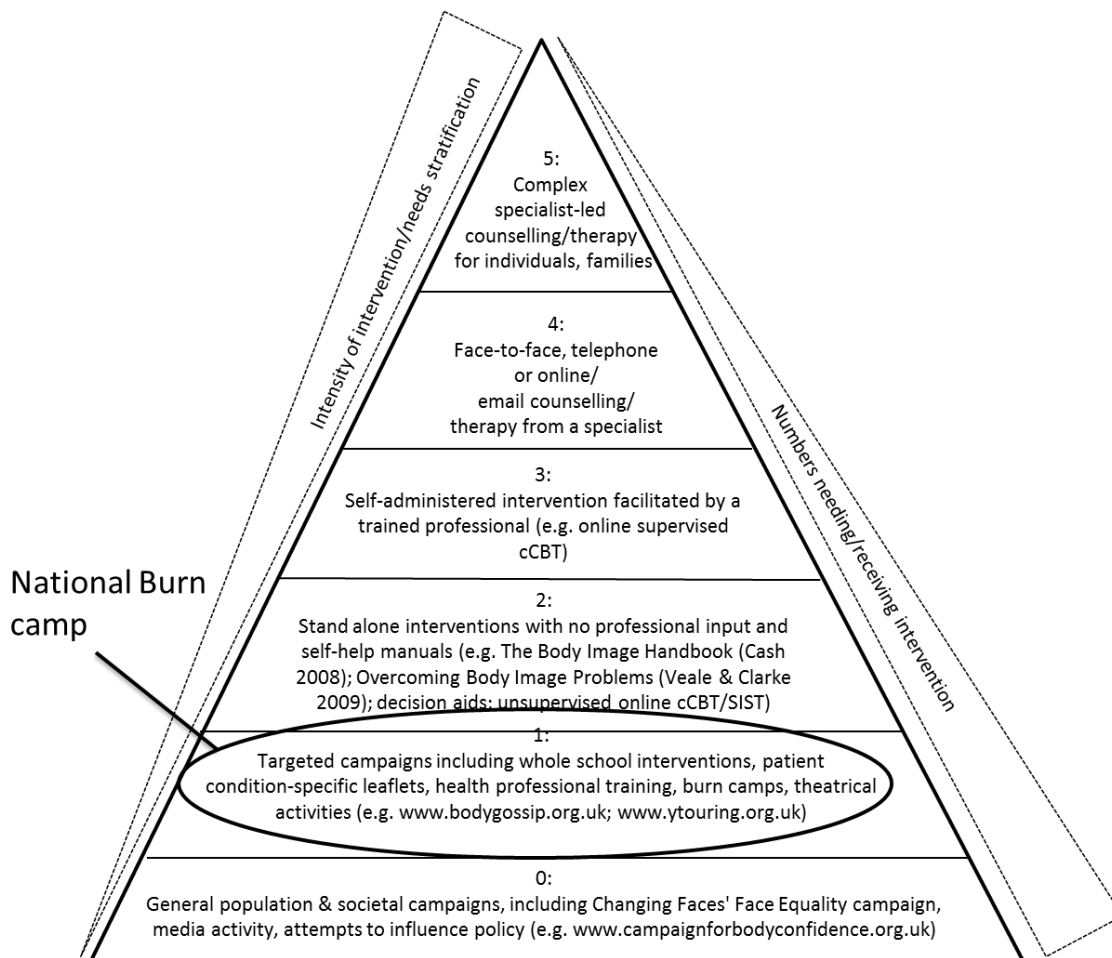
Figure 11 The location of National burn camp on the CAR pyramid of appearance-related interventions

The previous study determined that burn camp may provide a number of benefits to attendees, but did not specifically examine whether outcomes changed as a consequence of attending camp. Therefore the current study evaluated a child-only burn camp, utilising outcome measures to explore whether scores changed when compared before camp, after camp, and at a 3-month follow-up. These camps have been evaluated previously in the literature, although previous studies have included a range of methodological limitations which are discussed below. The current study aimed to improve on the methods of previous studies with the aim of producing a more comprehensive picture of burn camps.

Burn camps are specialist activity holidays for children with burn injuries, to allow them to meet other children who have been through a similar experience. The UK National Burn Care Review

(2001) recommendations state that burn club and camp programmes are a necessary aspect of burn rehabilitation. The first burn camp, 'Camp Celebrate' was held in North Carolina in 1982, and was a weekend camping experience for CYP who had been treated in burn centres throughout the state, aiming to help improve self-concept through the acquisition of new skills and overcoming challenges (Rosenstein, 1986). According to the British Burn Association burn camps began to develop in the UK in the 1990s and there are now 13 burn clubs/camps in the UK (British Burn Association, 2016). These vary in size but the largest is the National Camp accommodating around 50 CYP from the other burn clubs, organised by 'Burns Camps', a charitable organisation which funds and runs the camp each year (Burns Camps, 2016). The majority of camps are funded without any support from the NHS, through fundraising events and donations, and staffed by volunteers from both NHS and non-NHS backgrounds.

Although the majority of burn camps do not offer specific psychological interventions, they can offer many psychosocial benefits (Bakker, Van der Heijden, Van Son et al, 2011) such as making new friends and learning new skills. The aim of burn camps is to provide children with a fun and supportive environment, in which they carry out activities designed to help them deal with the challenges of a burn injury (Gaskell, 2007). It is thought that helping CYP to succeed at physical activities may help them feel better about what their bodies can do which promotes a more positive body image and improves self-esteem (British Burn Association, 2016a).

There is a limited amount of research into burn camps, and the existing studies focus on the link between participation and reported psychosocial outcomes. Results have demonstrated remarkable consistency across qualitative studies with participants, parents and staff indicating that they believe the experience to be hugely beneficial to CYP. For example, Williams, Reeves, Cox and Call (2004) conducted focus groups with 52 CYP across three burn camps in the USA and found that campers described camp as having provided them with a sense of acceptance, a greater sense of purpose within life, and increased confidence and self-esteem. Cox, Call, Williams and Reeves (2004) used the same participant sample to specifically investigate whether burn camp had an effect on body image, and found it helped CYP to feel more comfortable about their appearance. More specifically, camp was a place where they felt accepted by others, which in turn helped them to accept their own scars. Spending time with other children with burns reduced campers' desire to cover up their scars, as they did not feel they would be stared at or judged by the other campers. This helped them to feel more comfortable with their own bodies, and ultimately feel more confident.

A Belgian qualitative study by Maertens and Ponjaert-Kristoffersen (2008) asked CYP to complete evaluation forms with open-ended questions at three time points: the first day of the burn camp, the last day of the burn camp, and at a 3-month follow up. Parents were also asked to complete an evaluation form three months after the camp. Before the camp, children said they were particularly looking forward to the activities and seeing their friends again, and although some children were worried about issues such as homesickness, the majority were not worried about anything. After the camp, both parents and CYP reported that the main benefits related to psychological issues, such as improved confidence and a better perspective on the injury, followed by improved social skills. While this study compared CYP's expectations and experiences both before and after camp, it would also have been interesting to explore parents' expectations before the camp, and assess how these measured up to the actualities of the camp.

Mixed methods studies have reported similar findings from their qualitative elements. For example, Gaskell (2007) collected both qualitative and quantitative data over a five-year period. The qualitative element included open-ended questions to determine if CYP enjoyed the camp and whether it had it helped them. Parents were also asked to complete open-ended questions about their perceptions of benefits for the children. The results revealed consistent results across the five-year period. Children and their parents reported that CYP had learnt to manage the challenges they faced, gained confidence, and improved their social skills. These effects were considered to be a result of meeting other children who had been through a similar experience, as well as engaging in challenging activities.

Gaskell, Cooke, Lunke et al (2010) collected data from five European burn camps (Russia, Belgium, Norway, and Manchester and Pinderfields from the UK). Their evaluation followed the same format as that used in Gaskell (2007), employing both Likert scales and open-ended questions relating to children's enjoyment and positive outcomes from the camp. Reported benefits from both the CYP and parents referred to shared experiences, friendship and social skills, improved confidence in self and appearance, and putting the injury in perspective. Although these findings are promising, a limitation of both Gaskell's and Bakker et al's studies, is that although quantitative measures were administered both before and after the camp, the qualitative elements were only employed after the camp. Therefore, little is known about CYP's and parents' expectations before camp, and how these fit in with their actual experiences of it.

As evidenced by these studies, it should be clear that qualitative results from the burn camp literature have produced consistent results. However, the findings from the quantitative elements of these mixed methods studies have not replicated those of the qualitative elements, and other

studies using solely quantitative techniques have also produced inconsistent results. For example, Maslow and Lobato (2010) reported that the majority of quantitative research into burns camps used the Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965), a generalised measure of self-esteem. While some research (Biggs et al, 1997; Arnoldo et al, 2006) has not identified any improvement in self-esteem, Rimmer et al (2007) discovered that campers' self-esteem improved from the beginning to the end of camp, although this effect was relatively minor. The cause of these conflicting findings remains unclear. Gaskell (2007) refers to the complex nature of self-esteem and the multifaceted constructs of which it is formed, so it is possible that a single measure of self-esteem may be insufficient to properly evaluate the effects of camp. Indeed, Rimmer et al (2007) suggested that future research may benefit from implementing alternative measures of self-perception.

Rimmer (2012) used the Youth Experience Survey 2.0 to measure the developmental experiences of the campers, which was designed to measure CYP's experiences in organised activities. The survey asks CYP to rate the extent to which they agree with a number of statements (e.g. "learned a lot about helping others" or "learned to push myself") on a four-point scale. CYP reported that camp had helped them in a multitude of ways, such as improving problem-solving, goal-setting, communication and physical activity, and the authors concluded that burn camp helped the participants develop coping strategies and social skills. While this study provided an indication of the wide range of potential benefits gained from camp, it did not collect any data before the camp and therefore it is unknown how any of the CYP were managing their injury prior to this.

The aforementioned study by Gaskell (2007) used a number of quantitative measures which aimed to evaluate the effect of camp on self-esteem, social relationships and emotional/behavioural wellbeing before and after camp. In contrast to her qualitative findings, no consistent quantitative results emerged over this period. Gaskell administered the measures in her study 1-2 months before the camp, and 1-2 months after the camp. Therefore, while the pre-camp measure can be considered to provide a sound baseline measure, there is no examination of children's scores immediately after camp. It is possible that the children in this study experienced a short-term benefit from the camp which had lessened in the two months since they returned home. An additional measure on the last day of camp could have investigated the effects further. Furthermore, the sample sizes in Gaskell's study were small, ranging from 14-23 participants over the five years. However, while this may be viewed as a shortcoming of the research, it also appears to be an unavoidable limitation of research into burn camps in the UK, since the number of campers is fairly low to begin with. As mentioned earlier, even the National Camp can only accommodate around 50 campers, and the high non-participation and attrition

rates within burns research (McQuaid & Barton, 2003) means it is unlikely that all campers will acquiesce to participate in research.

More recent research has taken additional psychosocial constructs into account when conducting quantitative studies. For example, Bakker et al (2011) examined the relationship between camp, self-esteem and body image at three time points: three weeks pre-camp, 1 week post-camp, and 16 weeks after camp. They also used the RSES, but also included a burns-specific measure of body image, a Dutch version of the Satisfaction with Appearance Scale (SWAP; Lawrence, Heinberg, Roca et al, 1998). The study also included a comparison group of children with burns who chose not to attend camp, identified from the 'Foundation Child and Burn' database which holds information about all CYP treated in Dutch burn centres. Results did not identify a change in self-esteem scores for either the camp or comparison group, in either the short- or longer-term. A small improvement in satisfaction with appearance was noted among the campers when comparing the pre- and post-camp measures, although this effect was not maintained at the 16-week follow-up. This study had a number of strengths. In addition to providing the first quantitative investigation of the effect of burn camp on appearance satisfaction, it included a much larger sample size than Gaskell (2007), with 83 participants. Furthermore, the inclusion of the additional measure one week after camp indicated that benefits may be experienced in the shorter-term. However, although Bakker et al (2011) found a small improvement in satisfaction with appearance among campers, the Dutch version of the SWAP had not been validated prior to their study. The authors suggest that their results regarding the effect of camp on appearance need replicating.

The lack of significant quantitative findings in many of the earlier studies may be due to the strong focus on self-esteem, despite qualitative evidence that campers experience benefits extending far beyond self-esteem (Maslow & Lobato, 2010). The positive results from Bakker et al's (2011) study suggest that investigating additional constructs may provide a more comprehensive evaluation of camps. Although Gaskell (2007) examined constructs other than self-esteem, such as social competence, social worries and physical appearance, she did not find any consistent quantitative results and she speculated that this may be due to the measures she used in the study. Such generalised measures may not be specifically relevant to CYP with burn injuries, and may fail to consider the issues commonly experienced by CYP as outlined in chapter 1. Therefore, in order to quantify the observed benefits of burns camp, it seems there is a need for further research implementing measures that are appropriate for the young burns population, to consider a range of psychosocial constructs. Kent (2000) recommends that visible difference research should assess the effect of stigmatization within disfiguring conditions, while Jenkinson

et al (2015) suggests that measures designed to assess constructs such as appearance satisfaction or social confidence should be used when conducting research into interventions for CYP affected by appearance-altering conditions.

These suggestions tie in with the previous qualitative findings, which have indicated that camp can improve CYP's feelings towards their appearance (Cox et al, 2004) and confidence within social situations (Gaskell, 2007). Furthermore, parents' qualitative responses in the aforementioned studies have referred to a wide range of effects observed in their children, including a number of emotional, social and behavioural benefits such as increased confidence, improved conduct with other people and a new sense of independence. In summary, there is a need to evaluate a range of psychosocial constructs using appropriate quantitative measures. Therefore, the current study examined satisfaction with appearance and social concerns as reported by CYP with a burn injury, and also asked parents to report on their children's general behavioural and social concerns. However, it is also considered important to include a qualitative element alongside quantitative methods in order to contextualise results and explain any unexpected findings (Bishop, 2015), so the questionnaire packs also included open-ended questions.

The specific research questions were:
1. Does burn camp impact on CYP's social concerns? If so, how?
2. Does burn camp impact on CYP's satisfaction with appearance? If so, how?
3. Does burn camp impact on CYP's behaviour? If so, how?
4. Does burn camp have any additional benefits for the CYP that attend?

5.2. METHOD

5.2.1 Design

The study aimed to evaluate an existing intervention for CYP with a burn injury, while addressing the methodological issues encountered in previous research discussed above, such as unsuitable outcome measures and no follow-up. Based on Leech and Onwuegbuzie's (2009) three-dimensional typology model (see section 3.1.3), this study used a fully mixed concurrent equal status designs (e.g. QUAN + QUAL), mixing quantitative and qualitative methods across the research objective, data and analysis, collecting quantitative and qualitative data concurrently, and giving quantitative and qualitative methods equal status.

The study collected data from CYP and their parents over a four-month period. They were asked to complete questionnaire packs one month before camp and at a 3-month follow up, and CYP were also asked to complete questionnaire packs on the last day of camp. The questionnaire included outcome measures (discussed in more detail below) and open-ended questions. This pre-post and follow-up design was based on the fact that Gaskell's (2007) study failed to find significant differences when comparing data from 1-2 months before camp and 1-2 months after camp, whereas Bakker found a difference in scores three weeks before camp and 1 week after the camp, but no effect at the three-month follow-up. Therefore, the time points in the current study were chosen to determine whether any observed effects would be present only immediately after camp, or whether they would be maintained over a longer period of time.

A comparison group was not used in this study for several reasons. The lack of a comparison group in previous studies is indicative of the difficulties in using an appropriate comparison group. Out of the 11 studies reviewed above, only two included the use of a comparison group, one of which (Rimmer et al, 2007) included a comparison group of children without burns. It can be argued that this group cannot be considered comparable to the participants in the study, as many of the aims of burn camps (e.g. improving feelings towards scars and managing the injury) are not relevant to children without burns. Bakker et al (2011) included a comparison group of children with burns from a group who were not attending the camp, and no difference was found between the participants and comparison group in terms of age or number of previous burn camp attendances. However, almost half of the comparison group had been invited to attend the camp but had declined the invitation, and no information is provided around the reasons for choosing not to attend. This makes it more difficult for future research to include an equivalent comparison group.

Bakker's study is an example of the potential problems in selecting a suitable comparison group for burn camp research. If CYP are invited to camp but choose not to attend, then this alone is a noteworthy way in which they differ from CYP who do choose to attend. It would be essential to explore in greater detail the specific reasons why the CYP do not want to go to the camp. It was not considered possible to select a suitable comparison group without a thorough exploration of these reasons, which was deemed to be beyond the remit of the study due to the difficulty in identifying potential participants discussed in section 3.4. Although CYP with burn injuries can come from a diverse range of backgrounds, the CYP attending camp all have the camp in common, which is the focus of the study.

Finally, a process of randomisation was considered, in which children who had expressed an interest in camp would be randomly allocated into a group which would attend camp, and a waiting list control. However, it was decided that such a process would be unethical as it would be denying children the chance to attend the camp, which only runs once a year. Bottomley (1997) discusses a number of disadvantages to randomising participants in psychosocial intervention studies. While randomisation may compare an intervention group with a control group, it does not usually take into account the characteristics of those who choose not to take part in the study at all. Parents are unlikely to be willing to allow their child to take part in a study which could ultimately deny them the chance to attend camp, and so this could drastically reduce the participation rate in the study. Furthermore, Bottomley points out that large numbers of participants are required to ensure that confounding variables will be equally distributed between the groups, and the sample size in the current study was small even without being divided into an intervention and control group.

The study evaluated National Burn Camp, which began in 1996 and is run by the Burns Camps UK charity. Children aged 8-17 from burn clubs around the country are invited to Grafham Water Centre in Huntingdon, Cambridgeshire. The camp runs over seven days and is usually attended by around 50 children, and 20 volunteers. Parents do not attend the camp. Although children arrive at the camp with their individual burn clubs, they are then split into around six groups based on their ages, and participate in a morning, afternoon and evening activity each day. Morning and afternoon activities take place at the centre and include kayaking, wall climbing, archery, high ropes and mountain biking. The evening activities usually occur off-site and may include trips to the cinema, swimming pool, or bowling.

5.2.2 Participants

CYP with burn injuries aged 10-17 who had been invited to attend the UK National Burn Camp, and their parents/carers were eligible to take part. The CYP had all been treated for a burn and were referred to the camp through their individual burn clubs, located across the country, who make the decision on whether each child is ready to attend camp after their injury. Fifty one children attended the camp, 23 (45% of total attendees) of whom elected to participate in the study. 22 (43% of total attendees) parents/carers of the CYP who participated in the study also took part.

5.2.3 Measures

5.2.3.1 Quantitative measures

The following outcomes were assessed in the current study, and are provided in appendices 13-16:

- Social concerns, as evaluated by CYP using the Perceived Stigmatization Questionnaire (PSQ) and Social Comfort Questionnaire (SCQ) (Lawrence, Fauerbach, Heinberg et al, 2006)

- Satisfaction with appearance, as evaluated by CYP using the Satisfaction with Appearance Scale (SWAP; Lawrence et al, 1998)

- Behaviour, as evaluated by parents/carers using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

Perceived Stigmatization Questionnaire (PSQ) and Social Comfort Questionnaire (SCQ); Lawrence, Fauerbach, Heinberg et al, (2006)

The Perceived Stigmatization Questionnaire (PSQ) is the first questionnaire designed to measure stigmatizing behaviours experienced by those with a visible difference, and was originally validated with a sample of adult burn patients (Lawrence, Fauerbach, Heinberg et al, 2006). The PSQ has 21 items and contains 3 factors (absence of friendly behaviour, confused and staring behaviour, and hostile behaviour), which convey social acceptance, social discomfort, and social rejection to the perceiver. Total and subscale scores can be calculated. The Social Comfort Questionnaire (SCQ) has eight items and aims to measure an individual's perceived violation of privacy and feelings of social isolation (Lawrence, Fauerbach, Heinberg et al, 2006). Total scores can range from 1-5 on both measures and higher scores indicate higher levels of perceived stigmatization and social comfort respectively. These measures are not widely used, but have both been validated for use with the paediatric burns population, demonstrating reliability scores ranging from 0.78-0.89 (Lawrence et al, 2010).

The Satisfaction with Appearance Scale (SWAP; Lawrence et al, 1998)

The Satisfaction with Appearance Scale (SWAP) was designed to measure subjective satisfaction with appearance and the social-behavioural impact of burn scars (Lawrence et al, 1998). The SWAP has 14 items and has been validated for use in the burns population (Lawrence et al, 1998) and used within previous paediatric burns research (e.g. Bakker et al, 2011). Total scores can

range from 0-78, with higher scores indicating greater dissatisfaction with appearance and poorer satisfaction with appearance. The SWAP demonstrated a high level of internal consistency (Cronbach's alpha, r. = .87) and test-retest reliability of (r = 0.59).

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

The SDQ is a behavioural screening tool designed for completion by parents of 4-16 year olds (Goodman, 1997) which has also been used with paediatric burn patients ages 8-18 (Gaskell, 2007). It contains 25 items divided into 5 subscales: emotional symptoms, conduct problems, hyperactivity/attention, peer relationship problems and pro-social behaviour. Each subscale can score between 0-10, with higher scores on the first four subscales indicating a higher incidence of problem behaviours, and higher scores on the pro-social subscale indicating an increase in behaviours such as sharing or volunteering to help others. A total problem score can also be calculated by adding the scores of the first four subscales together. Goodman (2001) found that the SDQ demonstrated acceptable levels of internal consistency (Cronbach's alpha 0.73), and test-retest reliability (0.62). This measure has been used in previous burn camp research (Gaskell, 2007).

4.2.3.2 Open-ended questions

The questionnaire packs administered one month before camp and at the three-month follow-up also included open-ended questions, to compare children's and parents' views before and after the camp, which was an approach previously adopted by Maertens and Ponjaert-Kristoffersen (2008). Questions in the first pack asked children and their parents what they hoped the children would gain from camp, and whether there was anything they were worried about. The final questionnaire pack asked children and their parents for their views on what the children had enjoyed, whether they had gained anything from camp, what they felt was good about it and what, if anything, could be improved.

5.2.4. Data collection

Once ethical approval had been received from the University's Research Ethics Committee (UREC), the camp organisers sent out questionnaire packs to the parents of all the children attending camp (appendices 13-16). These packs included a covering letter from the researcher, separate information sheets for CYP and parents to allow families to make an informed decision about whether they would like to participate, consent forms to be completed by CYP and parents,

and the four measures and open-ended questions outlined above, along with a pre-paid envelope to return the packs to the researcher. Two weeks before camp the organisers asked club leaders to send out a reminder about the study to all of the children in their club who were due to attend camp.

The second data collection point took place at camp, with steps taken to minimise disruption to the ongoing activities and ensure that children who had consented to be in the study did not feel 'singled out' from those who had not, or vice versa. On the final afternoon of camp, all the children took part in the 'Grafham Challenge', a team-based event which involved groups of children rotating through a number of activities, such as archery or orienteering. Each group had a break with refreshments before they started the archery and it was decided following a discussion with camp organizers that this would be the most appropriate time to collect data. Children who had consented to be in the study completed the measures while the other children were given puzzles, which were also provided to participants after data collection.

The quantitative element of all three packs was identical, but included different open-ended questions at the one-month pre-camp and three-month post-camp time points. Therefore while the entire pre-camp questionnaire packs are included in the appendices (appendices 13 & 15), only the open-ended questions from the post-camp questionnaire packs are included (appendices 14 & 16).

5.2.5 Data analysis

The questionnaire data were considered too skewed (Appendix 18) to meet parametric assumptions (Coolican, 2014), so were analysed with SPSS using a Wilcoxon signed ranks test. However, as well as reporting any statistically significant differences between the scores in the study, it is also important to report effect sizes. These allow comparison between a variety of studies which have employed different variables, or used different scales of measurement, and so therefore makes the findings of the study more generalizable (Field, 2013). In addition, as the sample size of a study affects the standard error (and therefore the significance), the effect size can provide a more stable measurement of an outcome than simply examining the significance value alone (Field, 2013). Effect sizes were calculated using the formula outlined in Field (2013), where z is the z-score produced by SPSS and N is the number of participants in the study:

$$r = \frac{z}{\sqrt{N}}$$

Content analysis was employed as a method of analysis for answers to open-ended questions within the questionnaire booklets. Content analysis may be used as a descriptive technique to allow quantification of data, such as the frequency of particular responses to open-ended questions. Previous research into burn camps (e.g. Gaskell, 2007; Gaskell et al, 2010) has used content analysis to explore participants' experiences in this way. Content analysis involves the formation of categories, and then quantifying the number of times a particular response, or section of text, falls into that category (Silverman, 2011). As the current study examined the impact of burn camp on specific psychosocial constructs, it utilised a pre-set coding approach. Vaismoradi et al (2013) outline a procedure for conducting content analysis in healthcare research consisting of three stages: preparation, organising and reporting. Preparation involves transcription of responses and a complete immersion in the data. Organising involves grouping the responses into categories; in this case the psychological constructs outlined in the research questions. The final stage involves the reporting of the results from the first two stages. Reliability was ensured by asking a second member of the research team to review the codes (Coolican, 2014). Some of the parents' qualitative responses fit into more than one category, so the number of responses may exceed the number of participants, which is the case for the qualitative responses throughout the study. A summary of the results is discussed below.

5.3 RESULTS

While 23 CYP and 22 parents completed the first questionnaire pack, 21 (91%) of the CYP attending camp completed the pack on the last day of camp. The three-month follow-up packs containing child and parent measures were posted to families, and 13 CYP and 12 parents returned them to the researcher (50% and 48% of participating CYP and parents, respectively). The demographic characteristics of the participants who completed the questionnaires are outlined below in Table 3.

Demographic characteristic	N
Gender of CYP	8 male: 15 female
Mean age of CYP (range)	13.7 years (10-17 years)
Ethnicity of CYP	15 white: 1 Asian: 3 black: 4 mixed/multiple ethnic groups
Time since injury (range)	8.14 years (1-15)
Previous camp attendance	22 yes: 1 no
Number of previous camp attendances (range)	4.10 (1-18)
Gender of parents/carers	2 male: 20 female
Ethnicity of parents/carers	15 white: 2 Asian: 2 black: 2 mixed/multiple ethnic groups
Relationship status of parents/carers	2 single: 15 married/domestic partnership: 1 widowed: 4 divorced
Relationship to child	21 parent/carer: 1 grandparent

Table 3 The demographic characteristics of the participants

The scores from the standardised measures are presented in Table 4 and both quantitative and qualitative responses are discussed within each relevant section. SPSS output from the inferential analysis is provided in Appendix 19.

	Pre-camp Mean (SD)	Last day Mean (SD)	Follow-up Mean (SD)
Perceived Stigmatization Questionnaire (PSQ) total	1.99 (0.60) n=22	1.86 (0.55) n=21	1.86 (0.52) n=13 *
PSQ Absence of friendly behaviour subscale	2.12 (0.62) n=22	1.96 (0.59) n=21	1.98 (0.59) n=13
PSQ Confused/staring behaviour subscale	2.05 (0.84) n=22	1.90 (0.65) n=21	1.85 (0.76) n=13
PSQ Hostile behaviour subscale	1.70 (0.79) n=22	1.66 (0.73) n=21	1.68 (0.70) n=13
Social Comfort Questionnaire (SCQ)	3.94 (0.65) n=23	3.97 (0.74) n=21	3.93 (0.64) n=12
Satisfaction with Appearance Scale (SWAP)	20.05 (9.12) n=22	17.80 (9.92) n=20	13.18 (9.98) n=11 *
Strengths and Difficulties Questionnaire (SDQ) total	7.90 (6.87) n=22		9.08 (4.60 n=12
SDQ Emotional subscale	1.95 (2.19) n=22		1.50 (1.68) n=12
SDQ Conduct subscale	1.55 (1.44) n=22		1.67 (1.30) n=12
SDQ Hyperactivity subscale	3.14 (2.90) n=22		3.58 (2.54) n=12
SDQ Peer problems subscale	1.27 (1.90) n=22		2.33 (2.61) n=12

Table 4 Summary of scores from the PSQ, SCQ, SWAP and SDQ (*significant difference at p < 0.05 level between pre-camp and follow-up scores)

Does burn camp impact on CYP's social concerns?

SCQ scores can range from 1-5, with higher scores representing higher levels of social comfort. Participants' reports of perceived social comfort improved from pre-camp to end of camp, but had then decreased again by the three-month follow-up (Figure 12). While none of the differences were found to be statistically significant, a medium to large effect size was found between the scores on the last day of camp and at the three-month follow-up (r = -0.49).
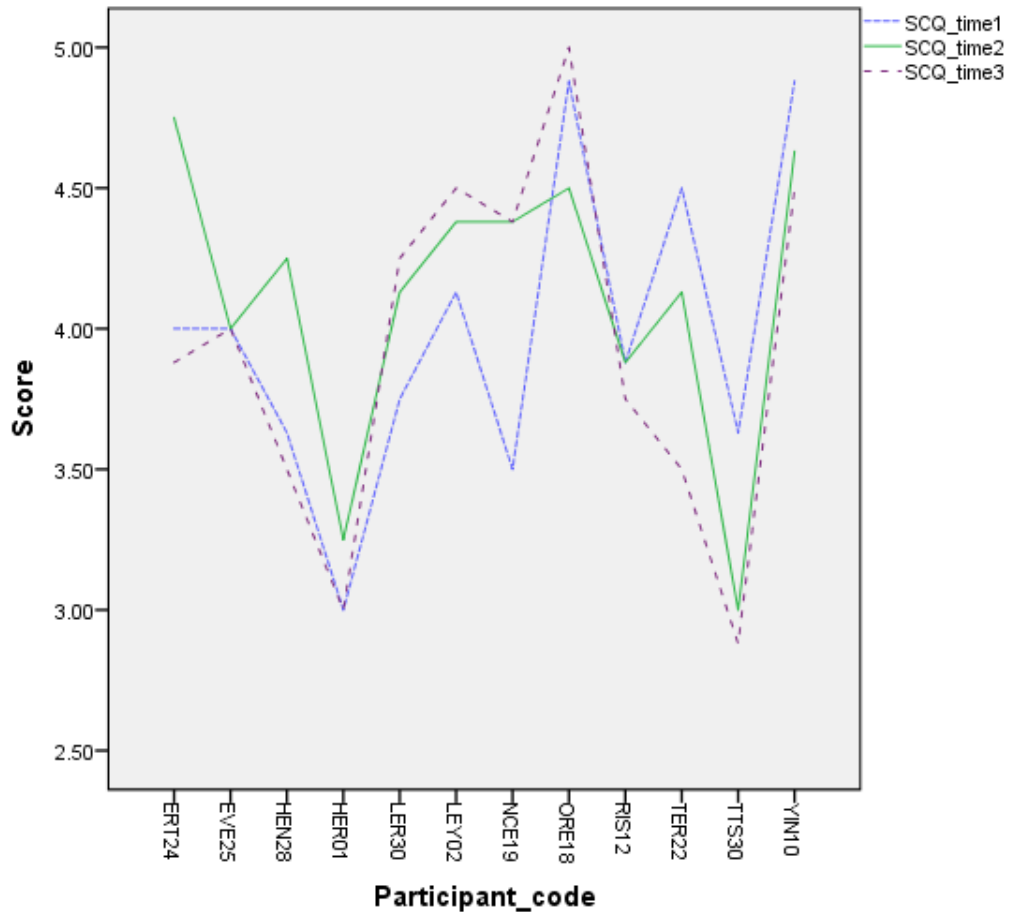
Figure 12 CYP's scores on the Social Comfort Questionnaire

PSQ scores range from 1-5, with higher scores indicting higher levels of perceived stigmatization. Higher scores on the PSQ as a whole indicated that participants perceived fewer stigmatizing behaviours at the end of camp when compared to pre-camp data, and this effect was maintained at the follow-up (Figure 13). This effect was statistically significant ($p = 0.02$) and demonstrated a large effect size ($r = -0.64$), indicating it was both statistically and substantively significant. In terms of the subscales, participants reported positive changes (an increase in others' friendly behaviour and less confused/staring and hostile behaviour) after camp, but an increase in confused/staring and hostile behaviours and less friendly behaviour at the 3 month follow-up. None of these effects were statistically significant, however a medium to large effect size ($r = -0.48$) was found between the pre-camp and follow-up scores on the confused/staring subscale.
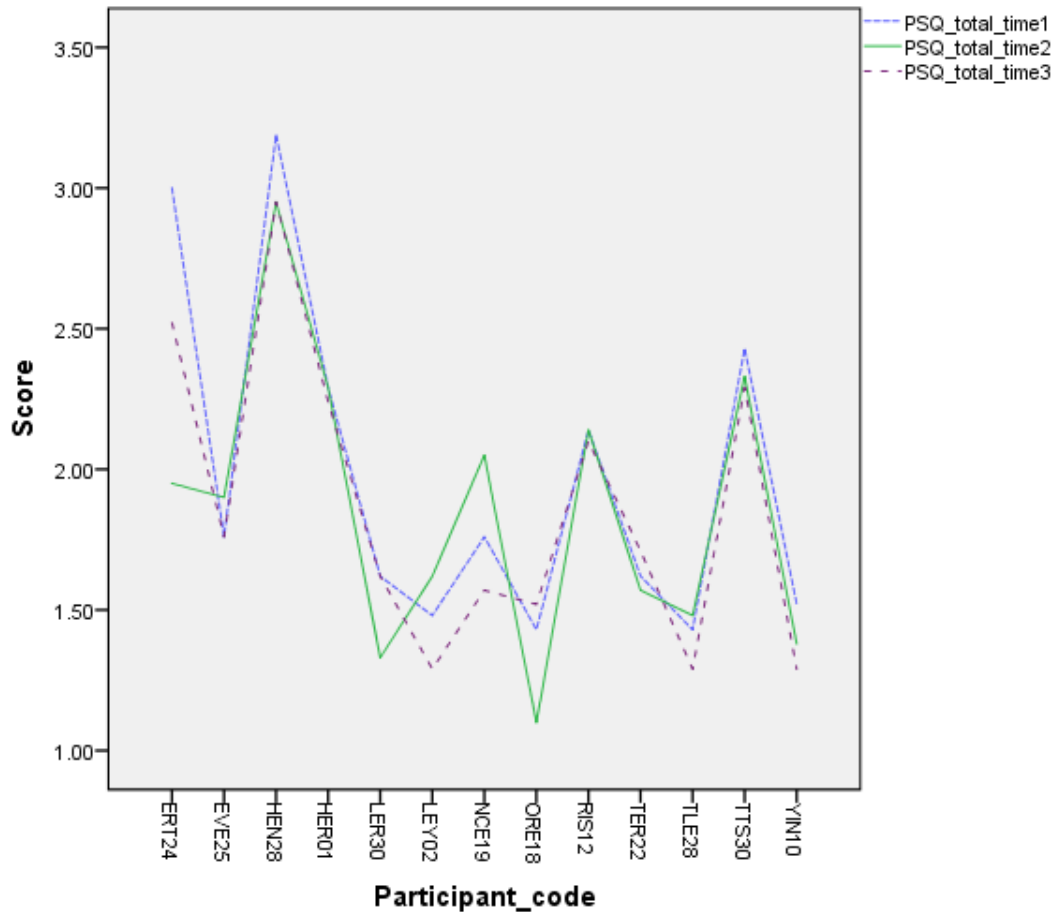
Figure 13 CYP's scores on the Perceived Stigmatization Questionnaire

The most common social-related qualitative responses before the camp tended to be related to making new friends, which was referred to by 15 CYP and four parents, while five CYP and 10 parents talked about the chance to meet other CYP who had been through a similar experience, "I love spending time with people who understand my feelings and have similar experiences as me" (girl, 13). This relates to item 2 on the SCQ "No one can understand me". Two parents hoped that camp would provide their child with the chance to meet a range of people from different backgrounds, while one thought it might improve communication skills, "Communication with people she does not know, due to soon applying to uni" (mother of girl, 17). After the camp only three CYP talked about friendship generally, whereas ten felt that they had benefitted from meeting others with similar experiences, and these responses were also given by four and eight parents respectively. Finally, three CYP felt that they had experienced negativity from one member of their group, "The negative people, being with them and how that affects the rest of the group" (girl, 17). While the type of negativity was not specified, it may relate to certain items on the PSQ, such as the extent to which people feel others are friendly towards them, or treat them with respect.

Scores on the SWAP can range from 0-84, with higher scores indicating greater dissatisfaction with appearance. Participants reported feeling more satisfied with their appearance at the end of camp when compared to the pre-camp measure, and this improved again at the follow-up (Figure 14). Only the difference between scores one month before camp and three-month follow-up was found to be statistically significant ($p = 0.03$) and, furthermore, this result also demonstrated a large effect size ($r = -0.65$), producing a result that is both statistically and substantively significant.
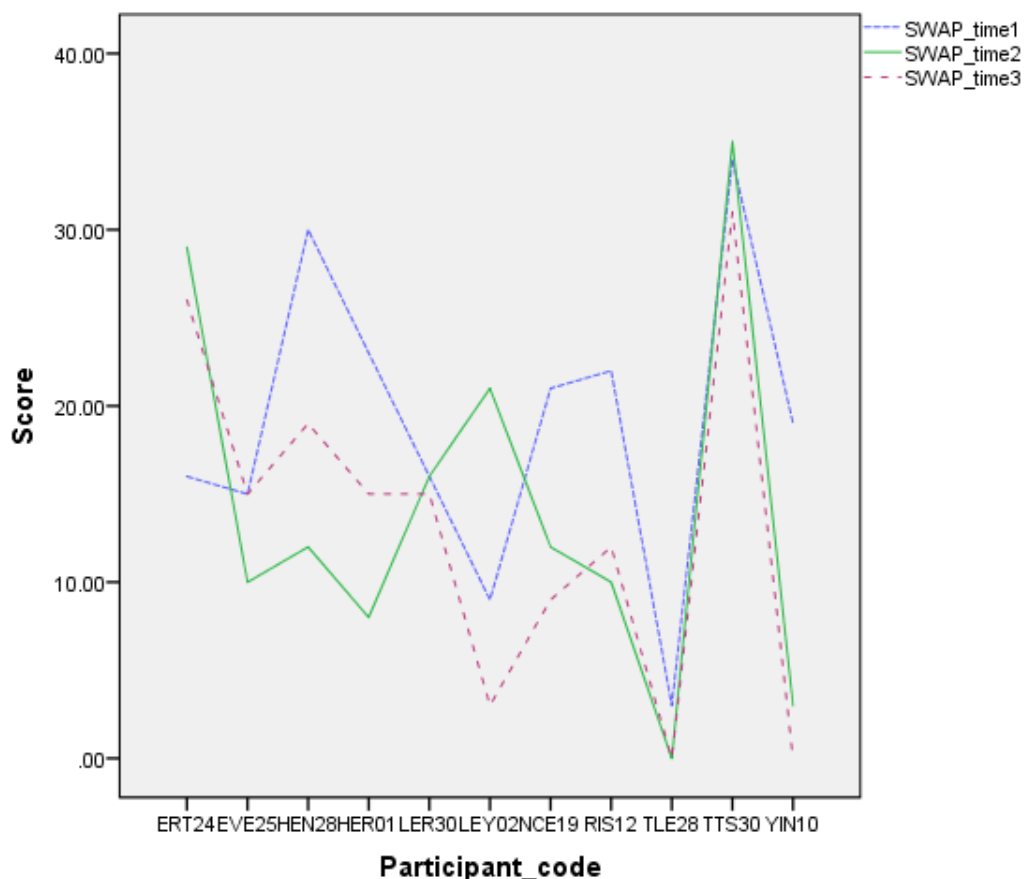
Figure 14 CYP's scores on the Satisfaction with Appearance Scale

The qualitative data revealed that only one CYP referred to appearance before camp, appreciating that they did not anticipate that they would feel embarrassed about their scars while they were there, "I love that everyone is in the same situation so there is no need to feel embarrassed about scars" (girl, 16). This can be considered in the context of the first two items on the SWAP: "Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my friends/strangers". One parent thought that her daughter would be able to talk to other CYP about her scars, "Speak to other children about their scars as she did on last camp" (mother of girl, 14). Prior to the camp two parents hoped that their child's appearance-related confidence

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would improve, while another hoped it would provide their child with some perspective on their injury, "Understand she is not the only one with a burn scar" (mother of girl, 12). While appearance-related confidence and perspective were not referred to by any CYP before camp, they were considered to be a benefit by three and two CYP afterwards, "I'm not the only one with scars. Also people have it much worse than I do" (girl, 17).

Does burn camp impact on CYP's behaviour?

Total difficulties scores on the SDQ can range from 0-40, with higher scores indicating a higher level of problem behaviours. Overall, parents' scores on the SDQ indicated a higher incidence of problem behaviours in terms of the emotional, conduct, hyperactivity, and peer problem subscales, and reduced pro-social behaviour three months after camp compared with before camp (Figure 15). Although these effects were not found to be statistically significant, a medium to large effect size was found for the overall SDQ (r = -0.46) and peer problems (r = -0.45) subscale scores, while a large effect size was found on the prosocial subscale (r = -0.5). All of the mean scores fell within the 'close to average' range outlined on the SDQ scoring instructions (see Appendix 17).
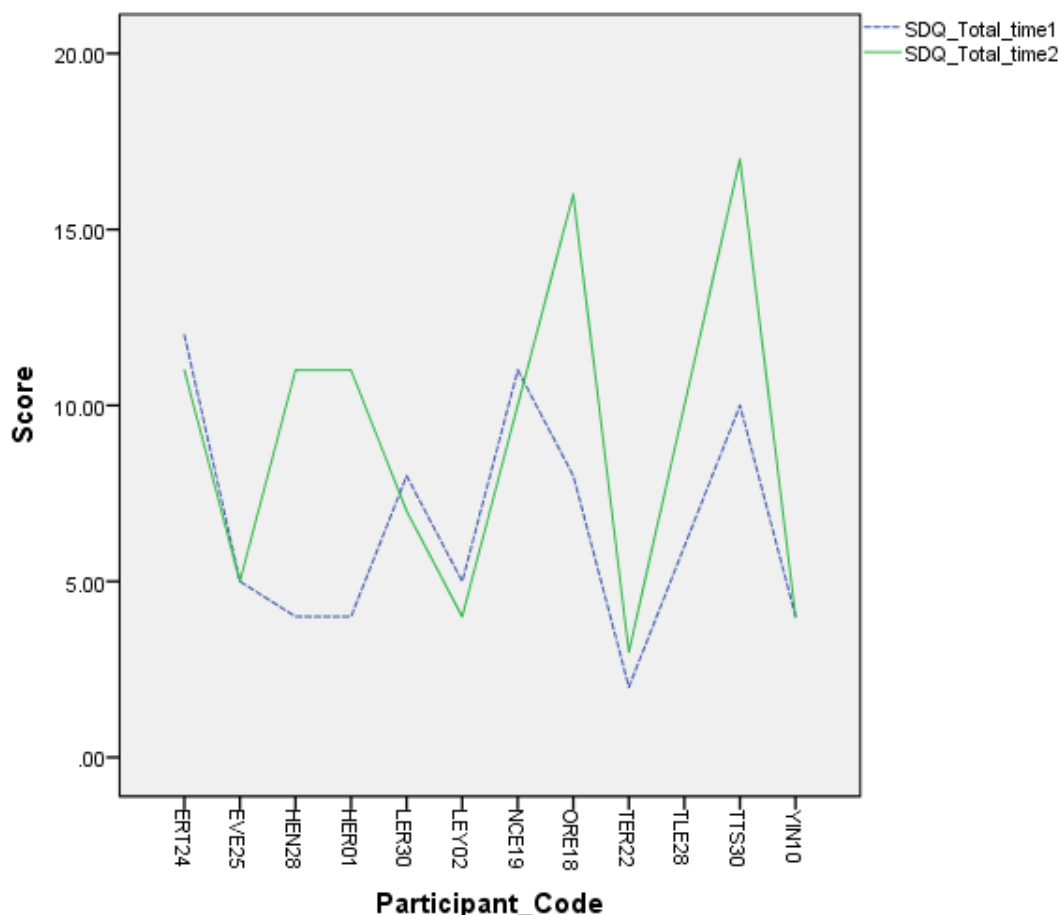

Figure 15 Parents' scores on the Strengths and Difficulties Questionnaire

The qualitative responses indicated that before the camp one CYP and three parents were concerned about behavioural issues, "That people will make me angry and I do something immature" (girl, 11), similar to item 5 on the SDQ: "Often has temper tantrums or hot tempers". One CYP and two parents hoped that camp would help CYP to become more accepting of their injury. Confidence in social situations was referred to by 12 parents prior to camp and nine afterwards, and while no CYP mentioned this beforehand, six thought that their confidence had improved after camp, "My confidence has improved so much. I used to be so shy and would have no confidence at all. Since camp my confidence has went right up" (boy, 16). Improved confidence relates to item 16 on the SDQ: "Nervous or clingy in new situations, easily loses confidence". Before the camp, two parents felt that camp may help their child become more mature, while another hoped it would help her daughter gain compassion, "I hope [she] will gain compassion towards others" (mother of girl, 13). This relates to the first item on the SDQ: "Considerate of other people's feelings". One parent thought camp may teach her son to be more independent, and two parents thought increased independence had been a benefit afterwards.

<u>Does burn camp offer any additional benefits to the CYP that attend?</u>

Responses to the open-ended questions indicated that some CYP and parents thought that camp had provided additional benefits. CYP tended to focus on having fun and activities, referred to by 18 CYP/4 parents before camp, and 16 CYP/3 parents after camp. Two parents thought that camp may lead to opportunities to arrange support for both parents and older children, "I think we could have a get together for the parents or share emails so the parents as well could organise some get together" (mother of boy, 11), while one recognised that CYP had the chance to talk to adults with burn care knowledge. One parent also felt that camp had provided a positive from a negative, "Continues to provide a positive focus for them after a terrible experience that could have such a negative effect on them" (mother of boy, 13).

5.4 DISCUSSION

This study explored the impact of burn camp on CYP's social challenges, satisfaction with appearance and behaviour. The analysis of qualitative data from both the children and parents revealed findings very similar to those reported in previous research (Bakker et al, 2011; Gaskell, 2007), referring to positives in the form of the chance to spend time with other children with burn injuries, gain confidence, increase self-esteem, master new skills and learn to accept their scars. The current study used a generic measure of parent-rated behaviour but employed three measures of children's social challenges and satisfaction with appearance developed specifically

for use with CYP's with burn injuries. The quantitative results are described in more detail below – it is important to recognise that the small sample size in the current study mean that the statistical significance of some findings should not be over interpreted, although can be considered indicative of the effects of camp. Furthermore, the Strengths and Difficulties Questionnaire is the only measure used in the current study which publishes information on norms. Therefore, while the results in the current study demonstrate an improvement in scores on outcome measures, it is not known how clinically important these differences are to participants.

Children's perceptions of stigmatizing behaviours, such as staring, name-calling or bullying, decreased from one month prior to camp, to the last day of camp and slightly increased again at the three-month follow-up. These findings suggest that children felt less stigmatized while at camp, and although perceived stigmatization scores worsened slightly after leaving camp, scores at the follow-up were still better than before camp. The confidence gained at camp which was described in the qualitative data may have helped children to become less troubled by perceived stigmatizing behaviours, or perhaps re-evaluate previous misconceptions of others' behaviours as less stigmatizing, and appears to have been more or less maintained after camp. Although other quantitative studies have not examined perceptions of stigmatizing behaviours, participants in Cox et al's (2004) qualitative study referred specifically to camp as a place where they knew they would not be stared at or judged by their appearance. The Social Comfort Questionnaire aims to determine CYP's level of comfort within social situations. Gaskell's (2007) study used the Social Worries Questionnaire (SWQ; Spence, 1995), which includes some similar items to the SCQ, such as those relating to meeting new people or crowded situations. Both Gaskell's study and the current study failed to find any significant impact of camp on the SWQ or SCQ scores respectively, suggesting that camp might not have a significant impact on CYP's feelings of social comfort, irrespective of the measure used.

CYP reported greater satisfaction with their appearance at the end of camp than one month prior to attending, and again at the three-month follow-up. While it is important to remember that numerous other factors may have had an influence on all the results in the three months since leaving camp, these results suggest that burn camp may have played a part in helping CYP to feel more positive and accepting about their appearance, a finding supported by several of the participants' qualitative responses. When asked how camp had helped them the majority of responses related to 'confidence', 'learning they are not alone', 'acceptance', and 'putting the injury into perspective'. Therefore it is possible that camp challenged CYP's negative thoughts about their appearance, which continued to improve once they returned to everyday life.

These results can be compared to those of Bakker et al (2011), who used a non-validated Dutch version of the SWAP and found that satisfaction with appearance improved in the short-term (comparing the scores 3 weeks before camp and 1-week post-camp) but not in the longer-term (comparing the scores 3 weeks before camp and 16-weeks post-camp). Bakker et al did not compare the scores 1-week post-camp and 16-weeks post-camp. The differences between Bakker et al's findings and those of the current study may relate to the use of the translated version. McKenna and Doward (2005) point out that translation is the just the first stage in creating a version of a measure in a different language, and that full adaptation can only be achieved after a full assessment of psychometric properties. Therefore, until the Dutch version of the SWAP is validated, caution is needed when comparing the results of Bakker et al's (2011) and the current study.

Analysis of the SDQ demonstrated that parents reported a higher frequency of problem behaviours three months after the camp than they had done one month before camp. However, it is notable that all the parents reported pre-camp scores that fell into the 'close to average' range outlined by the SDQ scoring instructions (SDQ Info, 2016), indicating that they considered their children to exhibit a low incidence of problem behaviours at this point. It is not known whether children displaying a higher incidence of problem behaviours would have benefited any more from camp than those who attended in the current study. Similarly to Gaskell (2007), who speculated whether camp may benefit some children more than others, the sample size in this study was too small to compare the scores of CYP scoring high or low on each measure.

An interesting interpretation of the SDQ behavioural scores 'worsening' is that the reported improvements in confidence may have led to an increase of behaviours which are rated by parents as problematic. For example, while a parent might indicate on the SDQ that their child fights more with other children, a possible interpretation is that increased confidence may have increased their willingness to participate in group discussions and argue a point in which they believe to be true, which are not listed as specific items on the SDQ. Blakeney et al (1993a) suggest that an increase in scores labelled as 'delinquent' or 'externalising' demonstrates an increase in CYP's assertiveness and expression of feelings, including those which may be construed as negative (e.g. anger). The finding that the most common qualitative response from parents referred to an increase in their children's confidence may support this finding. Therefore, the increase of 'problem' behaviours should not necessarily be construed as a negative finding.

5.4.1 Limitations and Future Research

The small sample size is a limitation of the current study, which resulted from nonparticipation and then attrition. Although around 50 children attended the camp, only 23 CYP and 22 parents elected to take part in the study, and almost half of these did not return the follow-up questionnaire. This is indicative of the difficulties in recruiting for, and maintaining interest in, burns research (McQuaid, Barton & Campbell, 2003). It has been suggested that the lack of personal contact related to postal questionnaires may contribute to attrition rates (McQuaid et al, 2003); however, this was considered the most suitable method for the pre-camp and follow-up questionnaires in the current study since participants were based across the UK.

The current study only involved one camp so it is not possible to generalise findings to others. However, the similarity of the qualitative responses in this study to past research investigating a variety of other camps suggests that generic benefits may be experienced by children attending burn camp, irrespective of practical factors, such as its location, staff and the activities on offer. It is also important to note that, unlike study 1A which involved solely first time campers, only one child in the current study had not been to burn camp before. The other participants had, on average, been four times previously. Therefore it is not known if the benefits of attending camp for the first time are the same as for those who are returning. While the longitudinal nature of Gaskell's (2007) study distinguishes it from other burn camp research, future studies could map responses from individual participants to examine whether cumulative attendance at camp produces any different effects.

It is also important to remember that the sample consisted solely of participants who had chosen to attend burn camp. It is possible that some CYP may choose not to attend because of social concerns or worries about appearance. Since burn camp has been found to improve issues such as these, it is possible that some of the CYP who could potentially gain the greatest benefits from going to burn camp may actually be avoiding it. Some CYP could benefit from additional support prior to attending camp, and this issue should be explored in future research.

5.5 CONCLUSION

The results from this study indicate that burn camp may provide a number of psychosocial benefits to the CYP that attend, although it is important to interpret the significance of the findings with caution due to the small sample size. While it is acknowledged that the intervention was not available for other family members, parents were asked to provide their perspectives on

the camp. The second research question asks how interventions meet different levels of need. The qualitative findings from the current study concurred with numerous past accounts of burn camps from both CYP and parents, indicating that the practical aspects such as location or timetable of activities at a burn camp may be less important than the inclusive experience of spending time with other people who have been through something similar. The quantitative findings indicated that in the short term camp may indeed improve feelings of social comfort and body satisfaction, while reducing perceptions of stigmatizing behaviours. While social comfort scores had decreased again at the 3-month follow-up, perceived stigmatization scores were maintained and satisfaction with appearance had improved further.

Although parents reported a higher incidence of problem behaviours after the camp than before it, this may have related to increases in their children's confidence. While it is important not to assume that any observed effects at the follow-up were due to the burn camp alone, these findings do lend support to the importance of using outcome measures which specifically address psychosocial constructs relevant to CYP with a burn injury. The positive results reported by many participants suggest that camp may be beneficial to a large number of CYP who attend.

A strength of this study was that it revealed similar qualitative and quantitative results, so it may be considered a first step in closing the gap between the two methods of data collection in burn camp research. This study also supports study 1A in the thesis, as it revealed a number of similar benefits, in addition to demonstrating how outcome scores changed over time. Studies 1A and 1B support the notion that a lower-level intervention may be appropriate for the majority of CYP with burn injuries and their families. However, it is recognised that burn camps do not tend to offer targeted psychosocial techniques to CYP and more research is therefore needed to evaluate the effects of psychosocial interventions for CYP with a higher level of psychosocial need. The next study in the thesis thus involves an intervention at a higher level on the CAR framework.

6.1 INTRODUCTION
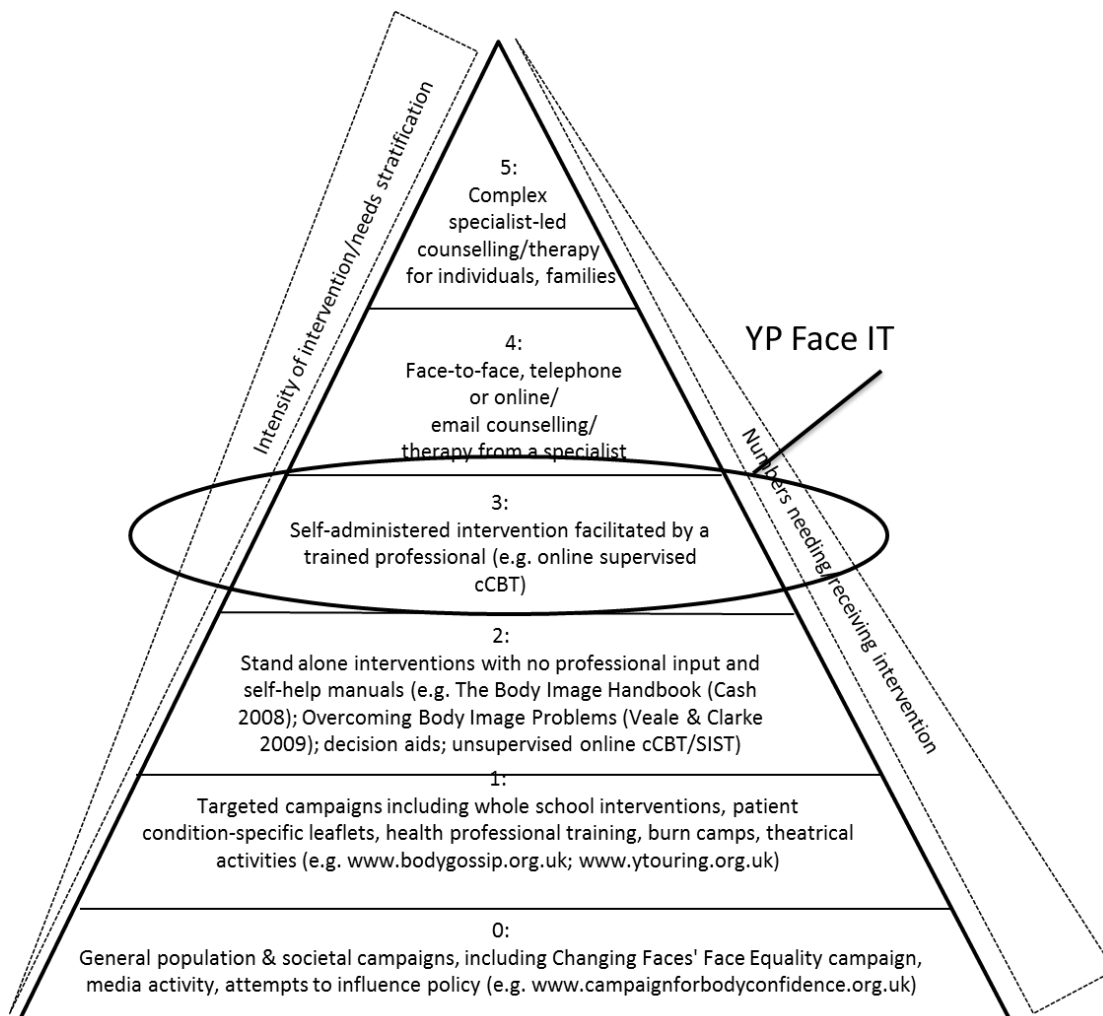
Figure 16 The location of YP Face IT on the CAR framework of appearance-related interventions

This chapter focuses on an online intervention, YP Face IT (www.ypfaceit.co.uk), located at level 3 of the CAR framework. As described in section 2.2 and study 3, the majority of research into psychosocial interventions for CYP with burn injuries tends to focus on burn camps or one-to-one therapy, although it is recognised that these techniques may not be the most appropriate for everyone (discussed further in 7.3). While there are currently no burns-specific online interventions, YP Face IT (YPF) was designed for CYP with any appearance-altering condition or injury who are experiencing appearance-related concerns, similar to those often found following a burn injury (see section 1.3). Previous research has found YPF to be acceptable to CYP with a range of appearance-altering conditions (e.g. cleft lip and/or palate, scarring, skin conditions), parents and health professionals (Williamson, Griffiths & Harcourt, 2015). It was therefore considered important to examine whether the programme would be feasible and acceptable

within the paediatric burns population. The chapter begins with a discussion of previous research into online interventions, and then outlines the development of YPF. The feasibility and acceptability of the programme to CYP, carers and clinical psychologists was explored using a mixed methods approach.

6.1.1. Online therapy

Online therapy was introduced within section 2.2 and can take a number of different formats. Griffiths (2003) suggested that there are three main types of online therapy: websites providing information; peer-delivered therapeutic support and advice (such as self-help or peer-support groups); or professionally delivered therapy (such as email responses to queries or live chat rooms). More recently another model of online therapy has emerged, which involves a self-management psychological intervention with interactive activities and automated responses. Such interventions are often based on CBT techniques and have been found to be as effective as the more commonly used group-based CBT (Bergstrom, Andersson, Ljotsson et al, 2010).

This style of therapy can significantly improve symptoms of anxiety and depression within secondary care settings (Learmonth, Trosh, Rai et al, 2008), even with minimal supervision such as bi-weekly telephone calls (Bell, Colhourn, Carter & Frampton, 2012). It has also demonstrated high uptake and completion rates similar to those of traditional therapy and has received generally positive feedback from patients (Carter, Bell & Colhourn, 2013). Furthermore, Learmonth et al (2008) found that only 1 out of 5 adult patients suffering from anxiety and/or depression required referral for face-to-face therapy after completing a programme of online therapy, and that the capacity of a specialist CBT centre studied was increased by 50%. YPF is an example of self-management online therapy, so the term 'online therapy' throughout the rest of this chapter will refer to this style of intervention. A number of interventions for other conditions have been previously evaluated such as FearFighter, Beating the Blues, and MoodGYM, which provide close models of support to delivery to YPF.

Beating the Blues and MoodGYM are programmes of online CBT aiming to reduce symptoms of depression. Beating the Blues involves a 15 minutes introductory video followed by eight one-hour interactive sessions to be completed online on a weekly basis (Kaltenthaler, Parry, Beverley, et al 2008), while MoodGYM involves five interactive modules to be completed on a weekly basis, followed by a refresher of all content during the sixth week (Christensen, Griffiths & Jorm (2004). FearFighter provides patients suffering from panic/phobic anxiety with six sessions of computer guided self-help along with printable information, homework diaries and progress charts

(Kenwright, Liness & Marks, 2001). All three studies have been evaluated by asking participants to complete sessions with minimal involvement from a health professional, with positive results.

Significant improvements have been found for symptoms of depression and anxiety in adult patients following completion of both Beating the Blues (Proudfoot, Ryden, Everitt, et al, 2004) and MoodGYM (Christensen, Griffiths & Jorm (2004). Hayward et al (2007) determined that FearFighter led to a number of improvements including social anxiety, depression and agoraphobia scores in adult patients living in rural areas. Furthermore, the majority of patients found the service to be good or excellent and were satisfied with the help and guidance they had received. The majority of GPs in the study felt that their patients had benefitted from FearFighter and agreed that it was a suitable mode of therapy for patients living in rural areas. However, while two-thirds of patients reported the lack of a face-to-face therapist as a benefit due to increased confidentiality and autonomy, two-thirds felt that they missed having someone to talk to directly; suggesting that contact with a therapist may be beneficial throughout the duration of the programme.

Participation and attrition rates varied across the three studies. For example, 146 participants were allocated into the treatment group completing Beating the Blues, with around 40 patients being lost at each of the four follow-ups (post-treatment, 1-month, 3-month and 6-month) and resulting in a final sample of 92 participants (Proudfoot et al, 2004). 83% of participants in Christensen et al's (2004) study returned the post-intervention questionnaires, while 79% of participants completed MoodGYM. Fifty five participants (62% of those referred by GPs) were deemed suitable for inclusion in Hayward et al's (2007) study, 35 of whom actually started the programme. The majority (26 participants) completed the intervention and provided post-treatment data and six of the remaining nine participants provided post-treatment data after completing part of the intervention.

While studies such as these have demonstrated that online therapy can be very helpful for certain people, a number of unhelpful aspects of the technique have also been reported, including the amount of work required to complete the programme, the pace of the programme and issues relating to the content and delivery of the software (Richards & Timulak, 2012). Some patients have reported feeling unsupported to help them adhere to the programme, or experienced technical issues (Gerhards et al, 2011). However, sufficient levels of support (Gerhards et al, 2011) and user testing prior to release may address these issues (Richards & Timulak, 2012).

Mental health professionals have reported positive feedback towards online therapy (Macgregor et al, 2009), although have cautioned against the use of freely available programmes for children and adolescents (Stallard, Richardson & Vellemann, 2010). It is recommended that online therapy should involve support from a trained mental health professional rather than a layperson such as a teacher; however research has indicated that support can be carried out by a facilitator with minimal CBT training, rather than a CBT therapist (Stallard, Richardson, Velleman & Attwood, 2011). The facilitator can reduce any confusion CYP may experience with the software, and can help the patient apply the knowledge gained throughout the programme to their individual circumstances.

6.1.2. The development of Face IT/ YP Face IT

The systematic review of psychosocial interventions for individuals with visible differences (Norman & Moss, 2015) discussed in section 2.2 found that none of the included studies sufficiently demonstrated the effectiveness of the reported interventions. However, it did provide some support for the use of CBT and SIST. Face IT (Bessell, Clarke, Harcourt et al, 2010) is a programme of online therapy for adults with visible differences, developed to target issues such as social anxiety and poor self-esteem. It consists of eight weekly sessions of around 40-60 minutes, incorporating CBT strategies aiming to develop self-management skills to reduce levels of social anxiety and negative thoughts related to one's own appearance, and SIST strategies aiming to teach how to manage negative reactions of other people and help improve social relationships.

Face IT was developed with the input of user perspectives at every stage (Bessell et al, 2010), and then tested against a non-intervention control group, as well as a conventional face-to-face CBT group. Both conventional CBT and the Face IT programme produced improvement in psychological functioning, an effect which was found to be maintained at three and six-month follow-ups. Face IT was found to effectively reduce symptoms of anxiety, depression and appearance-related concerns, whilst positively promoting healthy adjustment (Bessell, Brough, Clarke et al, 2012). The positive findings from this study generated a need to investigate whether the programme could lead to similar results in CYP. The acceptability of Face IT to CYP with a visible difference was evaluated using a participatory approach, taking into account the views of the researchers themselves, along with those of CYP with visible differences, parents and health professionals.

This approach was deemed essential to the development of the intervention as it allowed all relevant stakeholders to make relevant contributions to the future implementation of YPF. For example, the researchers contributed their knowledge of evidence-based intervention development, while the CYP outlined the realities of living with a visible difference. Parents and health professionals discussed their experiences of living, or working, with CYP affected. Overall, feedback from 32 adolescents, parents and clinical experts led to the decision to adapt Face IT for CYP rather than use it in the adult format (Williamson, Griffiths & Harcourt 2015). The suggested amendments to the design of Face IT led to the development of a young person's version of the software (YP Face IT: YPF).

Like Face IT, YPF incorporates aspects of both CBT and SIST to promote self-management techniques to improve self-perception (self-worth and romantic appeal), body-esteem, and social functioning (perceived stigmatization, social anxiety and social skills). YPF was based on Kent's (2000) integrated model (introduced in section 2.1.5). According to Kent's model, a triggering event, such as a negative reaction from others, can lead to the development of body image disturbance which YPF addresses by targeting negative assumptions about one's own appearance according to cultural and societal appearance norms, and by tackling negative cognitions relating to body image. The CBT element of the programme applies here and aims to address appearance-related concerns and negative thought patterns associated with one's own appearance, as well as the behaviour of others around them.

According to Kent's model the development of body image disturbance can then lead to a reduction in social contact or avoidance behaviours, and reduced social skills. The SIST element of YPF aims to address this outcome by targeting CYP's social skills and helping build or improve relationships with others. The programme therefore focuses on helping CYP to develop their own techniques to deal with their individual circumstances. If CYP want to complete the programme in full they are asked to complete 7-weekly sessions, each lasting around 35-45 minutes and containing different activities and exercises. The sessions are structured as follows:

Session One: Common problems

This session begins by explaining that the aim of YPF is to provide CYP with a toolbox of skills to help them deal with the challenges of a visible difference by improving social skills and psychological adjustment. It introduces CYP to common challenges or issues faced by those with a visible difference, such as social anxiety, negative reactions, becoming preoccupied with appearance, body image and self-esteem. Finally it starts to consider what strategies may be available to CYP to help them cope with their difference. Key points include:

- Why does society place so much emphasis on appearance?
- Why do people react in certain ways to a visible difference?
- How will YP Face IT help CYP employ strategies to help them feel better?

Session Two: Improve your social skills

The session aims to improve social skills to help CYP look and feel more confident, focussing on the importance of body image and learning helpful talking skills. It includes quotes from other CYP with visible differences discussing their experiences of how improving their social skills and body language has led to more positive social interactions. A range of different body language (e.g. posture, eye contact, gestures) and talking skills (tone of voice, active listening, starting a conversation) are introduced, along with exercises to help CYP practise these skills.

Key points include:

- What are social skills and why are they important?
- How can changing tone of voice, actively listening and starting conversations affect social interactions?
- Examples of helpful and unhelpful reactions to social situations using interactive scenarios allowing CYP to choose how they would act and how this might cause others to react.

Session Three: Don't be SCARED, REACH OUT

This session focuses on using the Changing Faces SCARED and REACH OUT models to overcome difficult social interactions. The SCARED acronym represents how the person with the visible difference and another person may feel within a social interaction as follows: If you behave Shy, Cautious, Aggressive/Anxious, Retreating, Evasive or Defensive then other people may behave Staring/Speechless, unComfortable, Awkward/Asking, Rude, Evasive or Distracted. REACH OUT is an acronym relating to both verbal and non-verbal skills to help CYP cope with difficult social situations as follows:

R = Reassurance (reassuring people to put them at ease)

E = Energy, Effort and Enthusiasm (a way for CYP to show others that they are willing to make the effort to be sociable using positive body language)

A = Assertiveness (CYP sticking up for themselves and letting others know how they feel and what they need)

C = Courage (using courage to tackle difficult situations)

H = Humour (making jokes or focusing on the funny side of things to reduce the impact of negativity and put others at ease)

O = Over There (strategies to stop people focusing on a CYP's visible difference)

U = Understanding (accepting that some people do not know how to deal with visible differences)

T = Try Again (not giving up)

Key points include:

- What are the SCARED and REACH OUT models?
- How can CYP manage difficult social situations? For example, through the use of positive social skills and body language.
- Examples of positive and negative social skills using interactive videos.

Session Four: Think, feel, do

This session examines how CYP's thoughts can affect their feelings and behaviour. It explains how negative thinking traps can cause CYP to misread situations and provides quotes from other CYP with visible differences who have experienced negative thinking. It provides CYP with advice on how to 'catch it' (learn to notice negative thoughts), 'check it' (assess whether the negative thought is true) and 'change it' (from a negative to a positive thought). Finally, it uses interactive examples of social situations to help CYP distinguish between positive and negative thoughts. Key points include:

- What are the types of negative thinking traps experienced by CYP?
- How does negative thinking affect socialising and lower self-esteem?
- Catch it, Check it, Change it: how to think more positively

Session Five: SMART goals

This session helps CYP to use SMART (specific, measureable, achievable, realistic and time-based) goals to overcome any problems. It begins by introducing the notion of goal setting and how this can be important for self-esteem, and includes quotes from celebrities with visible differences about their experiences. It outlines how CYP can use action plans to tick off smaller goals on the way to reaching their overall goals. It also includes a section on romantic relationships with quotes from other CYP and how they have experienced relationships with others. It provides CYP with various romantic scenarios and asks them to choose how they may react, providing feedback for each of their choices. Key points include:

- How can CYP use SMART goals to overcome their problems?
- Examples of setting goals to overcome problems such as going swimming or going back to school
- A section on romantic relationships based on research that suggests CYP with a visible difference can struggle with these (Griffiths et al, 2012).

Session Six: Beating anxiety

This session considers anxiety and how it makes CYP feel. The session includes a video relating to hyperventilation and the panic cycle, as well as quotes from other CYP with visible differences who have experienced anxiety. CYP are introduced to the idea of 'testing the water' by practising the things they find difficult until they have overcome their fears. An example of a fear ladder (rating the situations which CYP find scary from 1-10) is provided to help CYP work out which situations are the easiest to begin with. Key points include:

- What is anxiety and what are the symptoms?
- Skills to beat anxiety, e.g. exercise, deep breathing, muscle relaxation, distraction and mind games
- How can CYP test the water to practice their anxiety beating skills?

Session Seven: Looking at your progress

This session reviews all of the information CYP have received in the first six sessions. Key points include:

- How can positive social skills improve social interaction?
- Understanding and changing negative thinking patterns
- Using SMART goals to overcome any problem

There is also a 'homework' assignment each week, to help CYP practise the skills they have learnt in the previous week. Six weeks after the final session they are asked to complete a 'booster quiz' to reinforce the skills they have learnt throughout the programme. CYP who would like to use YPF are given a secure login to access the software using their own computer and automated text and email reminders are sent to participants prior to each session so that they know when each is due.

The specific research questions were:

1. How feasible is it to conduct a study of the effectiveness of YPF in secondary burns care?
2. How acceptable is YPF to YP with burns?
3. What are parents' views on their children using YPF?
4. How acceptable is the therapeutic content and mode of delivery YPF to clinicians?
5. How would clinicians incorporate YPF in practice?

6.2 METHOD

6.2.1 Design

Feasibility studies are a useful tool to determine whether an intervention should be subjected to additional testing, which can help to identify those interventions which are most likely to be effective (Bowen et al, 2009). However, rather than directly assessing the effectiveness of the intervention (Lancaster, 2015), they are considered a key part of the development and testing of an intervention (Craig, Dieppe, Macintyre et al, 2008). They can be used when there is limited published literature on a specific intervention (Bowen et al, 2009), which is appropriate for the current study as few studies have been conducted using YPF. Feasibility studies may explore issues such as the number of eligible participants, clinicians' willingness to recruit participants, and adherence rates (Arain, Campbell, Cooper & Lancaster, 2010). An important element of an intervention-based feasibility study is the acceptability of the intervention to both those who deliver and receive it, by investigating constructs such as satisfaction with use, how appropriate the intervention is perceived to be to the individual or within a particular organisation, or whether participants intend to continue using it (Bowen et al, 2009).

The current research was a feasibility (including acceptability) study of YPF for CYP with a burn injury treated within secondary care. There is no standard model for the conduct of feasibility studies (Vandelanotte & De Bourdeaudhuij, 2003) but it has been suggested that they should involve basic quantitative measures with more in-depth qualitative techniques to achieve a comprehensive insight into how the intervention may function on a small scale (Moore, Audrey, Barker et al, 2015). Therefore, this was a fully mixed (QUAN + QUAL) design, as it employed both quantitative and qualitative techniques across the research objective, type of data, type of analysis and type of inference (Leech & Onwuegbuzie, 2009). As discussed in section 3.1.4, qualitative elements can used to add depth to statistical findings from a quantitative study, which can in turn add precision to qualitative findings (Greene & Caracelli, 2003). The current study used quantitative measures pre- and post-intervention, to examine whether scores differed at these two time points. This was considered an important part of the feasibility element as changes in scores could help determine which aspects of the programme should be evaluated in future research. The interviews were intended to explore participants' experiences in greater depth, to consider whether the study was acceptable to CYP with burn injuries and their families, as well as psychologists working in secondary care.

The design of the study was similar to that of previous feasibility and acceptability studies, such as that conducted by Rudolph, Christie, McElhone, et al (2006), and the aforementioned study by Hayward et al (2007). Hayward et al (2007) employed outcome measures before and after treatment, and at a 6-month follow up, and administered both patient and professional satisfaction questionnaires immediately after treatment. Rudolf et al (2006) conducted a pilot study of a community-based intervention called WATCH-IT, aimed at helping obese CYP lose weight. There were three different aspects to Rudolf et al's pilot study:

1. A process evaluation – measuring attendance, the amount of support received from staff, and staff views of the intervention.

2. User views – qualitative interviews with the children to determine their views and experiences of using the intervention.

3. Change in Body Mass Index, psychological wellbeing and quality of life – measured at baseline and at three and six months.

Healthcare professionals in the current study were clinical psychologists identified through the British Burn Association Psychosocial Special Interest Group. Psychologists needed to be working within paediatric burns services in secondary care, and be confident that they would be able to recruit eligible participants into the study. They were first asked how many patients they identified as being suitable for the study, and how many of those patients elected to take part and completed the intervention. As one of the key research questions for the current study was to examine how clinicians would incorporate YPF in practice, psychologists were asked to use the intervention in the manner they deemed most appropriate, recording the length and type of support they provided for each session and for each individual patient. In accordance with both Hayward et al (2007) and Rudolf et al (2006), CYP were invited to an interview following completion of the programme to explore their experiences of using the programme, and levels of satisfaction. Parents/carers were also invited to discuss their thoughts on their child's use of the programme. Finally, healthcare professionals were interviewed to find out how feasible they found YPF to be within their practice.

Like the study by Hayward et al (2007), the current study did not use randomisation or a control group. Bottomley (1997) questions the ethical implications of randomising participants into a non-intervention group, as this may ultimately be denying them treatment which could improve their psychological wellbeing. Furthermore, randomisation was not used as psychologists were asked to specifically select patients whom they felt may benefit from taking part, a process that would be used if the programme were rolled out into routine care. Therefore, it was important to ensure that this process of selection was suitable for use with YPF.

6.2.2 Participants

Participants were those who were expressing appearance-related concerns or experiencing teasing as a result of the burn injury, and their parents/carers. The severity of the burn was not considered to be a deciding factor as previous research has suggested that it is not the size or severity of the burn which determines an individual's psychosocial adjustment to the injury (see sections 4.3.1 and 8.2.2 for more discussion around this). There were a number of inclusion criteria for the study. The first three criteria were introduced specifically for the current study, while the remaining criteria were previously selected by the developers of the intervention and were based on feedback from clinical experts:

- CYP aged 11-18 years (the study originally aimed to include those aimed 12-17 but ongoing PPI work with psychologists revealed that they felt it would also benefit those aged 11 and 18, so the age criteria was later amended).

- Those who are at least 12 months post-burn. PPI discussions with clinical psychologists prior to the study indicated this would help to reduce the likelihood of participants currently suffering from PTSD symptoms, which YPF is not designed to target.

- Those with an altered appearance as a result of a burn injury.

- Those expressing appearance concerns, appearance-related anxiety or appearance-related teasing / bullying at school.

- Those who are fluent in speaking English.

- Those with parental consent to take part in the study.

- Those with access to a private computer with an internet connection.

The programme was not suitable for those:

- With a history of clinical depression or psychosis.

- With an eating disorder.

- With post-traumatic stress disorder (PTSD) a risk associated with traumatic injury.

- With a learning disability severe enough to compromise informed consent.

- Currently receiving a structured psychological intervention.

The inclusion criteria for the health professionals in the study were that they needed to be qualified clinical psychologists working within paediatric burns in secondary care in the NHS. Ten clinical psychologists from nine different NHS trusts took part in the study. Ten CYP originally consented to take part in the study but only three completed the whole study. Details of these

three participants are presented in Table 5, while further information about the participants who did not complete the study can be found in Table 6. All names are pseudonyms.

Name	Nature of participant
Jasmine	CYP aged 14
Alisha	CYP aged 17
Zoe	CYP aged 17
Suzanne	Guardian of CYP aged 14
Fiona	Psychologist
Cynthia	Psychologist
Kelly	Psychologist
Lynda	Psychologist
Kim	Psychologist
Dee	Psychologist
Joanna	Psychologist
Gwen	Psychologist
Teresa	Psychologist

Table 5 Participants in the study of the acceptability and feasibility of YP Face IT

6.2.3 Measures

As discussed in section 3.4, PPI work was conducted with clinical psychologists prior to the start of the study, to decide upon the most appropriate ways of collecting data to answer the research questions. Six quantitative measures were included to examine self-perception, body image and social functioning, while qualitative responses were obtained using interviews. Participants completed measures at baseline and after the programme had been completed. CYP were also asked about their experiences of completing the measures and psychologists were asked about the suitability of these measures.

Self-perception

1) Self-Perception Profile for Adolescents (SPPA) (Harter, 2012a)

The SPPA aims to assess how CYP evaluate themselves differently across the different areas of their life (Harter, 2012a). It has been found to be a valid and reliable self-report measure of adolescents' self-perception (Harter, 2012a; Rose, Hands & Larkin, 2012). Rimmer (2007) recommended its use with CYP with burn injuries. The self-perception profile for children (SPPC; Harter, 2012b), which is designed for children aged 8-15 was also used with CYP with burns by Gaskell (2007), when evaluating the effects of burn camp. The scale was developed to measure various components of self-evaluation and is designed to reduce the likelihood of socially

desirable responses. The child is presented with two statements for each question and asked to decide which statement they feel most accurately reflects them. They then decide whether the statement is "Really true for me" or "Sort of true for me". Each subscale has five items. The following two subscales from the SPPA were used.

1a) Global self-worth subscale

This subscale examines the extent to which a CYP is happy with the way they are as a person and the way that they are leading their life. It is similar to Rosenberg's (1979) concept of self-esteem. Global self-worth scores on the SPPA have also been found to be strongly related to scores on the Rosenberg's (1965) self-esteem scale, suggesting that both scales measure similar concepts (Hagborg, 1993). This subscale has an internal reliability of 0.8-0.89.

1b) Romantic Appeal Subscale

This subscale examines the extent to which a CYP believes they are romantically attractive, fun and interesting, and that they are dating the people whom they want to date. This scale has an internal reliability of 0.75-0.85.

Body image

2) The Body Esteem Appearance subscale from Mendelson, Mendelson and White's (2001) Body Esteem Scale for Adolescents and Adults

The Body Esteem Appearance subscale measures a CYP's general feelings about their appearance. It has 10 items on a five-point scale ranging from 0 (never) to 4 (always). A higher score relates to more positive body esteem. It has demonstrated good internal consistency (0.92) and re-test reliability (0.89), and also been found to relate to global self-esteem (Mendelson et al, 2001). It has been used specifically to evaluate the body esteem of burn survivors (Lawrence et al, 2004), producing an individual subscale coefficient alpha of 0.95.

3) Satisfaction with Appearance Scale (SWAP, Lawrence et al, 1998)

Characteristics of the SWAP are described in section 5.2.3. The SWAP was used in conjunction with the appearance subscale of the Body Esteem Scale (BES). The BES is a measure of general body esteem often used in the general population, whereas the SWAP was designed for use in the

burns populations. The two measures were compared to identify whether the programme had an effect on general body satisfaction and/or a more burns-specific measure of body satisfaction. One of the research questions within the current study aimed to determine how feasible it would be to conduct a study of the effectiveness of YPF in secondary burns care, so it was considered important to examine whether future studies involving YPF should focus on general or more burns-specific appearance outcomes.

Social functioning

4) Perceived Stigmatization Questionnaire (PSQ; Lawrence, Fauerbach, Heinberg et al, 2006)

The PSQ is designed to measure stigmatizing behaviours experienced by those with a visible difference and is described in detail in section 5.2.3.

5) The Social Anxiety Scale for Adolescents (SAS-A; LaGreca & Lopez, 1998)

The SAS-A has 22 items (four of which are filler items) and is divided into three subscales: Fear of Negative Evaluation (FNE, eight items); Social Avoidance and Distress Specific to New Situations (SAD–N, six items); and Generalized Social Avoidance and Distress (SAD–G, four items). FNE relates to worries about negative evaluation from peers, SAD-N relates to anxiety in new situations and SAD-G relates to general social anxiety. Each item is scored on a 5-point scale and the subscale scores can be added to form an overall score. A higher score represents higher levels of social anxiety. The SAS-A has been selected as a psychometrically sound measure for assessing social anxiety in adolescents (Inderbitzen-Nolan & Walters, 2000). Internal consistencies for the three subscales are 0.91 for FNE, 0.83 for SAD-N and 0.76 for SAD-G (Cronbach's alpha). This measure was also selected as it is the only measure to assess SAD-N and SAD-G separately. As previous literature has indicated that new social situations can be extremely challenging for those with a visible difference (Robinson, Rumsey & Partridge, 1996), this measure was used to determine whether YPF can improve feelings towards these different social situations.

6) Social Skills Improvement System questionnaire (SSIS-RS; Gresham & Elliot, 2008)

The SSIS-RS was chosen to evaluate the social skills that YPF is aiming to improve. The scale assesses communication, cooperation, assertion, responsibility, empathy, engagement, and self-control, so it was being used to assess which areas of social skills YPF is most successfully targeting. The scale has 46 items and asks participants to rate how true each statement is on a 4-

point scale from "not true" to "very true". The scale demonstrates good internal consistency (0.85) and re-test reliability (0.76), (Gresham & Elliot, 2008).

Interviews

All of the CYP who took part in the study and their parents/carers were also invited to an interview. The current study therefore asked participants how helpful they found YPF, how easy they found it to use, and how their psychologist supported them throughout the programme. It also allowed them to express any additional comments about the programme. The parents' interview questions were designed to explore topics such as whether they believed that YPF had an effect on their child, how much support the child needed from their parent and psychologist, and how easy their child found the programme to complete.

Psychologists were interviewed to determine the strengths and weaknesses of using YPF in secondary care burns from their point of view, and allowed them to provide their opinions on how, if at all, YPF could be implemented within secondary care. It was structured in a similar way to ask how easy they found YPF to use, how helpful they found it, and how they chose to support their patient throughout the programme. It also allowed them to state whether they would use YPF in the future, and how they felt the programme can best support CYP in secondary care, along with any additional comments.

6.2.4. Data collection

Both NHS and university ethics approval was obtained for this study, and Research and Development (R&D) approval was also granted from each of the nine NHS Trusts involved in the study. Clinical psychologists working with young burn patients in secondary care were asked to refer patients to the programme. Psychologists used a range of different strategies to recruit CYP into the programme, outlined in Table 6, including contacting current/previous patients, liaising with colleagues, consulting the database and speaking to families at burn camps/club events. Prior to the psychologists inviting CYP to take part in the study, the researcher visited each Trust in person to train the psychologists on using the programme, by running through set-up and supervision of a dummy patient. This also allowed the psychologists to ask the researchers any questions and ensure they felt comfortable with the process before supervising any CYP.

Once they identified CYP who they would consider using YPF with in their care, they provided CYP and their parents with information packs prepared by the researcher. If they wanted to take part

in the study, the healthcare professional asked the CYP and their parents to sign consent forms. Psychologists then returned the consent forms to the researcher. Psychologists and CYP decided together whether they would complete the programme in its entirety, or just specific sessions which were most relevant to their particular concerns. This was achieved by a consideration of CYP's concerns and an examination of the session content, to arrive at a collaborative decision as to which sessions would be most appropriate for the CYP. Psychologists were shown how to set CYP up on the programme, and asked participants to complete the measures outlined above before starting the sessions. Participants were able to complete the sessions with the psychologist at the hospital, at home by themselves, or using a combination of the two. Potential safeguarding issues were considered, relating to the possibility of CYP becoming distressed by any of the topics in the programme while completing sessions at home. PPI work with psychologists before the study led to the recommendation that any distress could be minimised by providing support to the CYP after each session had been completed; however it was agreed that psychologists could use their clinical judgement to decide how to provide this support, e.g. online review, phone, email or face-to-face. This support entailed reviewing the CYP's progress on the programme and then speaking to them to identify any potential areas of concern, which they would then address by employing their clinical expertise. In addition, CYP were told that they could contact their psychologist should any topics arise which they would like to discuss.

After the CYP had completed their sessions they were asked to complete the measures online again. Reminder emails and calls from both the researcher and the psychologist were necessary to ensure that the CYP completed the follow-up measures. CYP, parents and psychologists were also interviewed about their experiences. Nine psychologists, two CYP and one CYP's guardian were interviewed about their experiences over the phone. The CYP's interviews lasted for 30 and 25 minutes, while the carer's interview lasted 29 minutes. The psychologists' interviews ranged from 41-55 minutes, with a mean time of 47 minutes.

Site name / Date of R&D approval	Recruitment strategies used	No. of CYP who consented to participate and outcome	Reasons for non-participation (if provided)
Bristol 13.11.14	• Contacted seven current/previous patients • Liaised with colleagues	Three: • One completed entire programme • One completed one relevant session • One never started and the psychologist was unable to make further contact	• One CYP did not meet the age criteria • Three CYP said that they were already coping well
Birmingham 17.12.14	• Contacted one past patient • Liaised with colleagues	One: • One never started and the psychologist was unable to make further contact	
Liverpool 26.9.14	• Sent information packs to ten families • Each psychologist spoke to two families directly • Sent out recruitment flyers to 130 CYP	None.	• One CYP did not feel like they needed support • One CYP had improved by the time he met the psychologist to start the programme • One CYP wanted support but preferred to receive this on a face-to-face basis. • Psychologist was not able to engage with other families
Manchester 13.11.14	• Contacted six current/past patients • Liaised with colleagues	Two: • One left the burns service before starting YP Face IT • One only felt able to address her difficulties in therapy sessions and did not want to face them at home.	• One CYP wanted support but preferred to receive this on a face-to-face basis. • One CYP had improved by the time he met the psychologist to start the programme • Psychologist was not able to engage with other families

Mid Essex 28.1.15	• Considered a database of 250 CYP • Called 16 families and sent out eight recruitment packs • Research nurses spoke to two CYP in outpatient clinics	Two: • One never started and psychologist felt she was not motivated enough • One started but his concerns escalated and he was referred to a local CAMHS service	• Two CYP who spoke to research nurses did not feel they needed support. • Psychologist was not able to engage with other families
Newcastle 11.9.15	• Contacted three patients from current caseload • Spoke to five patients at burn club events • Spoke to four people at burn camp	None.	• Ten CYP did not feel like they needed support • One CYP wanted support but preferred to receive this on a face-to-face basis. • One person disengaged from the service
Salisbury 15.10.15	• Spoke to one CYP after a referral from a nurse • Posted information about the study on social media and in the newsletter • Spoke to staff at a burns awareness day • Reviewed burn camp folder	None.	• One CYP did not feel like they needed support
Sheffield 25.9.15	• Liaised with OTs and play specialists • Attended outpatient clinics	One: • Participant never started and the psychologist was unable to make further contact	• Two CYP did not feel like they needed support
Swansea 6.8.15	• Psychologist and ward manager spoke to families at burn camp and made follow-up calls to four families.	One: • One completed entire programme	• One mother expressed an interest but her child did not want to participate. • Psychologist was not able to engage with other families

Table 6 Recruitment strategies employed by psychologists across sites, response rates and reasons for non-participation

6.2.5 Data analysis

Due to the very small number of CYP completing the intervention, the data from them are presented as case studies, in accordance with the aforementioned study by Spence et al (2008) which examined the effect of online CBT on childhood and adolescent anxiety, rather than being considered as a type of methodology in their own right (Yin, 2012). Case studies may be used to define, rather than analyse, individual cases (Gerring, 2004). Therefore, these case studies are used to illustrate the acceptability of the programme, as well as the feasibility of a study to test the intervention in secondary care on a larger scale in the future. Similar to Spence et al (2008), the case studies were prepared by considering a number of factors including the presenting difficulties, any previous support received, session and activity completion, therapeutic alliance and participant satisfaction with the intervention, and a consideration of pre-post outcome scores. Direct quotes from the interviews are provided within the case studies.

Data from the interviews with psychologists were subjected to a thematic analysis using the procedure outlined in section 4.2.5, and results are outlined below. Five themes were initially generated: 1) recruitment strategies; 2) difficulties with recruitment; 3) perceived benefits; 4) how the programme would be used; 5) support for the CYP. These were then refined into four themes: 1) potential benefits for CYP with burn injuries; 2) flexibility within a tiered model of care; 3) considering all possible avenues of reaching CYP; 4) the many challenges of recruitment.

6.3 RESULTS

Two CYP completed the entire programme, while another completed one relevant session following a discussion with her psychologist on the most appropriate way to utilise YPF. One started the programme, but his concerns escalated and he was referred to a local Child and Adolescent Mental Health Service (CAMHS). Three CYP never started the programme and the psychologist was unable to make further contact. Another CYP never started and, although the psychologist managed to make further contact, was not able to motivate her to complete any sessions. One CYP felt that she was only able to face her concerns within a face-to-face session and did not want to think about them once she left the psychologist's office, while the remaining CYP left the burns service altogether before starting YPF.

6.3.1 The acceptability of YPF from the CYP and one CYP's guardian's perspective

Case study 1a. Jasmine

Jasmine has a complex family history and is cared for by close relatives. She has historically experienced episodes of low mood and anxiety compounded by appearance concerns about her scars. She sustained a scald injury on her legs from a hot drink in 2001 with a TBSA of less than 5%. Jasmine attended a scar management clinic and expressed concerns over her scars to the surgeon, who put her in touch with Kelly (clinical psychologist). Kelly suggested that YPF could help Jasmine with her self-confidence and Jasmine *"thought it sounded a bit like counselling or something, but differently in that way, it's basically doing counselling but online. So it was much easier, she said it was a much easier option and I agreed with her"*.

Jasmine had already had several sessions with a school counsellor to discuss mainly non-burn issues, but the computer-based aspect of the programme appealed to her as she preferred the idea of accessing support in private to talking face-to-face. Jasmine completed the sessions at home and occasionally asked her guardian for advice on how to answer some of the questions, but mainly completed it alone. Kelly reviewed each session online which Jasmine preferred as she often gets nervous talking to people on the phone. However, Kelly did speak to Jasmine halfway through the programme, which Jasmine appreciated as they could discuss her progress and Kelly reassured her that she was doing well.

Jasmine thought that the programme was engaging when she first logged on *"it was interesting and it had some good information, because sometimes you go on something and you're like 'oh, this isn't helpful at all and I don't know what it's talking about, but it gave some really good advice, and it was clear, and it was colourful."* She found that she could identify with feelings described by other people on the site *"that was another thing that I was like 'oh, I'm not...', I mean obviously I'm not the only one but it was quite nice to know that, well not nice *laughs*, but to hear that other people felt what I felt as well",* and that this provided her with a sense of perspective *"I've realised that there are other people...my life doesn't really need to revolve around my scars".* She also directly related one section of the programme to her own life *"I was worried about people seeing [my scars] in public, and there was like goals, I think there was something about a smart target and that was helpful. I'm going on holiday this year, so I was going to wear...it was something about going on holiday and wearing my like costume with my scars showing, so I quite liked planning that out *laughs*. I'm definitely going to use that".*

Jasmine found that completing the sessions at home was a more relaxing environment than previous counselling sessions at school *"I'm not very good at just talking face-to-face and just talking, I'm like 'I've got to answer this' and I feel a bit under pressure, but with this I could just do it in my own time, I could wait and spend as long as I wanted on it and maybe come back to it and do some more, and then come back to it."* However, she did say that she often found it difficult to make time to complete sessions. Overall, Jasmine said the programme was very helpful, but she also thought that certain sessions were not very relevant to her *"I had to fill out the activities for anxiety and I wasn't really, like, not being funny or anything, I was like 'I don't really need this'"*. While Jasmine completed the programme in full, she found it quite difficult to remember when to complete each session, so did feel that she needed the automated reminders.

When asked about her experiences of completing the questionnaires before and after YPF, she stated that *"they were good, some interesting questions on there. They were quite easy, I quite liked that you just, you didn't have to write much, you just ticked boxes for the questions, that was pretty easy".* Jasmine's scores from the pre- and post-measures are detailed in Table 7. Jasmine's scores improved on the Satisfaction with Appearance Scale but not the Body Esteem Scale, indicating that Jasmine felt more comfortable about the burn-specific areas of her body, and adding strength to the qualitative finding that she intended to employ SMART goals to help her reveal her scars in public. Scores also improved on the social avoidance and distress specific to new situations subscale and general social anxiety subscale of the Social Anxiety Scale for Adolescents, all aspects of the Perceived Stigmatization Questionnaire apart from the hostile behaviour subscale and both the self-worth and romantic relationships subscales of the Self-Perception Profile for Adolescents.

Measure	Normative score	Score pre-intervention	Score post-intervention
Body Esteem Scale	2.1	2.8	1.8
Satisfaction with Appearance Scale	N/A	45	26 *
The Social Anxiety Scale for adolescents	40.46	42	43
SAS-A - SAD new subscale	15.86	18	15 *
SAS-A – FNE subscale	17.52	16	21
SAS-A – SAD Gen subscale	7.08	8	7 *
Perceived Stigmatization Questionnaire	N/A	2.24	1.57 *
PSQ - Absence of friendly behaviour	N/A	3.25	1.88 *
PSQ - Confused/staring subscale	N/A	2	1.25 *
PSQ – Hostile subscale	N/A	1	1.6
Self-Perception Profile for Adolescents	3.0-3.2	1.8	3 *
SPPA - Romantic relationships subscale	2.4-2.7	1.8	2.4 *
Social Skills improvement System	N/A	74	72
SSIS – Communication subscale	11-17	18	14
SSIS – Cooperation subscale	11-19	16	8
SSIS – Assertion subscale	10-17	11	7
SSIS – Responsibility subscale	11-19	14	11
SSIS – Empathy subscale	11-17	18	12
SSIS – Engagement subscale	11-18	23	13
SSIS – Self-control subscale	7-14	15	7

Table 7 Jasmine's scores pre- and post-intervention (*scores improved)

Case study 1b. Suzanne

Jasmine's aunt and guardian, Suzanne, was also interviewed after Jasmine had completed the programme. Suzanne said that she and Jasmine had never had any psychological help with the burn before and found it very emotional speaking to Kelly for the first time *"we both sat and cried actually, Jasmine and I, because she hadn't had any help and we didn't know, and there's quite a big background with Jasmine because I'm not her mum, he mum died seven years ago and I'm her auntie, so… I just sort of picked up the pieces".*

Suzanne felt that it had been useful for Jasmine to receive counselling before being offered YPF *"she was very closed to the idea of counselling for a long, long time, so to actually do face-to-face counselling…to then move on to this programme which was more specific, I think was perfect for her".* She felt that the previous counselling had helped Jasmine to complete the programme *"I think for her because she was in, she's already completed a bit of face-to-face counselling then she was already in the right place. I think possibly if she hadn't had that then she would've needed more support".* She also appreciated that Jasmine could complete the programme at home as *"she's got a lot of pressure at school and she does an awful lot of extracurricular stuff… so the fact that she could do it at home meant that she could fit it in around other things".*

Suzanne had recently noticed a difference in Jasmine in terms of the clothes she chose *"I'm not saying that she's uncovering now because she still likes to keep her scars covered, but obviously this would be something that came from the programme rather than the counselling, but I have noticed that she'll perhaps use her hair to cover her scars rather than her clothes, and things like swimming in the past she wouldn't wear swimsuits on the beach or swimming, she always had to have like a Rash vest, she'd always wear that, that's a lot better now".* This may reflect the improvements to Jasmine's score on the SWAP, indicating that she was less self-conscious about her scars following the intervention.

Suzanne also felt that YPF had helped Jasmine to be able to talk about her scars *"She did say that there was a boy that she'd been seeing…and that he knows about her scars and he'd seen them, and she just mentioned it completely in passing, and that to me was huge, to be able to just say 'yeah I'm fine, that was ok'".* This indicates that certain sessions of YPF may have been particularly helpful, such as the section on romantic relationships in this case, which adds depth to the finding that Jasmine's score on the romantic relationships subscale of the SPPA improved after the intervention. However, Suzanne thought that Jasmine may have found YPF more relevant closer to the injury *"the scarring happened a long time ago, she's been coping with it for a long time… so some of the things I think she's already sort of learnt to cope with, would that make sense? I think if it had happened to Jasmine within 18 months…it would have been a lot more useful to her".* Suzanne also mentioned support for parents *"I think it would be useful for a parent to also have a certain level of counselling because of the guilt that they carry because of the accident".*

Case study 2. Alisha

Alisha sustained a contact burn from an iron on her chest in 2000 with a TBSA of less than 5%. She had met with Kelly several times in the past and Kelly suggested YPF as Alisha was expressing worries about becoming intimate. Kelly suggested that Alisha focus on the content concerning relationships within session five of the programme. Alisha accessed the programme at home and did not feel she needed any help to complete the activities, although she said that it might have been helpful to complete some of the content with Kelly in a therapy session to get used to the programme. While she was using the programme she met Kelly twice for face-to-face sessions.

Alisha thought that the main benefit of the programme was that she could complete it on her own, as she was unwilling to talk to anyone else about her concerns. She suggested that it might be helpful for children who feel that they cannot talk to parents who blame themselves for the

burn injury *"for children who don't want to, you know, who feel that they can't talk to their parents about it, because of feelings like guilt and everything, I think it's very useful."* While she felt that it was positive to show a range of visible differences in the programme, she said that seeing other CYP with more visible differences than hers made her feel guilty *"why am I so concerned about mine when I can easily cover mine up and it's so hard for them?"*. She also felt that the programme would be more suitable for younger children due to *"the look of it with the bright colours, and the pictures of the children shown, they looked younger"*.

Alisha said that she did find the content on romantic relationships helpful *"I did particularly like the part about the romantic relationships, that was my issue in the first place, so I felt that I could easily relate to the issues that, the examples shown. Like how they were nervous about even beginning to get into a relationship, I thought that was quite helpful".* However, she felt that it was also necessary to speak to Kelly on a face-to-face basis *"the issues are kind of raised and it's good to tell children that but actually bringing it into real life, you kind of need a person there with you to bring it more outside of the virtual world and bring it more into real life as well… If you covered something in the programme and then you went back over it, or you tried it out in real life with another person, someone like Kelly."*

She felt that the programme could be used as a first point of call *"I think I'd probably look at the programme first and then if it didn't become helpful then I'd talk to [Kelly]"* and felt that it could be an important resource for CYP with visible differences *"I think it's a really important issue, children with differences. I think it's really important to address that. It's definitely good for children who don't feel that they can talk to anyone so it's a good starting point for them to find some information and answers".*

Alisha completed the pre-post questionnaires at home and said that she *"understood why they were being asked, how they would relate to the issues being covered in the programme as well"* The scores from Alisha's pre- and post-measures are presented in Table 8. Alisha's scores improved on both the generic and burns-specific measures of appearance satisfaction, the total Social Anxiety Scale for Adolescents (SAS-A) score as well as the SAS-A Fear of Negative Evaluation subscale, the total and all subscales of the Perceived Stigmatization Questionnaire, the romantic relationships subscale of the Self-Perception Profile for Adolescents, the total score on the Social Skills Improvement System Questionnaire (SSIS) as well as the cooperation, assertion, responsibility and empathy subscales. The most notable of these findings is the improvement to the romantic relationships subscale, as this was the concern for which Alisha was referred to the programme, and reported finding it a helpful aspect of YPF in her interview.

Measure	Normative scores	Score pre-intervention	Score post-intervention
Body Esteem Scale	2.1	1.8	2.2 *
Satisfaction with Appearance Scale	N/A	30	26 *
The Social Anxiety Scale for adolescents (SAS-A) –	40.46	69	65 *
SAS-A - SAD new subscale	15.86	21	23
SAS-A – FNE subscale	17.52	35	29 *
SAS-A – SAD Gen subscale	7.08	13	13
Perceived Stigmatization Questionnaire (PSQ) – Total	N/A	2.29	2.05 *
PSQ - Absence of friendly behaviour subscale	N/A	2.63	2.38 *
PSQ - Confused/staring subscale	N/A	2.13	1.88 *
PSQ – Hostile subscale	N/A	2	1.8 *
Self-Perception Profile for Adolescents (SPPA) - Self-	2.9-3.1	2.2	2.2
SPPA - Romantic relationships subscale	2.5-2.7	1	1.2 *
Social Skills improvement System Questionnaire (SSIS)	N/A	101	102 *
SSIS – Communication subscale	11-17	15	14
SSIS – Cooperation subscale	11-19	17	19 *
SSIS – Assertion subscale	10-17	12	15 *
SSIS – Responsibility subscale	11-19	18	19 *
SSIS – Empathy subscale	11-17	17	18 *
SSIS – Engagement subscale	11-18	10	6
SSIS – Self-control subscale	7-14	12	11

Table 8 Alisha's scores pre- and post-intervention (*scores improved)

6.3.2 The acceptability and feasibility of YPF from the clinical psychologists' perspective

The analysis of the interviews with psychologists suggested both the acceptability of YP Face IT within practice (potential benefits for CYP with burn injuries and flexibility within a tiered model of care) and the feasibility of both the programme and the study (considering all possible avenues of reaching CYP and the many challenges of recruitment). A thematic map of the results is provided in Figure 17. The four themes are coded as follows:

- Potential benefits for CYP with burn injuries – orange
- Flexibility within a tiered model of care – green
- Considering all possible avenues of reaching CYP – blue
- The many challenges of recruitment – purple

The themes are presented in the circular boxes and sub-themes found within each theme are presented in the rectangular boxes. Relationships between sub-themes are indicated by the dotted lines.

150

Key
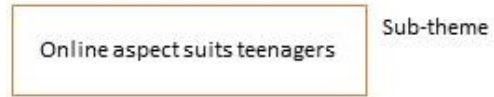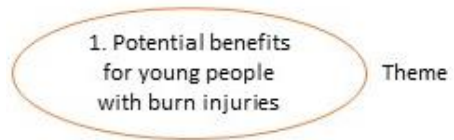
1. Potential benefits for young people with burn injuries	Theme
Online aspect suits teenagers	Sub-theme
————————————	Relationship between theme and sub-theme
- - - - - - - - - - - - - - - - -	Relationship between sub-themes across different themes

Figure 17 Study 2 Thematic Map

1. Potential benefits for CYP with burn injuries

While one-to-one support may only be necessary for those with the highest levels of psychosocial concerns (see section 2.2), psychologists reported that YPF could be beneficial to anyone experiencing any form of appearance-related or social concerns.

Fiona   I think it's suitable for anyone with a visible difference who has some concerns about how they cope socially, about their sel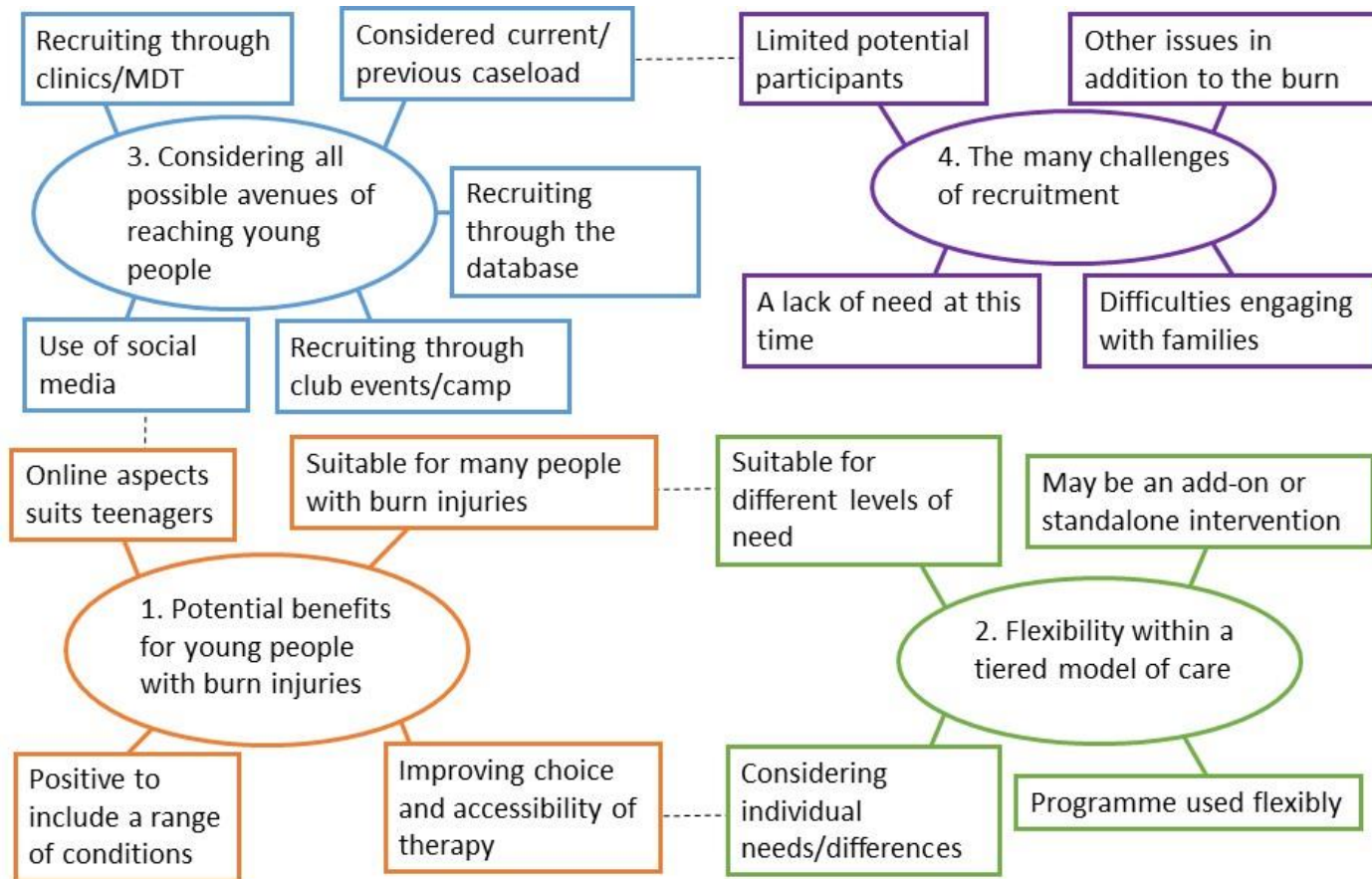f-image. I think that actually anyone, even if they don't feel that they have many concerns, could benefit from going through it.

Another perceived benefit was the potential for YPF to improve patients' access to therapy. The psychologists described how they saw patients from a large geographical area, and that many families found it very difficult to return to the hospital for therapy sessions. Therefore they felt that the online nature of the programme would be particularly suitable for those CYP who lived some distance from the hospital.

Cynthia   Sometimes you might get some people who live quite a long way away, we might discharge them from coming back to regular follow-up here but there might not be anywhere locally for them to go in terms of specific psychological support. I mean there's the general stuff, you've got CAMHS and things, but something more specific about the appearance-related side of things, it would be really good to be able to offer them something.

In addition to reducing geographical barriers, psychologists also felt that it could improve access to support for CYP who found it difficult to talk to a therapist on a one-to-one basis.

Fiona   I think maybe where it is relevant, and maybe where I was keen to get involved were those people that won't come in, is those people who won't come in, for whatever reason, and so that's where I see a gap and I still believe that there are people who would do that, rather than come and meet with someone face-to-face, it's just how to get those people started on it *laughs*.

Psychologists referred to the importance of involving patients in decision-making surrounding their care, and felt that YPF could provide patients with the option of an added level of care, in

addition to the interventions currently available, which are primarily one-to-one therapy or burn camps.

Cynthia   Yeah, I definitely would use it, and it's something that I was thinking "oh, I hope it does become something we can use", so that when and if patients do come up it's just something else in the toolbox, really, to offer patients, so that they've got a choice of how they access psychology or therapy.

As discussed in section 2.1.5 it is important to provide CYP with a toolbox of strategies to choose from depending on the particular situation they are in, and Cynthia's comment strengthens this idea by suggesting that YPF can extend the toolbox available to psychologists as well as that used by CYP. In addition to making support more accessible, the online aspect of YPF was thought to be particularly suitable as a method of delivering an intervention to CYP.

Kelly   And being able to use it at home obviously meshes well with the way that teenagers exist, through their screens and all the rest of it. So in that way it's definitely the way to go, in the digital age.

Psychologists also felt that the visual aspect of the programme would appeal to CYP, and thought that it could deliver therapeutic principles in an engaging way.

Fiona   And I think because you can do it at home…and it's based on sound principles that a lot of us working in visible differences use, such as self-esteem and social skills training, things that have evidence base behind them, in an interactive, fun kind of way.

A final benefit referred to by a number of psychologists was the use of real-life examples in the programme. As discussed throughout the other studies in this thesis it can be far more powerful to hear from other people who have been through similar experiences as oneself than a health professional who may not be able to fully understand what a CYP has been through.

Lynda   I think that CYP get a lot from just hearing that other people have been through something similar, even if it's not exactly the same, but have just had similar experiences and I think even if we tell them that as therapists it's not quite the same as actually watching a little video with someone else talking about it.

While one psychologist felt that a burns-specific support programme may have been more relevant to the needs of CYP, others felt that it was beneficial to include a range of conditions within YPF.

Kim   I actually think that that's a really positive thing, because I think it's kind of saying to people "lots of people have this for lots of different reasons". It's kind of almost more normalising I feel.

2. Flexibility within a tiered model of care

In addition to the various benefits envisaged by the psychologists in the current study, there was also a general consensus that YPF could be used flexibly to fit within a tiered model of care, which was considered particularly important when considering the needs of CYP with burn injuries and their families.

Joanna   Yeah, I think it definitely has to be used flexibly, just because of the population of families that they come from.

It was deemed essential to take CYP's individual needs and differences into account when considering how YPF might be used to provide support. Many psychologists felt that the programme could be adapted to suit individual needs to enhance the support they provided for CYP, either by implementing YPF as a supervised but standalone intervention, or by using it as an adjunct to their existing therapy sessions.

Kelly   The ideal way for me to use the programme would be to incorporate into my therapy and encourage them to use the programme as well, at home…so making the most of the therapy sessions when I do see them, and perhaps have my computer on in the room and go through some of the modules, just to reinforce what I'm saying as a therapist, so that they complement each other.

While some psychologists felt very comfortable with the idea of using YPF content within their own therapeutic sessions, others were quite reluctant to change their current working style, and could only envisage themselves asking CYP to complete the programme outside of sessions. Three of the psychologists invited CYP to take part in the study, who then declined on the basis that they would rather have one-to-one support with a psychologist.

Fiona   I could use it more in [burns] club if I wanted to and was able to, but the thing is I
               have my own models and ways of working that have been, that are proving to
               work. I think that's the thing as well, you get people who are doing things the way
               that they want to, or have been, and see that that's efficient so bringing
               something different...I think that's always a challenge.

Psychologists believed that some CYP would be completely capable of working through the
programme at home by themselves, but felt that if they were holding clinical responsibility for
that CYP's care then they would want to regularly review their progress. This was thought to be
possible via a number of different mediums, but most felt that it would be necessary to contact
the CYP after completion of each session, and to follow this up with an assessment after
completion of the programme.

Kim   If it had been someone on my caseload I would've had a time each week to
               review it I think, so I would've reviewed what they'd done before and kind of
               spent ten minutes of the session set aside for that. I think if other people had
               come from the Grafters [burn club], I think I would've had telephone contact with
               them, to kind of review it.

In addition to the use of YPF as a method of enriching one-to-one support, many psychologists
also felt that it would be suitable for individuals with lower levels of psychosocial need, which is
what the programme was originally intended for generally.

Lynda   It's maybe that level of people where they're not actually making it to more
               specialist services because they're not quite concerned enough, but actually
               there's something there, and that that might well be targeted at them and I'm
               sure that there's a proportion of those in our burns service because in psychology
               we only see a small proportion of the families who come through the service.
               There probably are a lot of other families there who might just benefit from a
               little bit of support at some point, but don't feel the need to see a psychologist.

Psychologists in the current study described how they are very under-resourced, and many
wished that they had more time available to more fully support their patients (see section 7.3).
Kim felt that using YPF as a method of providing support to CYP whose needs were not great
enough to require face-to-face therapy could improve her availability to treat those with higher

levels of need. This reflects two potential uses of YPF: patients requiring clinician support who can use YPF alongside face-to-face support, and those needing lower input who could use YPF independently at home.

Kim   Well I think that it could, if people had lower levels of difficulties where they didn't necessarily need a psychologist, then you could see lots of people which would then give more time to give more complex patients, who do need to see somebody face-to-face.

Several of the psychologists alluded to the ways in which YPF could be used to address varying levels of psychosocial need, represented by the levels of the CAR framework of appearance-related interventions (section 2.2). Dee felt that parts of YPF (such as the first session) could be used preventatively.

Dee   It has the potential to be an early intervention, to be a preventative intervention as well… I was just thinking back to talking about school reintegration and managing those initial comments and questions…going back to 'normal life' after a burn injury, and whether there's aspects that it would fit quite well with that, and that could actually be quite separate to psychology input.

This suggests that parts of YPF could be used as method of providing self-help information as starting point in a tiered model of care (level 2 of the framework), a point which was emphasized further by Teresa who felt that this level of intervention could then be escalated if it was not found to be effective.

Teresa   One of the ways we're working now is moving more towards stepped care and it might be that people start there and then if there's other issues they then see somebody one-to-one.

In contrast to the possibility of using YPF to enrich one-to-one therapy sessions, Dee raised a point regarding the use of the programme as an adjunct to burn camps.

Dee   I'm just thinking about the younger kids camp maybe, where they kind of come and perhaps go home with more thoughts about having met other people with a burn injury and those interactions, and some of those stories about what's

happened, and whether the programme could potentially be, it could potentially fit quite nicely after the camp, as something to do.

3. Considering all possible avenues of reaching CYP

It was considered important to explore potential ways of recruiting CYP into the study both to consider how clinicians may reach CYP in future practice and to inform recruitment for future studies. The psychologists in the current study used a wide range of recruitment strategies, but there was a general consensus that the age range was the first criterion to consider. Some of the psychologists considered their past patients, as well as discussing the study with CYP on their current caseload. Psychologists attempted multiple approaches to recruitment, targeting the same participant on more than one occasion.

Joanna   The one who said no for example, who benefitted from the face-to-face contact, I did a few things. I gave her the paperwork for her to go and read, in one of the sessions I even showed her the website and then she went away again, and then I think it was actually the third time that she said no, she didn't want to do it.

The site which successfully recruited two participants employed this strategy, as one participant had been known to the psychologist previously. The second participant was recruited when she attended a scar-review clinic and mentioned that she was having some worries about her appearance. Many of the other psychologists also attended regular clinics, but on the whole this was not found to be a particularly successful way of reaching CYP.

Lynda   Often our teenage group had their burn injuries as young children so they're not having very active follow-up anymore, so often they're only coming for maybe an annual review. So if they didn't have an appointment in that year then we wouldn't see them, and for some of them it's like 18 months or two years until their next review, so there would've been a group of young people that we just didn't see, even just going along to the clinics.

Several psychologists considered utilising the database of CYP who had been treated by the burns service in the past. The psychologist from one site phoned families whose child met the age criteria, while another service sent flyers about the study out to 130 people but received no response. It was thought that this might relate to the fact that many of the recipients had not had previous contact with psychological services. One strategy which successfully led to one

participant being recruited was to consider the CYP attending burn camps, although this was achieved with the help of the ward manager.

Gwen   She knows the children who are coming through the service really well, so it was her that I went to and sat down with… we had to be a bit careful, she was saying "I'm not 100% sure whether this person has got body image issues at the moment or not" so that's when she thought "I'll sit down with all the people in this age group and go through the study and I'll see who's got an interest".

Gwen felt that this prior knowledge of the CYP was significant to successfully recruiting a participant into the study, and the importance of this existing relationship was alluded to by Joanna, who was concerned that burn camp staff may not know enough about the children attending to be an appropriate choice for introducing the study.

Joanna   The staff that are there wouldn't necessarily have prior knowledge of the family background…they might not necessarily know for every child that goes if they had particular concerns about their burn.

This is likely to at least partly explain the lack of response to invitations to take part as it was suggested that an existing relationship between the CYP and health professional would be necessary for initial engagement in the research.

Kelly   I think…it's very difficult because I think probably to get it moving you need to have that relationship with people in the first instance.

However, other psychologists attempted to recruit CYP through other members of the MDT without much success. While nurses and consultants were not always thought to pick up psychosocial concerns as discussed in section 7.3.2, physiotherapists and occupational therapists were thought to be more sensitive to identifying potential concerns.

Teresa   I think if they had someone particularly in mind then they would be referring them through psychology anyway, because we have a fairly low threshold for referring in, so generally I'm aware.

A final strategy used by two of the sites involved social media. One site posted on the burn club's Facebook page, while the ward manager mentioned by Gwen followed up the CYP who had

attended the burn camp to remind them about the study. This further reinforces the need to be very proactive when attempting to recruit for the study rather than relying on only one strategy (as discussed by Joanna at the start of this section).

Gwen   [The ward manager] Facebooked a couple of times, so it's not like we just gave them the information and said ring back if you're interested, she Facebooked them a couple of times and then rang from the ward and said are you happy for the researcher to contact you.

In total, around 50 CYP and families were spoken to directly about the study, and the psychologists reported that many initially seemed interested in the research, but wanted some time to think about whether they would like to take part.

Kim   The people I had on my list, sounded very positive about it and I expected them to bring them back with the consent forms completed ready to start, but then that didn't happen.

Despite the apparent interest, very few participants actually consented to take part in the study. Reasons for non-participation are reported in Table 6 (where provided). However, there was a strong consensus from all of the psychologists that this was not simply due to the methods employed to try and recruit participants. The potential issues which may have adversely impacted recruitment are considered now.

Kelly   If we were starting again I'm not sure how I would do it differently really. I think we gave it a good go.

4. The many challenges of recruitment

Although it was agreed that all possible avenues of reaching CYP were considered, recruitment rates were disappointing. Only NHS sites where psychologists were confident that they would have eligible participants were included in the study. However, they reported that the pool of potential participants actually transpired to be far more limited than first thought, with a number of possible reasons suggested by the psychologists. Firstly, the majority of CYP in the burns services were toddlers and young children. It was acknowledged that the programme could potentially be of benefit to these children in the future as they reached adolescence.

Kim   It was a combination of limited number of burns, and limited number of burns within the age range. Lots of the people we work with are, kind of, young families or parents on their own of very young children… they're too young but potentially could benefit from it at a later point.

When asked about CYP who had been burned years ago as young children and who would now meet the age criteria for the study, it was revealed that many of the services did not historically include a psychologist. Therefore the invitation to the study may have been the first contact some families had had from a psychologist working in burns. It was also suggested that some CYP who were burned at a young age may simply have been lost to the system.

Lynda   We often tend to discharge young people and kind of almost leave it in the family, or leave them with the responsibility to get back in touch if they have any concerns, and whether actually there are young people in that population that we're just not seeing anymore, but who don't feel that their concern is sufficient to come back to clinic.

In addition to the limited number of potential participants, another common issue was the difficulty experienced by the psychologists when trying to engage with the families they had identified. Although around 50 families or CYP were spoken to directly, and recruitment packs or flyers were sent out to around 150 more, the main problem was a persistent lack of contact. Psychologists tried to follow-up with families using emails, phone or social media but received no response; however they said that it is common for them to have difficulty contacting families.

Lynda   We have similar issues even with things like when we're recruiting for burns camp… we will try and phone people, we really struggle to get hold of them by phone, we will write to people, and we'll write with a deadline, and sometimes there'll be people who express a real interest but again more often than not we just hear nothing back...so I guess that's interesting in that that pattern wasn't unique to the YP Face IT mailout, actually we get that for burns camps as well.

It was also reported that CYP with burn injuries and their families have a poor level of engagement with therapy generally, so the lack of response to the study was considered indicative of the population.

Fiona   But actually, in the whole of the team we struggle to get long…I don't want to use the word longer-term, but we struggle to get any children with burn injuries to…we don't often have many that are involved in a period of treatment

Several reasons were suggested for this lack of engagement, some relating to the stigma surrounding the term 'psychology' (discussed in more detail in section 7.3) and some relating to the fact that CYP in the age bracket have a number of other priorities in their lives, such as friends, exams, and extracurricular activities. This concurs with Jasmine's experience in section 6.3.1 who reported that although she found YPF helpful, she often found it difficult to find the time to complete each session. Psychologists also felt that the demographic of those often affected by burn injuries was a key factor in the lack of engagement to therapy.

Teresa   I think partly it reflects the demographics that you see in the burn service, so quite a lot of low socioeconomic status which we know is harder to get into services, different cultural populations, so they're also families that are less likely to access psychology generally, and I think just if there's a lot going on in families, if they've got financial difficulties, if social services have become involved, often psychology isn't their first priority, or they're not in a place where they might engage with that.

A large proportion of CYP did not feel the need for any therapeutic support. Many of the CYP who psychologists were able to speak to directly had either received one-to-one support in the past or attended burn camps or club events, meaning that they may have already overcome a number of difficulties by the time they were approached about the study.

Gwen   So they're already getting protective factors around them, which makes them less vulnerable to developing some of the body image issues because they're interacting so much with other children with those same issues really.

A number of CYP reportedly told psychologists that they thought the programme sounded helpful in general and they could imagine it helping other people, but that they did not feel it was relevant to their needs. Several also mentioned that it might have been more beneficial in the past, but that they were no longer experiencing concerns.

Cynthia	I think she had it [the injury] when she was a toddler… she did say that it was probably something she would have thought about when she was mid-teens, probably.

Therefore, a number of factors contributed to the difficulty in recruiting participants, which were summed up by Lynda.

Lynda	That patient group is just very small and to then find somebody within that group with the right kind of concerns, at the right time, who then also is happy to have some therapy and try out something new, I think it's just such a small group that that's what made it difficult to recruit somebody.

6.4 DISCUSSION

Results from the study indicated that all participants felt positive about the possibility of using YPF within future care provision, indicating that its use would be acceptable within this population. Responses from the psychologists demonstrated that YPF reflects current treatment strategies used in their therapeutic sessions, which lends further support to its acceptability. Although participation was limited, the CYP in the current study did find YPF to be beneficial, even though they had different experiences of it. Jasmine completed the programme after having received a number of counselling sessions at school, and her guardian, Suzanne, suggested that it was this combination of counselling followed by YPF that really helped Jasmine with a number of difficulties. Conversely, Alisha completed parts of YPF alongside face-to-face therapy sessions and felt that while the programme had raised some important issues, the opportunity to discuss these with a psychologist face-to-face had been a crucial step. This highlights not only the flexibility of YPF, but also the importance of considering individual needs and differences within the delivery of psychosocial support. While Jasmine expressed a preference for the online aspect of the programme, Alisha found the face-to-face contact more helpful.

Psychologists strongly agreed that the difficulties in recruiting did not mean further use of YPF should be discouraged as they felt that it has the potential to offer a great deal of benefits to CYP. In accordance with MacGregor's (2009) study of an online support programme to target panic and phobic anxiety, it was suggested that YPF could improve access to therapy for those living a long way from the burns service. However, it was also suggested that it may improve access to therapy by providing another option to CYP in need of support. As discussed in section 7.3.4, a number of children struggle with face-to-face therapy and are unwilling to engage with

interventions such as burn camp. While burn camp has been shown to be effective for some CYP (see studies 1A and 1B), it is possible that others may require a more direct method of information provision and support.

Furthermore, CYP with social anxiety may find the idea of both face-to-face therapy and burn camps to be quite daunting, and may therefore benefit from an online programme of support which can allow them to work through their difficulties in privacy, using a medium with which they are familiar. Lynda suggested that CYP might find it beneficial to use YPF after attending a burn camp, but it is also possible that YPF could help a CYP feel more prepared to attend burn camp, or even face-to-face therapy sessions. Finally, supporting people with lower levels of need using YPF could create more time for psychologists to treat those with higher levels of need using face-to-face techniques. As many of the psychologists in the qualitative study in chapter 7 talked about their time and budget restrictions, this could mean that YPF may also be effective as a time- and cost-saving method. With a current NHS deficit of £2.26bn (NHS Trust Development Authority, 2016), health professionals may experience pressure to save costs wherever possible, but it is essential that this does not supersede a careful consideration of the most appropriate interventions to meet clients' individual levels of need. This suggests a need for a health economic evaluation of the use of YPF, and other interventions, within secondary burns care.

This possibility for YPF to be used in conjunction with other types of therapy has important clinical implications, as it could transform the way in which health professionals choose to support their patients. As well as implementing it with other types of therapy in a sequential manner as described above, many of the psychologists in the current study also felt that they could use it within their current therapy sessions, either by working through the content with CYP, or asking CYP to complete the programme between therapy sessions, and then review their progress together. This means that YPF, when used in this manner, may actually be suitable for CYP with the highest levels of need (levels 4 and 5 of the CAR framework as outlined in section 2.2), in addition to those at level 3 of the framework as originally thought.

This method of delivery was referred to by Alisha who completed YPF at home and then discussed it with her psychologist in a face-to-face setting, but actually suggested she may have found it more beneficial to complete some of the programme within a therapy session. It is also worth noting that Alisha experienced feelings of guilt when working through YPF for having concerns about her own visible difference which she perceived as less severe than others' differences. By completing only one session of YPF, Alisha missed the introduction to the programme which aims to normalise appearance concerns and explains that the severity of a visible difference does not

contribute to an individual's feelings about it. One possible solution to both of the issues in this paragraph is for CYP to complete the first session of YPF with their psychologist, both to get them used to the programme and to introduce them to the concepts used throughout the rest of the programme.

The psychologists in the current study suggested that it may also be suitable as a method of providing self-help information to those with lower levels of need, and may even be beneficial as a preventative intervention to be routinely offered to anyone treated by the burns service. Similar results were found in Williamson et al's (2015) study, where psychologists felt YPF could be used as an introductory tool to prepare CYP for higher intensity psychological therapy. However, the use of YPF as a lower-level intervention would need to be implemented with caution. While it is acknowledged that it may not always be appropriate to make online interventions freely available to CYP (Stallard et al, 2010) the finding that support may be carried out by a facilitator with minimal CBT training (Stallard et al, 2011) means that it may be possible for other adults in the CYP's lives, such as school counsellors, to supervise them in these cases.

The perceived flexibility of the programme ties in with the fluidity of the CAR framework. It is possible that YPF may actually be appropriate for different levels of need depending on the manner in which it is delivered. Preliminary results from the current study suggest that it could be used within secondary care in the following ways:

- Level 1 of the CAR framework (patient condition-specific information) – offered as a preventative intervention to all CYP coming through the burns service.
- Level 2 (self-help materials) – providing access to YPF for CYP with lower levels of need with no input from a health professional.
- Level 3 (self-administered intervention facilitated by a trained professional) – used as originally intended by asking CYP to complete sessions at home with remote supervision from a health professional.
- Levels 4-5 (one-to-one support from a specialist) – either working through YPF with a psychologist within therapeutic sessions or completing the programme between sessions to discuss with a psychologist on a one-to-one basis.

The potential flexibility of the programme could make it an invaluable resource within burn care, as the need to provide support in a flexible manner to consider individual needs emerged as one of the most essential requirements in study 3. While this has positive clinical implications, it is important to remember that this notion is based on the suggestions of the psychologists in the current study, rather than on any empirical evidence. However, the professionals in this study are

all qualified clinical psychologists and many of them have several years' experience of providing psychosocial support to CYP with burn injuries.

While the acceptability of YPF was found to be good, the feasibility of the study in its current format was less promising. Psychologists felt that it was important to consider all possible avenues of reaching CYP when trying to recruit. While the age range was used as a starting point by all psychologists, the actual recruitment strategies used varied between services and included a consideration of past/current patients, consulting the patient database, and attempting to recruit through clinics, burn camps, and other members of the MDT. The only strategies which proved successful in the current study were a consideration of past/current patients, and recruiting through burn camp (with the help of another member of staff). The commonality between these two recruitment methods was the existing relationship between the CYP and the psychologist or ward manager respectively. While two other services contacted a much larger number of families by consulting their databases, it emerged that the majority of these families were unknown to the psychologists. The therapeutic relationship between psychologist and patient is thought to significantly impact treatment collaboration and outcome within child psychotherapy (Shirk & Saiz, 1992), and the psychologists in the current study acknowledged that an existing therapeutic relationship may have improved recruitment rates.

Psychologists suggested a variety of other reasons as to why recruitment was largely unsuccessful. They felt that in order for CYP to want to take part in the research they needed to meet several criteria in addition to the inclusion criteria provided by the researcher. For example, CYP needed to be in the right age range and be experiencing appearance-related concerns at that specific point in their lives, which needed to be high enough for them to feel like they required support. They also needed to be willing to receive this support via a website as part of a research study. Psychologists felt that even finding CYP in the right age range was more challenging than they thought, as the majority of those referred to them (either by A&E staff on admittance, ward staff on admission, or clinic staff during follow-ups) were very young children and their parents. Psychologists tried to consider teenagers who were burned in the past as young children, but the majority of these had been discharged from the services many years previously.

Some of the services did keep databases of all the children who had been treated in the hospital, but as previously mentioned these CYP tended to be unknown to the psychologists. While some burns services employed psychologists prior to the National Burn Care Review (NBCR), the requirement for a psychologist to be associated with every burns service did not come into place until 2001, and so some services may have had no, or inconsistent, psychological support

available. As demonstrated in study 3, many psychologists started in their roles far more recently than this, meaning that psychological services may be an unfamiliar concept to the families treated before this time.

A large number of the CYP who psychologists did manage to speak to in the right age group were not experiencing appearance-related concerns. This is a positive finding as it implies that the majority of CYP may be coping quite well with this aspect of their burn injury, as suggested by Patterson et al (1993). Several CYP did say that they had experienced concerns in the past, indicating that YPF may have been more relevant closer to the time of injury. This concurs with Partridge's (2006) notion that the third stage of adjustment to a burn injury (2+ years post-injury) involves an acceptance of the body (see section 1.3.2) and may be more relevant during the second stage (6 months – 2 years) when an individual is trying to overcome feelings such as anger or shame about their appearance.

Several of the psychologists also referred to the population considered in the current study. As discussed in section 7.3.1, many families in which a burn injury is sustained may face additional difficulties, such as mental health difficulties, alcohol or drug problems, or involvement from social services. Furthermore, burn injuries tend to occur more frequently in families with a lower socioeconomic status, which can be reflected by factors such as large families or single parents, low income, and illiteracy. Any one or more of these issues may mean on occasion that parental support is not at its optimum level, which may in turn make it more difficult to access or adhere to therapy. This is reflected in comments by several of the psychologists who reported that it is common to have difficulties contacting families in general, and that families' adherence to therapy sessions is often very sporadic.

As discussed in section 7.3, the idea of psychological support often comes with an automatic stigma attached, which may be particularly prevalent among families who have had past contact with social services or other agencies. It is also possible that the notion of taking part in a research study may have been off-putting to CYP. A number of psychologists in the current study stated that they did not believe the research element was a deterrent to the study, but it is unknown whether CYP may have engaged better with a routine intervention not requiring prior consent.

6.4.1 Limitations and future research

As discussed above, the small samples size may be considered a limitation of the current study.

However, this did not appear to reflect a negative perception of YPF by CYP and their families, but rather a lack of need for support at this moment in time. Indeed, a number of CYP and their families said that they thought the programme sounded interesting and could imagine it being beneficial to other people, or felt that it could have been helpful to them nearer to the injury or when they had experienced concerns in the past. A number of psychologists also pointed out that the recruitment window for the study had been limiting as they tended to see teenagers infrequently and that if YPF was available for their general use they could imagine it being a valuable resource as and when CYP with relevant concerns were referred to them in the future.

While it may be assumed that the small sample size caused the study to be less robust, there are a number of issues relating to sample size which may be taken into account. A common notion relating to sample size is that the number of participants should be sufficient to achieve data saturation. While it is sometimes thought that a larger sample size is more likely to reach data saturation, this is not guaranteed (Burmeister & Aitken, 2012) and it is important to remember that larger studies are not necessarily richer (Morse, 2000). Other considerations may also apply, such as the scope of the study. Broader research questions take longer to reach saturation (Morse, 2000), whereas the research questions in the current study can be considered quite specific.

O'Reilly and Parker (2012) believe that the term 'data saturation' is often unclear in meaning, and propose that it can be an inappropriate way of gauging the quality of qualitative research. It may be more effective to consider a suitable sample size as one which sufficiently answers the research question, for which single figures can be adequate for detailed studies (Marshall, 1996). In certain cases, such as that aiming to gain a deep understanding of a situation from various perspectives, a small sample size can actually be preferable to achieve a more personal understanding and contribute valuable knowledge to the literature (Myers, 2000).

Case studies in particular usually involve a single or small number of participants (Fitzpatrick & Boulton, 1994), and a review of PhD research by Mason (2010) found a number of PhD studies which involved as little as one participant. Morrow (2005) suggests that there are a number of aspects within qualitative research which are of far greater importance than sample size: sampling procedures; quality, length, and depth of interview data; and variety of evidence.

There are a number of different types of sampling procedure. Marshall (1996) draws a distinction between convenience sampling (involving the most easily accessible participants) and judgement sampling (actively selecting the most appropriate sample to answer the research question). While

convenience sampling may save the researcher time and effort, it is the least rigorous technique and may result in poorer quality of data. Judgement sampling is "criterion-based"; i.e. including participants who meet specific criteria or have experienced a particular phenomenon (Morrow, 2005). Rather than sampling respondents from a target population, participants in the current study can be conceptualized as "cases" within a particular set of circumstances (Crouch & McKenzie, 2006) – young people with burn injuries experiencing appearance-related concerns treated within secondary care.

Crouch and McKenzie (2006) state that this sampling procedure is the way that analytic, inductive, exploratory studies should be conducted. This purposive sampling technique is sometimes considered non-representative of the population and ungeneralizable; however Morse (1999) argues that in contrast to quantitative research which focuses on demographic characteristics, participants in qualitative research should be selected specifically for the contribution they can make to the emerging theory.

In terms of the quality, length and depth of interview data, Morrow (2005) highlights the importance of articulating the interview strategy, and believes that fewer, open-ended questions, involving clarification of answers throughout the interview are the most effective way of ensuring rich and spontaneous data. The interview strategy for the current study is described in section 6.2.3 and the interview schedules can be found in the appendices. The interview schedules each contained fewer than 20 questions, and included follow-up questions aimed at collecting rich and meaningful data. Morrow (2005) suggests that variety of evidence can be assured through the use of multiple data sources, such as interviews, site documents and electronic data – all of which were included in the current study. Considering the degree of convergence between different data sources is thought to be particularly salient within case studies, to try and ensure as accurate a picture as possible (Fitzpatrick & Boulton, 1994).

Overall, while the above research suggests that small sample sizes may still produce rich data, it is acknowledged that the small sample size in this study made additional analyses impossible. A larger, more diverse sample would have allowed for comparisons between boys/girls, young people of different ages, time since burn etc., to determine if the intervention may be more effective for particular individuals. This was not the focus of the current study, but may be of benefit within future research.

Another limitation is that psychologists tended only to speak directly to CYP who were already known to them, and who therefore may be more receptive to the idea of psychosocial support. As

discussed in study 3, many families are resistant to the notion of support even when they are offered it as inpatients. Families of teenagers who were burned as children before some burns services included a psychologist may also be reluctant to seek help due to associations of stigma within psychology. This, along with the fact that many CYP would have been discharged shortly after their burn injury, means that a large number of the paediatric burns population may not feel that support is accessible, even though they may be in need of it. Therefore, it is important to consider how to reach such families.

While the feasibility of this study for future research was disappointing in terms of the recruitment, it is also important to consider the methodology used. As recommended by Moore et al (2015), the study implemented a mixed methods approach, combining quantitative outcome measures with qualitative interviews aiming to obtain a comprehensive picture of the feasibility and acceptability of the intervention. The small sample size in the current study prevented analysis involving any statistical power being conducted on the quantitative results and results are therefore indicative only. However, as intended, the qualitative results added extra depth to the results of the study. For example, some of the increases on outcome measures scores were related to specific elements of the programme referred to as helpful in the qualitative interviews. This goes some way to indicating that the outcome measures were capturing relevant aspects of the programme, and should therefore be considered for use in future research involving YPF. Moreover, this congruence between the qualitative and quantitative findings within the study suggest that the mixed methods design was implemented successfully on this occasion, and may be appropriate for additional research involving this intervention.

6.5 CONCLUSION

In conclusion, while recruitment for this study was very low, this does not detract from the potential of the intervention. As discussed in section 1.1, the fact that only a minority of CYP may experience appearance-related concerns after a burn injury does not diminish the importance of providing appropriate support to improve psychosocial wellbeing. The results suggest that YPF may be able to provide a wide range of benefits to CYP, highlighting its potential suitability within the paediatric burns population.

While the difficulties in recruitment indicated that the study in its current format was not greatly feasible, it appears that this is reflective of the population included. More specifically, there were a limited number of potential participants meeting the age criteria, typically poor response rates to psychologists' attempts to make contact, and an often intermittent adherence to therapy.

Furthermore, participants who did fit the age criteria and were contactable did not tend to be experiencing concerns necessitating psychosocial support. However, this does not necessarily reflect the number of CYP in the general population for whom YPF would be beneficial, simply that the clinical psychologists in the current study did not have large numbers of suitable patients at this stage in time. Moreover, the positive findings from the participants who did take part indicates that future research should continue to investigate the contribution that YPF can make to burn care provision, considering reaching CYP using a range of media such as through schools or social media. It is also important to examine whether YPF can help to address concerns of individuals with differing levels of individual need, ranging from its use as a possible preventative intervention to incorporation into face-to-face therapy for those with the highest level of need.

Overall it appears that YPF was acceptable to psychologists and the small number of people who used it, so may have the potential to meet a wide range of individual needs found across the different levels of the CAR framework for appearance-related interventions. It contributes additional findings to those from studies 1A and 1B as it suggests that YPF may specifically target additional constructs, such as worries about romantic relationships, and provides an alternative option for CYP seeking psychosocial support. However, it was revealed in the current study that a number of CYP elected not to take part in the study as they expressed a preference for face-to-face therapy. The current study also excluded participants who may be demonstrating symptoms of PTSD, as YPF was not designed to target such high levels of psychosocial difficulties. Therefore, it was considered important to examine one-to-one support providing by mental health specialists for individuals with the highest level of psychosocial need. The next study explores the experiences of clinical psychologists working within paediatric burns.

CHAPTER 7. STUDY 3: CURRENT PRACTICES IN ONE-TO-ONE PSYCHOSOCIAL SUPPORT FOR YOUNG PEOPLE WITH BURN INJURIES AND THEIR FAMILIES
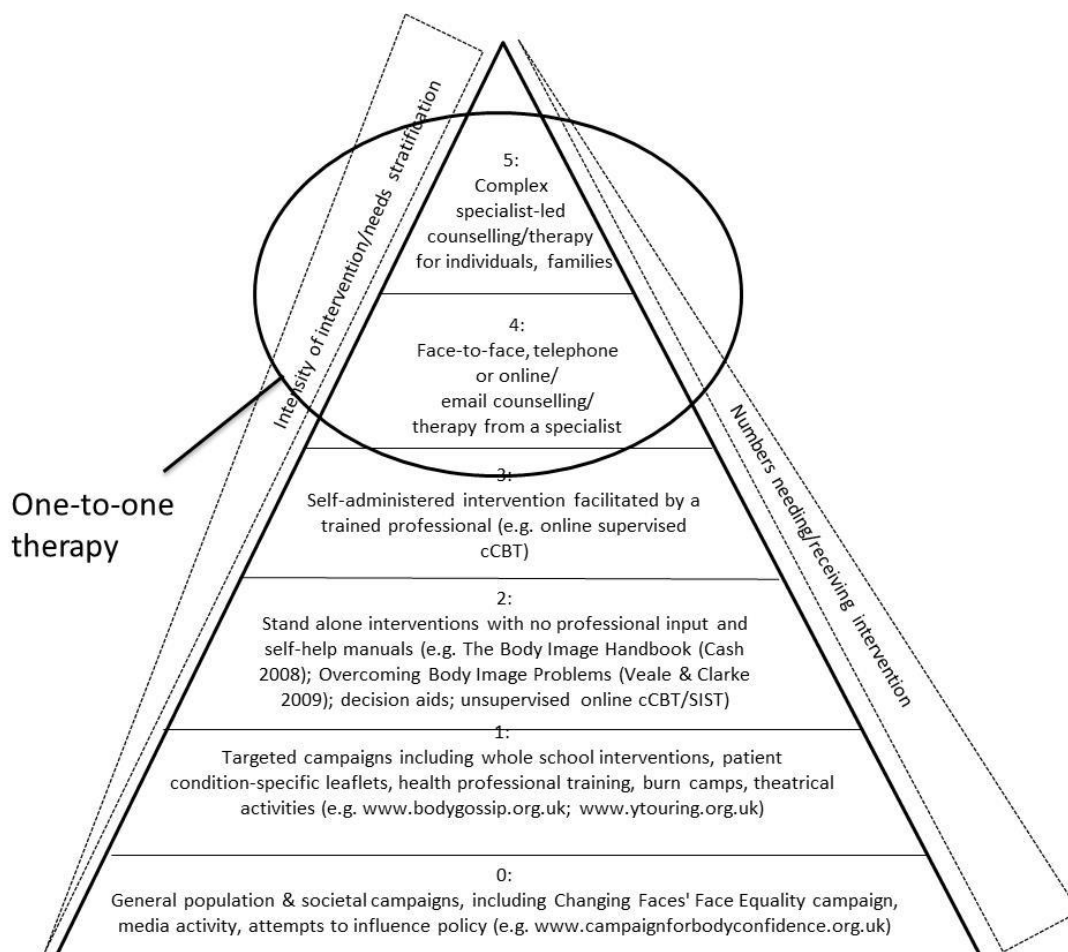
7.1 INTRODUCTION

Figure 18 The location of one-to-one support on the CAR pyramid of appearance-related interventions

Thus far the studies in this thesis have considered CYP and family members with low-mid levels of psychosocial needs. While the interventions considered throughout the previous chapters have demonstrated a number of psychosocial benefits, they are not considered appropriate for those with complex psychosocial issues. Such difficulties need to be addressed by mental health specialists with the highest levels of training, and the current study therefore explores the experiences of clinical psychologists providing therapy to CYP with burn injuries and their families within secondary care.

The National Burn Care Standards (2013) state that burns services must have suitably trained health professionals available to support patients with a burn injury and their families. Health professionals are required to have received training in psychological care which should be

delivered using a tiered approach according to individual roles within the burns team. There are five levels of psychological training for health professionals working with patients and their families/carers. Levels 1-3 range from receptionists and housekeepers to social workers or assistant psychologists. Levels 4 and 5 refer to mental health specialists with higher level training, such as clinical psychologists and psychiatrists. The standards differentiate between levels 1-3 and levels 4-5, stating that levels 1-3 should be available seven days a week, while levels 4-5 should be available five days a week.

The overall goals of therapy include support, adjustment, crisis intervention, symptom improvement (Feltham, 2012b) and concomitant improvement in physical outcomes. Screening is the first step in determining the psychosocial needs of both CYP and families (Kazak, Abrams, Banks et al, 2015). It is considered to be essential within burns based on the complexity of care and rehabilitation for those with burn injuries (Wasiak, Lee, Paul et al, 2014). Screening has been found to reduce referral time to appropriate psychosocial support (Braeken, Lechner, Eekers et al, 2013), and leads to improved communication between clinicians and patients (Carlson, Waller & Mitchell, 2012). There is a dearth of research into psychotherapy within the burns population, however the literature mainly refers to cognitive-behavioural therapy (CBT), social interaction skills training (SIST) and family (systemic) therapy. These approaches are discussed below.

7.1.1 Cognitive-Behavioural Therapy (CBT)

While there are a diverse range of cognitive-behavioural techniques, they share a number of common components in that they tend to be time limited and empirically based, focusing on problems, goals and the future (Grant, Young & DeRubeis, 2008). Mahoney and Arnkoff (1978) claimed that CBT could be divided into three main areas: cognitive restructuring, coping skills therapies and problem solving-therapies. Cognitive restructuring focuses on targeting negative thinking patterns which are thought to contribute to psychological problems such as anxiety and depression, using a combination of cognitive and behavioural techniques. Coping skills therapies focus on helping the client to develop a range of necessary skills to cope with stressful situations. Finally, problem-solving techniques may encompass cognitive restructuring techniques and coping skills therapies to develop more general strategies to cope with a broad range of personal issues.

Research into CBT within the visible difference literature was introduced in section 2.2, which highlighted how this has been limited within paediatric burns. However, the few studies which do exist have found that both individual and group-based CBT was an effective method for treating psychological issues often found in burns survivors, such as anxiety, depression and social phobia

in children and adolescents (e.g. Bernstein, Borchardt, & Perwein, 1996; Silverman, Pina & Viswesvaran, 2008; Kornør, Winje, Ekeberg et al, 2008). Maddern, Cadogan & Emerson (2006) conducted a study with CYP with a visible difference who were experiencing problems with teasing, social phobia and isolation, four of whom had scarring from burns injuries. They found that even a short-term CBT-based intervention including social skills and problem solving techniques could decrease the occurrence of reported teasing, as well as reducing anxiety and distress.

7.1.3 Social Interaction Skills Training (SIST)

Social Interaction Skills Training (SIST) aims to teach an individual the necessary skills for successful social interactions, which may include techniques such as observation, listening and non-verbal communication, implemented through the use of behaviour practice and feedback, role modelling, or homework (Houghton, 2008). Robinson, Rumsey and Partridge (1996) reported a reduction in social anxiety and increased confidence in social situations after an SIST workshop for people with a visible difference, and these effects were maintained at a 6-month follow-up. The strength in the findings from this study lies in the fact that the workshop was found to improve both generalised and social anxiety. In addition, the wide range of visible differences involved in the study indicates that the workshop was not condition-specific, although all participants were aged 17 and over, so it's applicability to younger individuals is unknown.

A study specifically investigating the effects of SIST on CYP with a burn injury found that both parents and CYP rated a significant reduction in problem behaviours at the one-year follow up (Blakeney, Thomas, Holzer, Rose et al, 2005). However, it is cautioned against making assumptions about the efficacy of the programme. The only contact the research team had with participants was a single phone call three months after the intervention to ask how the CYP was doing, but this did not involve any formal assessment. Therefore, it is unclear whether other factors contributed to the children's psychosocial wellbeing over the year, particularly as some members of the control group also improved over time. Furthermore, the authors acknowledge that the measures available to them at the time of the study (such as the Child Behaviour Checklist and Youth Self Report) did not particularly suit their aims. They recognise that these measures may be too generalised to capture the specific issues faced by CYP with burn injuries, and in particular did not suitably measure the constructs that the intervention was designed to target, such as stigmatization, social skills or social anxiety. Despite these shortcomings, Blakeney et al's (2005) study indicates the positive effect a programme of SIST may have on individuals with a visible difference who are struggling to interact successfully within social situations, and further

research involving more appropriate outcome measures and more regular follow-up is certainly warranted.

7.1.2 Family (systemic) therapy

The concept of a family as a system is introduced in section 1.4.1. While there is a marked lack of research into family therapy within the burns population, it has been suggested that family therapy may be an effective form of treatment for other issues experienced by CYP with burn injuries, such as an unwillingness to attend school (Elliot, 1999; King & Bernstein, 2001), or anxiety and depression (Trowell, Joffe, Campbell et al, 2007). Family therapy has been found to be as effective as CBT (Birmaher, Brent, Kolko et al, 2000), and in some cases may produce superior results to individual therapy (Wood, Piacentini, Southam-Gerow et al, 2006). Family therapy is thought to be particularly effective if parents were also suffering from anxiety (Cobham, Dadds & Spence, 1998), which is a common outcome for the parents of children with a burn injury (see section 1.4).

Therefore, it would appear that family therapy may be an effective technique for a range of psychological issues often experienced by CYP with a burn injury, and their families. Furthermore, a number of studies have examined the cost-effectiveness of family versus individual therapy and found family therapy to be more cost-effective than individual or mixed therapy for various issues, including depression (Crane, Christenson, Dobbs et al, 2013) and substance abuse (Morgan, Crane, Moore & Eggett, 2013). Equivalent retention rates have also been found across the two types of therapy (Masi, Miller & Olson, 2003). However, it is important to remember that a decision to implement a particular type of therapy should be based on a thorough evaluation of a client's individual circumstances (Kaslow & Racusin, 1990). Ensuring therapy is tailored to suit the needs of the family is essential to help to maximise the family's commitment and motivation to adhere to treatment (Ramchandani, Wiggs, Webb & Stores, 2000).

7.1.3 Psychosocial support for CYP with burn injuries and their families

While there are several studies exploring the effects of various types of psychotherapy as outlined above, research has yet to address the ways in which healthcare professionals provide psychosocial support for CYP with burns and their families. The aforementioned study by Lawrence et al (2016) did identify a number of different therapeutic techniques used by mental health specialists; however the authors acknowledge that the quantitative nature of the study prevented an in-depth exploration of the way in which psychosocial care is provided within burns.

Furthermore, this study included very few questions relating to support for families of those with burn injuries. Previous research has used interviews to explore the experiences of psychotherapists in a number of different situations such as contacting adolescent participants (Binder, Holgersen & Nielsen, 2008); confronting hopelessness (Beck, Halling, McNabb et al, 2005); and working with gay/lesbian clients (Phillips, Bartlett & King, 2001). Therefore, the current study was an interview study with health professionals to explore their views on the identification and treatment of psychosocial difficulties experienced by CYP with burn injuries and their families.

The specific research question is:

How do mental health specialists assess and treat CYP with burn injuries and families with the highest levels of psychosocial needs?

7.2 METHOD

7.2.1 Design

This was a qualitative interview study. Interviews were chosen as an appropriate method of data collection to explore participants' perceptions of topics in which they are personally invested (Braun & Clarke, 2013). As with study 1A, a solely qualitative method was implemented as so little is known about the ways in which psychologists identify and treat concerns in CYP with burn injuries and their families. Interviews were chosen as a technique to conduct an in-depth exploration of the different screening and therapeutic strategies used by mental health specialists. Focus groups were also considered, but are more suited to topics in which participants do not have a personal investment (Braun & Clarke, 2013). Some of the participants in this study were already known to each other, so it was felt that they would be more reticent to answer such questions in focus groups involving their peers. It was also recognised that participants may feel hesitant to answer questions even within individual interviews, in case their responses could be identified by colleagues. This was addressed by emphasizing the ethical principles discussed in section 3.2, most specifically the principles of confidentiality and anonymity, and providing an assurance that all names and identifying information would be removed from results.

The study used qualitative interviews as the research question aimed to explore participants' experiences of delivering interventions to CYP with burn injuries and their families, and participants were given the choice of a face-to-face or telephone-based interview. All but one elected to be interviewed over the telephone. There are a number of advantages to using the

telephone to conduct interviews, the first relating to the use of this technique to discuss sensitive topics (Trier-Bieniek, 2012). Indeed, Mealer and Jones (2014) claim that telephone interviews should be offered as the first option for interviews that include topics which could potentially damage participants' employability or reputation. The participants in the current study were being asked to discuss their roles, which would also inevitably include references to their colleagues and clients, so could be considered sensitive information. Participants seemed quite willing to discuss in-depth topics over the phone, which may relate to the increased use of technology within everyday life (Seymour, 2001). Sturges and Hanrahan (2004) also point out that offering participants a choice of face-to-face or telephone interviews may increase the number of respondents, as participants who are reluctant to be interviewed via one method may feel more comfortable with the other.

Telephone interviews can save time and money, especially when participants are located across the country (Chapple, 1999) as was the case in the current study. However, Shuy (2002) cautions against the use of this reason when deciding upon the best method of conducting interviews, advising that a desire to meet deadlines should not replace the need for a careful consideration of data collection techniques. Novick (2008) reports that there is an apparent bias against the notion of telephone interviews which appears to stem from the worry that the absence of visual cues could generate the loss or distortion, and subsequent analysis and interpretation of, data. In addition, the loss of facial and body expressions could lead to the misinterpretation of certain responses, and require the researcher to rely on tone of voice to gauge when it is appropriate to enquire about a particular topic further, or move onto the next (Chapple, 1999).

However, a number of studies (e.g. Sturges & Hanrahan, 2004; Greenfield et al., 2000) found no substantial differences in responses between interviews conducted via phone or in person, with Miller (1995, p37) concluding that "telephone interviews are not better or worse than those conducted face-to-face". Further, it is still possible to ensure an effective interview by employing alternative social cues during a telephone conversation (Opdenakker, 2006). For example, the lack of verbal cues within a telephone conversation means that it becomes even more important to build rapport with participants. The researcher achieved this in the current study by spending a few minutes talking to the participants before the interview began, to ensure that they understood the purpose and proposed structure of the interview, and to make sure that they were comfortable to continue. The researcher also followed Mealer and Jones' (2014) suggestion that compassion and empathy could be conveyed to participants by interpolating the conversation with phrases such as "please continue" or "take all the time you need".

7.2.2 Participants

This study aimed to explore the experiences of health professionals providing face-to-face psychological support to burn-injured children and their families with the greatest level of need for psychosocial care. Therefore, participants in this study were mental health specialists who have received the highest level of psychological training as described in section 7.1. The researcher contacted the burns services listed on the British Burn Association website http://www.britishburnassociation.org/ (British Burn Association, 2016b) to populate a list of psychosocial specialists and psychological staff working with paediatric burns patients. In addition, the researcher contacted all members of the BBA Psychosocial SIG.

Nineteen clinical psychologists from fifteen NHS trusts working in paediatric burns were identified and approached to participate in the study. Fourteen clinical psychologists from ten trusts across the UK elected to take part. Three psychologists felt that they were far too new in post to participate and two declined without providing a reason. Steps were also taken to recruit psychiatrists working in paediatric burns for the study but none were recruited. The researcher contacted the Royal College of Psychiatrists who could not refer to specific individuals and suggested a literature search of papers written by psychiatrists about burns. However, these were very limited and the authors were based in the US. The researcher also emailed Psychiatry UK, a national online psychiatry service, who were not aware of anybody specialising in burns. Participant details are outlined in Table 9 (all names are pseudonyms).

Name	Time in current role	Time since qualifying
Charlie	18 months	18 months
Alex	4 months	4 months
Olivia	5 years	15 years
Jessica	1 year	15 years
Vivian	1 year	10 years
Pat	3 months	12 years
Charlotte	3 months	5 months
Sam	8 months	8 years
Sophia	5 years	24 years
Emma	5 years	7 years
Jenny	5 months	1 year
Chris	3 years	3 years
Leigh	8 years	18 years
Claire	3 years	8 years

Table 9 Details of psychologists who took part in interviews

7.2.3 Materials

A semi-structured interview guide (Appendix 32) was used to address the research question outlined above. The researcher conducted a discussion with the British Burn Association (BBA) Psychosocial Special Interest Group (SIG), which is a group of multi-disciplinary health professionals with an interest in the psychosocial wellbeing of individuals who have sustained burn injuries. This discussion helped to identify relevant areas of enquiry. The interview guide was designed to firstly give an overall picture of the mental health specialists' roles within the NHS, and they were therefore asked about their experiences with CYP with burns and their families. The questions then aimed to explore a number of decision-making strategies, to determine the ways in which mental health specialists screen, assess and treat their patients to provide an overall care plan. They were asked how they establish whether treatment is working and whether any procedures are in place for following-up clients. Participants were asked how their role fits into the larger burn team, as well as other institutions within the patients' lives, such as school or work.

7.2.4 Procedure

University ethics was issued for the study and the researcher considered whether NHS ethics would also be required. Use of the Health Research Authority decision tool (Health Research Authority, 2016) confirmed that the study was not considered to be research, so NHS Research Ethics Committee (REC) approval was not sought. However, individual research and development (R&D) approval was sought from each of the trusts associated with the potential participants. Each of the trusts confirmed that the study was considered to be a service evaluation and therefore would not need REC approval, and consequently provided R&D approval for the study to proceed. The researcher then contacted each potential participant on the telephone to introduce herself and the study, and information sheets and consent forms were then sent to the psychologists who were interested in participating. Participants were given the choice of a face-to-face or telephone interview and all but one participant expressed a preference for a telephone interview. The researcher travelled to the remaining participant's place of work to conduct the face-to-face interview.

All of the interviews were recorded and then transcribed verbatim by the researcher. The researcher noted her feelings and attitudes towards the interview before and after each interview took place, to allow reflection on the effects this may have had on the interview (samples of

reflexive diary in Appendix 2). The length of the interviews ranged from 42-70 minutes, with a mean length of 51 minutes.

7.2.5 Data analysis

A thematic analysis was carried out on the data, following the techniques outlined in section 4.2.5. Thematic analysis was selected for the current study due to its ability to identify a rich and comprehensive account of participants' experiences across a whole dataset (Braun & Clarke, 2012). The analysis in the current study was approached from an inductive, experiential and essentialist perspective. More specifically, the research question in the study aimed to explore participants' experiences of providing psychosocial support to CYP with burn injuries and their families (inductive). The participants' own perspectives and interpretations of one-to-one support was the focus of the study, using the data to create meanings relevant to the specific research questions (experiential). The data were taken at face value to describe participants' experiences, which were then interpreted by the researcher to evaluate their significance in relation to current burn care provision (essentialist).
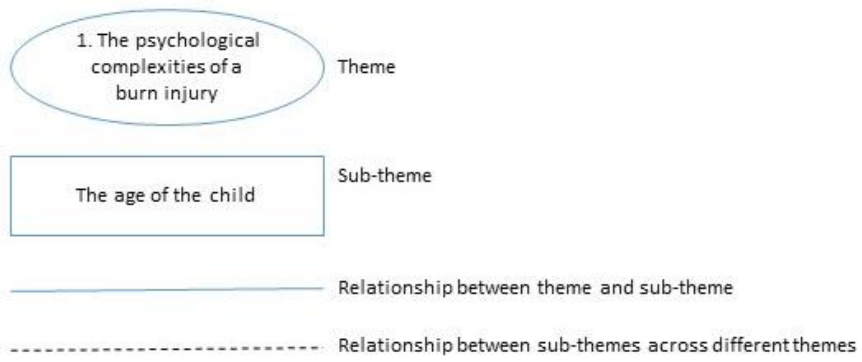
Initially, the relationships between codes and potential themes were considered and eight initial themes were generated: complex range of factors relating to a burn injury; therapy should be flexible and adaptive to suit the family's needs; needs differ at different stages; working collaboratively is necessary but challenging; differences in procedures between services; support for the whole family; engaging families in psychology; practical aspects of the role. These themes were then reworked into four main themes: the psychological complexities of a burn injury; differences between screening and assessment procedures; family support requires flexibility; a combination of therapeutic approaches to meet individual needs.

A thematic map of these results is shown below in Figure 19. The four themes are colour-coded as follows:
- The psychological complexities of a burn injury – blue
- Differences between screening and assessment procedures – pink
- Family support requires flexibility – orange
- A combination of therapeutic approaches to meet individual needs - green

The themes are presented in the circular boxes and sub-themes found within each theme are presented in the rectangular boxes. Relationships between sub-themes are indicated by the dotted lines.

Key

1. The psychological complexities of a burn injury — Theme

The age of the child — Sub-theme

————————— Relationship between theme and sub-theme

- - - - - - - - - - - - - - - - - Relationship between sub-themes across different themes
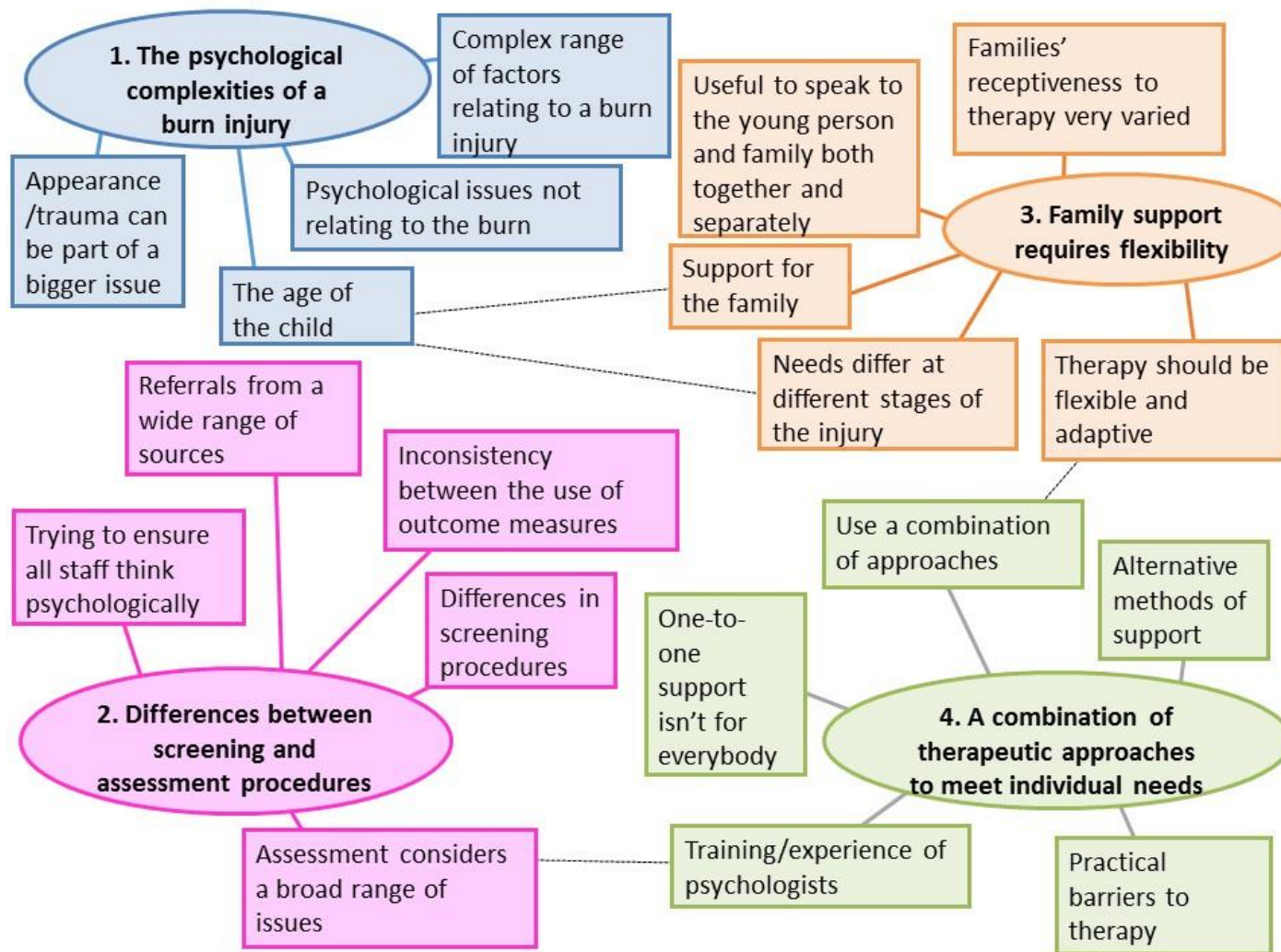
Figure 19 Study 3 Thematic Map

7.3. RESULTS

7.3.1 The psychological complexities of a burn injury

Participants in the study discussed the wide range of factors which may be associated with a burn injury, reporting that the majority of issues relate to either trauma or appearance-related concerns, or a combination of the two.

Jessica: Appearance concerns around the scarring as well as more long-term post-traumatic stress symptoms.

Jenny highlighted that even within the areas of trauma and appearance there are a number of different components which families must try to address. CYP may experience trauma, not only from the injury, but also from their experiences of their stay in the hospital.

Jenny: I think there's a real range actually, I think for young people there's kind of the initial shock of having the injury… so the trauma of the injury, the trauma of being in hospital and dressing changes and pain, and that first time that they see the scar and are struggling to understand and think about the fact that their body's changed and that the scar will also change but just that idea of not knowing what it may look like and future treatment may be needed and those sorts of things.

As well as the complex nature of trauma, it became apparent from participants' responses that appearance concerns are often also part of a larger issue. They talked about the frequency of appearance concerns, but recognised that these usually exist alongside other issues.

Sophia: If the child feels very inadequate or has low self-esteem or low-confidence and they have scarring in addition, when they feel low the scarring can dominate more then, so they're very interlinked.

Several participants reported that it can be difficult for the psychologist to identify specific appearance concerns from a CYP's overall demeanour.

Leigh: I think a child's appearance concerns can become really quite extreme before they're causing a problem for the grown-ups around them…the child that stops

wearing vest tops and just wears long sleeve t-shirts all through the summer isn't necessarily, if they're doing it quite quietly, causing problems.

This can make it difficult for a psychologist to treat appearance-related concerns, which may arise at various stages of the CYP's life. The majority of the psychologists in the current study discussed the way in which a burn injury can affect children of different ages. The general consensus was that while older children and adolescents often experience worries about appearance and reactions from others, younger children tend to cope quite well with the injury, and it is often the parents, and sometimes siblings, who present with difficulties.

Charlotte: When children are a little older it's mainly around visible difference if they've got any scarring, and being worried about what that might look like and reactions, coming to terms with what happened…I haven't come across many difficulties with the younger ones, it's mainly around working with the parents.

Many participants mentioned the fact that most of their patients are very young children, so felt that a large part of their role was actually supporting parents of children with burn injuries, rather than the children themselves. Participants reported that both parents and siblings experience many of the same difficulties as CYP, such as trauma symptoms (if they witnessed the accident) and appearance-related concerns, which is consistent with the research findings reported in section 1.4. Siblings also worry about answering questions relating to their brother or sister's injury, while parents often shoulder the burden of responsibility and guilt around the injury.

Sam: Particularly for the really young ones there's this expression of, you know, "I've damaged my child, people will look at them differently, and they'll never forgive me as they get older" so there's a lot of work around that.

The findings from study 1A support these statements, as parents talked about the severe levels of guilt and blame that they attributed to their child's injury. While there is obviously a considerable need for family support, the parents in study 1A said that the camp was the first time they had spoken to anyone else about their child's injury, even in cases when it had occurred many years previously. This suggests that although psychologists are providing support to the families referred to them, there may be many other family members in need of help who do not have access to appropriate support services or they may not be aware of the availability of support from psychologists in burn services. This may relate to screening methods, discussed further in section 7.3.2.

While children who are burned at a young age may appear to cope quite well at the time of injury, a number of psychological difficulties may emerge as they reach adolescence.

Leigh: We see is young people who do fine and then get to a point in their teenage years where they're starting to think about sexual relationships, and they've managed often their scars are hidden by their clothes but when they start to think about more intimate relationships that causes terrible worries.

Leigh's comments, as well as those made by Charlotte above, suggest that adolescents with burn injuries may experience similar difficulties, regardless of whether their injury occurred recently or historically. Adolescents may therefore be considered a high-risk group for issues relating to appearance, scarring and intimate relationships, and it is important to ensure that they have access to support at this stage of life regardless of when the injury occurred.

Another commonality amongst the participants relates to the transition from primary to secondary school. CYP can find it very difficult to move from a school where their injury is known by the other children to a new school where they will have to face comments and questions about their injury. Jenny pointed out that often children reach adolescence at around the same time as they transition to secondary school, so the combined worry of a new social environment and a developing body consciousness can be exceptionally difficult for them to manage.

Jenny: I think that can be a big factor for children who've had a historical injury as well where they might have grown up in a primary school where the other children have very much got used to their visible difference and then perhaps they may then go to a much bigger environment and be faced with new people and new friendship groups and new questions, at a time when young people are also starting to notice difference and perhaps become more body conscious. So it seems that it can sometimes feel like a double whammy I guess.

Jenny's observation lends further support to the need to ensure CYP with burn injuries are supported as they reach adolescence. However, the finding that the majority of patients are toddlers and young children has important clinical implications. If these younger children are not followed up into adolescence then it is possible that a large number of older children are struggling with psychological concerns unbeknownst to support services, and it may be unreasonable to place the onus on the CYP to seek help. They may not know how to contact an

appropriate source of support, and if they sustained the injury when they were very young they may not even know that their family received psychological support at the time of the injury. Furthermore, participants reported that there are a number of other potential barriers such as a reluctance to admit that they need help, and the potential stigma surrounding psychology. For some, contact with the psychology service may only be resumed when the CYP revisits the burn service for further treatment, which may be many years after the injury.

While most of the participants talked about the issues undergone by families which are directly related to the burn, a number of them also recognised that many families face additional difficulties. For example, some of the participants treat families who are asylum seekers, whose primary concerns relates to their living status and medical care, rather than thinking about psychological support. Jenny talked about the range of difficulties experienced by the families under her care.

Jenny: Some families where there is just a whole host of wider complexities within the family circumstances anyway… perhaps a chaotic family, or families where there might be a heightened risk of the child having sustained a burn injury anyway, where there's parents with mental health difficulties or alcohol or drug problems, or there's social services involved or that kind of thing.

These additional factors mean that psychologists have to take into account a number of other considerations when meeting a family affected by a burn injury. Some participants acknowledged that they can struggle to treat the more complex families, and in some cases would choose to make a referral to social services or the local CAMHS instead. A minority of participants had also made referrals to psychiatric services, in more extreme cases such as those relating to self-injury or where psychotropic medication is required.

This ties in with previous research which has focused on the effect that psychiatric problems can have on burn care and long-term adjustment. Tarrier, Gregg, Edwards and Dunn (2005) found that burn patients with a pre-existing psychiatric illness spent far longer in hospital and that their burn injuries took longer to heal than burn patients without a pre-existing psychiatric condition due to difficulties with communication and co-operation with treatment. They suggest that patients with pre-existing psychiatric illnesses will pose significant challenges when in their care, and that burn staff should receive specialist training on how to manage these conditions.

7.3.2 Differences between screening and assessment procedures

Screening helps to identify those who might benefit from psychological support, although the screening procedures vary greatly between the different services represented by participants in the current study, as well as between inpatient and outpatient services. While the participants acknowledged that inpatients should be screened, there were differences between who carried out the screening and the techniques used. Screening was carried out by a psychologist at four of the sites and the ward staff at the remaining six. Some screening assessments were more comprehensive than others, with methods ranging from tick box approach to an adapted version of the Psychosocial Assessment Tool (PAT), which is a measure originally designed to assess psychosocial risk in families of children newly diagnosed with cancer (Pai, Patino-Fernandez, McSherry et al, 2008).

Jessica: It's been quite informal previously, what we're doing at the moment is just literally a screening question…are there any concerns about psychological or emotional effects of the burn injury on the patient, and the dressing room staff have to tick yes, no or already referred.

Another inconsistency between services relates to the use of outcome measures. The majority of psychologists did not have a formal procedure in place for using outcome measures, and instead relied on their clinical judgement. This has both advantages and disadvantages. A number of participants mentioned that they were striving for more consistency across all burns services, so having a standardised set of measures may help to achieve this. However, it is possible that screening questions may not fully encapsulate the complexities associated with a burn injury and an overreliance on standardised measures could therefore mean that psychological difficulties are overlooked. A combination of screening measures and clinical judgement may therefore provide the best strategy to identify families who would benefit from support.

Charlie: We may ask more standardised screening questionnaires if we feel it's appropriate, but I feel that's something I probably use less in my work and would use more of a general screen.

In addition to initial screening procedures for inpatients, psychologists also receive outpatient referrals from a wide range of sources, including Multidisciplinary Team (MDT) meetings and other staff, outpatient clinics and burn clubs. Many of the psychologists attend regular MDT meetings, which provide them with the opportunity to speak to the staff on the burn ward.

Participants felt that these MDT meetings were a good source of referrals as having a physical presence in the meeting reminded other burn staff of the psychologists' role within the team. Several participants also attend outpatient clinics as frequently as they can. While participants felt that MDT meetings and outpatient clinics were a positive source of referrals, they did take up great deal of the psychologists' time. Psychologists from all of the services said that they were also supposed to receive referrals from staff on an ad hoc basis, whenever concerns arose about a patient's psychological wellbeing. However, participants felt that referrals were being made with varying levels of success as not all ward staff appreciated the benefit of psychological services.

Pat: I think when it's busy, I'm not sure it's prioritised to always ask those questions about how they're doing in terms of psychology and their adjustment, and I think sometimes people can appear to be ok but if the questions aren't asked and they're quite quiet and quite compliant, people aren't always, it's not always clear that actually they're struggling.

Several of the psychologists believed that a large part of their role is to try and ensure that all staff take a psychosocial perspective. There seemed to be a general feeling that nurses felt psychological screening should be up to the psychologist.

Emma: We've been spending a lot of time working on helping nurses to do quite a low-level screen of any psychosocial issues, and there's a lot of feeling that it's a psychologist's job and not theirs, so trying to move people towards an understanding of this being part of everybody's job can be quite challenging.

Emma suggested that medical staff may need to emotionally detach themselves from patients as a coping mechanism to enable them to carry out their jobs effectively. She also felt that even after five years, it was still difficult trying to promote psychological thinking within a team which had not had a designated psychologist previously. However, the ward staff in other services have received psychosocial training with very positive results.

Alex: We also do training with the nurses, we're actually going to train some of the paediatric nurses soon in kind of basic psychological skills because it's also about developing, actually you can listen and this is all part of your role *laughs* and you know, that you can do some of this stuff as well. So that's kind of another aspect of the role really, not just supporting the staff but kind of building up their knowledge and skills.

After patients have been screened and referred to support services, the psychologists aim to carry out an initial assessment of their needs. In contrast to the screening procedures which can be quite brief, assessments are carried out more thoroughly. Although there is no standard procedure in place, all of the techniques used by the participants are intended to elicit a comprehensive picture of the families' needs and circumstances. Sophia describes the assessment as an "eclectic process":

Sophia: It's a process that can take a while, it's observation, it's direct contact with the child, it's talking to the family, it's obviously being very au fait with any safeguarding concerns and social concerns and medical issues, and that would include therapy, like OT for scar management or physio.

The participants in the study did use outcome measures as part of their assessments, but this varied according to the psychologists' preferences as well as the difficulties with which their clients were presenting. While some sites use outcome measures more than others, one service in particular employed a formal process using routine measures at set stages of the injury.

Claire: We use the PedsQL so that looks at the family impact, it looks at the impact on the parent and the child, so we routinely administer those at assessment and then either halfway through or at discharge. Then the assessment pack has a number of different tools, so there's the PedsQL, the SDQ, so they're the routine kind of CAMHS ones, but then we also use the measures that have been put forward by the BBA outcomes group, so again that's the PedsQL, we use an appearance measure, and the impact of events scale to look at PTSD and that's routinely administered in the inpatient phase, six weeks post-discharge, between 4-6 months and 12 months.

This service is managed by the psychologist who has worked in her role for eight years, at least three years longer than any of the other participants, so it may be that she has had time to develop an effective system over the years. It is possible that the other sites could establish a similar system over time, and several of the psychologists did say that they were currently trying to develop a more formal process for using outcome measures and establish more consistency within the service. However, a common response from the psychologists was that current standardised measures do not necessarily capture the specific issues which they address with families in their sessions.

Jenny: Outcome measures that are standardised measures, which I guess I'd use varyingly depending on the presentation…I don't necessarily feel that there is always a questionnaire that can capture exactly what you've attempted to do in your work with the family.

A lack of suitable outcome measures within the paediatric burns population has been discussed elsewhere in this thesis (e.g. section 1.3.1). Even Claire, whose service most regularly used outcome measures, felt that they were often just trying to "cobble together" a number of different outcome measures to try and capture the complexities associated with a burn injury. Many of the participants referred to ongoing discussions amongst members of the British Burn Association Psychosocial Special Interest Group, aiming to agree on a set of appropriate outcome measures to be used by all services. Participants said that they would welcome some guidance on which measures to use and the chance to improve consistency across services.

Some participants choose to use standardised outcome measures with CYP and parents while some use more informal questionnaires, but all participants agreed that an essential part of the process is to talk to the family and try to elicit concerns from the family members themselves. Psychologists also rely on their own observations, and several discussed the importance of anecdotal evidence, e.g. speaking to schools, other family members or the medical staff who treated the patient for the burn injury. This anecdotal evidence can help to provide an objective account of a CYP's progress, and contribute to the psychologists' overall formulation about the CYP's wellbeing. Anecdotal evidence can also prove invaluable when trying to determine the developmental level of a child. Two of the most experienced psychologists (8+ years each in post) highlighted the possibility of children regressing to a developmental stage which is younger than their actual age due to trauma, so noted the importance of gathering information from those who are familiar with the child to assess any changes which may include nurseries or schools.

Pat: Children can regress quite a lot developmentally, temporarily, so it's just about gathering information from people that know them, also the nurses, in terms of how they're reacting to things really.

7.3.3 Family support requires flexibility

Participants in the study reflected on how they approach their therapy sessions, and the overwhelming consensus was that therapy is very much not a 'one size fits all' method. They emphasized the importance of carefully considering the families' individual needs throughout

therapeutic sessions. Participants felt that attempting to stick rigidly to a particular therapeutic approach is counterproductive, and instead described a more flexible, semi-structured approach which is based on personally-set guidelines, but led primarily by the patient.

Charlotte: I think sometimes if you go in with a structured approach that you want to take it never quite goes to plan and that you're guided by the person, what they're finding difficult, what support they would like, and sometimes even when you try certain approaches it might not work and then you might have to change that. So I would always be led by the individual, have a guideline in the back of my mind but be flexible with that.

The majority of participants also talked about the need to be flexible when considering whether to treat the CYP with the burn injury on their own, the parents on their own, or the whole family together. Many of the participants felt that it is important to assess the entire family, to determine the needs of the different family members and ascertain whether support would be beneficial for all. Participants felt that it is advantageous to provide support to the rest of the family, not only to help them with their own issues, but to ensure that they are in the best position possible to allow them to look after the burn-injured child.

Sophia: As we know family units interact usually quite closely and if you can help the parents, you can help the children. So that's something, sort of a service development thing that I'd like to look at more closely in the burns service.

When treating the family, participants talked about the best way to approach the sessions. Most participants felt that it is useful to speak to the CYP and the family both separately and together. Once again, it was agreed that sessions need to be approached in a flexible way, depending on both age and the individual preferences of the CYP and their families. For example, psychologists always see younger toddlers with their parents, whereas they tend to use a combination of sessions with and without parents for the older children. Psychologists may start a session with the whole family, then spend time alone with the CYP and/or the parents, and perhaps bring everyone back together to summarise the session at the end and ensure that the parents can continue to support the child at home.

Participants talked about the need to weigh up the benefits of speaking to the whole family versus speaking to the CYP on their own. It was felt that sessions with solely the CYP help to give that patient a voice, and allow them to speak more freely. However, this does raise issues of

confidentiality. A CYP may say something which the psychologist feels it would be helpful for their parents to know, or could raise safeguarding concerns, in which case the psychologist would be obligated to contact social services. While CYP may feel more comfortable opening up in a session without their parents, it was felt that sessions involving the whole family provides a clearer understanding of the dynamics within that family, which may then help the psychologist to deliver the most effective form of therapy to suit individual needs.

Pat: Sometimes they can be very protective about their parents, so it gives them a way of being able to say those sorts of things without worrying about hurting their parents, or their sibling, or whatever. Equally, if you see the family together you get a richer picture of the dynamics of the family and you're able to facilitate conversations between the family members that perhaps wouldn't happen otherwise.

Participants discussed the difficulties they can face when first approaching families for therapy, as their receptiveness towards the idea can be so varied. One of the main problems suggested by many of the participants related to families' previous experiences with support services; families with no prior experience of services may have misconceptions about what support will actually entail, whilst those who have had a negative experience in the past may be more reluctant to accept support.

Emma: I think if families have had difficult experiences with services in the past, then that can make engagement difficult. So sometimes we'll have families who have had a lot of mental health input in the past and haven't necessarily always found that helpful, and that can create a bit of a barrier in terms of us then engaging with them. I think sometimes in some of the cases there might have been quite a lot of social care involvement around the injury, or questions about if they're deliberately inflicted injuries or any of that questioning that's gone on, I think families can be a bit more reluctant to open up to you because they feel that they're being assessed by everybody and blamed really.

The majority of participants felt that the word 'psychologist' is associated with an automatic stigma, which may be aversive and prevent them from accepting help in the first instance. Families who are offered psychological support may become defensive and feel like they are being singled out. It may be a particularly sensitive time as many families will have been asked routine safeguarding questions about the injury, and so may already worry that they are being

blamed. Participants felt that the best way to approach families to offer support is to try and normalise the process, emphasizing that their service is available to everyone to ensure that families do not feel as though they are being targeted.

Charlie: I do know that psychology as a profession and as a label is still quite misunderstood, and people have a lot of strong feelings about it, so I do think that sometimes if people are told they're going to see a psychologist I understand that raises all sorts of thoughts and feelings for a lot of people, I think a lot of our role is demystifying some of that and explaining about what our role is.

Participants in the study recognised the need to treat families flexibly according to the different stages of an injury, as the psychological issues discussed in the first theme can vary over time. Several participants felt that it can sometimes be difficult to identify psychological issues, as these may arise at any point following the injury. Furthermore, psychological issues may change as the recovery from the burn injury progresses, so assessment and therapy may also have to be adaptive depending on the stage of the injury.

Jessica: There might not be concerns on Monday but there might be concerns by Thursday, or in a few weeks' time, psychological issues don't show themselves straight away do they?

For example, the majority of participants felt that inpatient work tends to focus on normalising families' reactions to the injury. Patients may experience anxiety about their current situation, such as worrying about dressing changes or skin grafts, whereas parents may suffer from extreme levels of guilt. Several participants said that their main role at this stage was to help families realise that their feelings are normal, and help them to cope with their time in the hospital. Participants talked about "watchful waiting" to monitor whether the initial distress develops into further problems, or whether it disappears on its own. Several participants felt that the more challenging difficulties may actually arise once the CYP leaves the hospital.

Alex: I think again, maybe I've said already, kind of at the acute stage it is just containing that initial distress and kind of just putting it into context, and then perhaps later on that is where sometimes things can become more complex because it can develop into other things.

Participants described how, in contrast to inpatient work which focuses on the injury and what has happened, outpatient work tends to involve a much greater range of issues relating to adjusting back to normal life and looking forward into the future. For example, parents may worry about how they will manage the injury in the home environment while CYP may worry about other people's reactions to the injury and returning to school. Families may also worry about how the burn will affect them in the future, as they experience uncertainty about how their appearance may continue to change over time, and whether their appearance will have an impact on future relationships.

Claire: Appearance concerns and body image, and coming to terms with the impact of having a long-term changed appearance to do with scarring. And then at the same time dealing with the social stigma attached to having scars as well, so dealing with the reactions of others, going into social situations, meeting new people, that's probably the main bulk of the work that I do in the outpatient phase.

7.3.4 A combination of therapeutic approaches to meet individual needs

Based on the need for flexibility outlined in the previous theme, none of the participants in the current study said that they use solely one approach during therapy, and all felt that it was important to use a combination of different techniques. The majority of the participants mentioned CBT and systemic approaches as their preference, but several felt that the main reason for this is simply because they have received the most training in this method.

Jessica: My core doctoral training is in CBT and systemic so they're things I fall back on quite comfortably…I probably do a combination of CBT and systemic, so more systemic ideas when I'm working with parents really and when I'm working with the nursing team.

While only two participants qualified as clinical psychologists less than a year ago, seven participants had been in their role in paediatric burns a year or less, so it is possible they have not fully developed their therapeutic repertoire specifically relating to this area. This is reflected in comments from several participants, who felt that although their clinical training provides them with a fundamental basis of the different therapeutic techniques, a large part of their role involves 'learning on the job'.

Sam: I think clinical training you can kind of transfer the skills, I suppose the things that I've been picking up and learning about is the process of being on the burns ward and the treatment, so yeah I don't think the training could've prepared me for that.

In addition to a large part of participants' training being focused on CBT techniques, many also felt comfortable using it due to its evidence base in both trauma and appearance-concerns. Olivia noted that while she preferred to use CBT, she would decide which approach to use based on which had the best evidence base at that particular time. Therefore, as more research is conducted into alternative approaches, it is possible that psychologists may alter their methods in accordance to recent findings. For example, Charlie discussed the growing evidence base around mindfulness to address pain, which she said she would often use near the time of injury or around surgery for inpatients. Several of the other participants used mindfulness to treat anxiety, but recognised that this was often delivered within a more general CBT approach.

Charlie: If there's anxiety as well, around the appearance concerns, then that might be when I'd use something like mindfulness, or a relaxation type approach to help with the anxiety side of things. So I think I'd probably use CBT as my core and then I'd probably include some other things as well.

In addition to making decisions relating to the evidence base of various approaches, all participants reiterated the importance of choosing techniques to suit their clients. For example, Emma discussed how she might draw on certain parts of different approaches to ensure that therapy can be suitably tailored to individual needs.

Emma: We might use things like motivational interviewing techniques, in terms of helping to move people forward with adhering to treatment and those kind of things. Bits of things, like mindfulness, increasingly using things like acceptance and commitment therapy as well, lots of little bits of different things really which we use interchangeably depending on the family and what seems to fit them.

Jessica also talked about the importance of considering social skills alongside a more cognitive or behavioural approach.

Jessica: A little bit more thinking about what I've done with children is thinking about other people's reactions, anticipating other people's reactions, how they are

going to respond to that, so thinking about some behavioural issues as well as cognitively, so I think more in those ways it's about social skills as well, which often comes from their concerns about their appearance and what people are going to say to them or how they're going to feel when they're out and about, staring and things like that.

This lends support to the idea that therapy is not a 'one size fits all' approach and highlights the importance of considering all of the different ways in which a burn injury may influence a child's life, and then selecting appropriate techniques to address each particular area. Sam and Sophia felt that visual and narrative approaches could also be valuable when working with CYP.

Sophia: I do focus on the visual way of communicating because I think that too much literature, too much stuff to read, is contraindicative for a lot of people, you know our culture is very visual so I'll use lots of pictures and things like that to help.

These findings reflect those reported in study 1A, which report that CYP may struggle with verbal techniques and prefer to use visual techniques to help them articulate their feelings. As mentioned earlier, the techniques used by psychologists may reflect their level of experience. Sam and Sophia are two of the more experienced psychologists, with over 8 years' experience in clinical psychology, so may have also developed additional methods of working over time. The ability to use various interventions according to individual need is a skill which is likely to develop over a number of years, and supports the need for the expertise of psychologists within burns services.

Some participants had also been trained in techniques in addition to their clinical training, such as hypnosis for pain management and anxiety or eye movement desensitization and reprocessing (EMDR; A therapy used to treat trauma and anxiety using a patient's own rapid, rhythmic eye movements to reduce emotional arousal) for trauma. Claire felt that EMDR is particularly effective for treating trauma in terms of time-efficiency and has found that effects are maintained at follow-up. Many of the other participants said that they would be interested in learning a variety of new techniques to allow them more choice when selecting the most appropriate technique for each patient, but budget constraints prevented them from receiving additional training.

Claire: I'm still quite new in using EMDR but when I have used it with trauma patients I have found that there's a much quicker effect, as in you need less sessions.

Whereas if you were doing the same approach with CBT, I think you'd still get there but it takes a lot longer. I mean I haven't had many cases but the ones I have…when it works it works well and quite quickly.

In addition to the need to be flexible when using face-to-face techniques, participants also raised the issue of the need to work flexibly to address a client's level of need. Participants recognised that one-to-one work can be effective for certain people, but perhaps not others. In certain cases, lower-level interventions such as burn camp are considered to be more effective than one-to-one therapy.

Jenny: I think there is a proportion of children where one-to-one therapy is not the answer and perhaps also that their willingness to engage and their ability to engage with one-to-one therapy means that it's not going to be effective, they find it incredibly difficult to sit in a room one-to-one and talk about difficult and sensitive issues and that's when the wider, more holistic and social-based interventions are crucial and certainly my experience of going on burn camps with young people is that I often think that can have, for some young people, just a bigger impact than eight sessions of therapy. I just think it's about assessment and knowing what's right for each person, and perhaps using them in conjunction as well.

This finding shows how important it is for therapy to be tailored to individual needs, which can change according to a number of factors such as the age of the child or stage of the injury, and can be represented by different levels of the CAR interventions framework. For example, some participants who suffer from anxiety may find it difficult to attend a workshop or group event and benefit from some one-to-one work to help them feel ready to attend such events, while others might think one-to-one sessions sound too intimidating and prefer a group event. Furthermore, in a similar way to using a combination of different face-to-face techniques as discussed above, psychologists also felt that it is often appropriate to combine therapeutic interventions.

Emma: One young person I worked with who does respond really well to therapy, and did make some changes and things were a bit better at school, but I then referred her on to the burns camp and I think at that point she'd never really met other young people with burn injuries, to speak to them about their experiences or anything like that, and I think that almost just got her past that last hurdle that maybe the therapy hadn't got her to.

Some CYP may find it difficult to talk to other people on a face-to-face basis regardless of whether they are speaking to a psychologist or other people their own age. Several participants referred to the notion of online support, and felt that this could provide access to therapy without the accompanying embarrassment or apprehension some people may feel about speaking to a psychologist. As discussed in section 2.2, online support has a wide range of benefits including increasing access to therapy, particularly for those who live far away from a support service and struggle to attend sessions, and appealing to those who feel that attending therapy sessions comes with a stigma attached.

Leigh: We're very excited about the online intervention, is it YP Face IT, because I think for some young people that's going to be very useful. I'm thinking of one young man who is not terribly socially adept, and so only gets so much out of peer interaction, plus he finds it very awkward and uncomfortable really talking in a therapy situation, but I think he may well feel more relaxed and able to explore the inner world more through an IT-based system, so I think having an array of different options, interventions, so that you can try and match a young person's needs to an intervention is really important.

Leigh's comment ties in with the notion of providing people with a toolbox of strategies to manage their concerns, rather than simply relying on one intervention strategy alone (discussed in sections 2.1.5 and 6.1.3).

7.4 DISCUSSION

This study explored how clinical psychologists identify and meet the psychosocial needs of CYP with burn injuries and their families. In accordance with previous research (discussed throughout chapter 1), the participants in this study described how burn injuries can be associated with a complex range of psychosocial issues. Although the most common difficulties experienced by CYP and their families related to trauma and/or appearance concerns, these usually existed alongside a range of other issues, such as anxiety or low self-esteem. Participants often also encountered areas of concern in addition to the burn injury itself, such as families with mental health difficulties or problems with substance abuse, both of which are risk factors for burn injuries (Klinge et al, 2009).

The age of the child was also considered to be another important factor within provision of psychological care. The majority of patients seen by participants were babies and toddlers, and in those cases support was usually required for parents experiencing overwhelming feelings of guilt and blame, rather than for the children themselves. This reflects the findings from study 1A, which found that some parents of children with burn injuries were still experiencing strong feelings of guilt and blame many years after the injury. While it is evident from the current study that psychologists do provide support for parents, study 1A found that camp had been the first time many parents had ever spoken to anyone else about the injury, suggesting that there are parents in need of, but not receiving, psychological support. The small sample size in study 1A prevents generalizability of findings, but does suggest a need for increased support for family members.

While trauma symptoms may be experienced by CYP of any age, appearance concerns tended to present primarily in patients burned during adolescence, or for patients burned at a younger age who were now approaching adolescence. This is consistent with the general population who often start to experience worries about their appearance during adolescence (Rumsey & Harcourt, 2004). This has important clinical implications as it suggests that adolescence may be a time when CYP have the greatest need for psychosocial support. However, the fact that the majority of patients are babies and toddlers, coupled with the finding that clients tend to be discharged from the service with an open invitation to return if problems re-emerge, means that the responsibility to seek help then lies with clients themselves. Longer follow-up procedures could help ensure that CYP in need of help are able to access support; however a general lack of resource within burns services referred to by the psychologists in the current study means that this may be an unrealistic aim.

There was a marked difference in the screening procedures used by participants, and several of the participants mentioned that they were unaware of procedures used by psychologists working in other services. A variety of different methods were also implemented by different participants, with some conducting far more comprehensive screenings than others. Outcome measures were used by some participants, but these were often selected on an ad-hoc basis, rather than following a more formalised process. As discussed by the participants in this study, as well as throughout this thesis (e.g. section 1.3.1), this is primarily due to a lack of suitable, burns-specific outcome measures, and it is hoped that the future development of such measures could improve screening and assessment among burn patients.

While there is little research on screening within burns, studies have been conducted within cancer. Pirl, Fann, Greer et al (2014) suggest that screening should be conducted using measures which have been validated within the cancer population, while Kazak, Brier, Alderfer et al (2012) refer to a link between a psychosocial model of tiered care and a standardised screening tool. The Paediatric Preventative Psychosocial Health Model (PPPHM; Kazak, 2006) provided the theoretical basis for the Psychosocial Assessment Tool (PAT; discussed in section 7.3.2), and matches treatment options to identified levels of risk. The model ranges from the Universal Level (where treatment should be basic psychosocial care such as resources and education), through to a smaller group of people at the Targeted Level (requiring targeted interventions to manage pain or anxiety), up to those with the most severe difficulties at the Clinical Level (usually involving longer-term, evidence-based techniques). This finding has associations with the CAR framework of appearance-related interventions, and suggests that the development of a validated burns-specific measure may help to identify need and then select, or direct people towards, appropriate interventions to meet that need (interventions that are at one level or another on the framework).

While some participants aimed to screen all inpatients themselves, others relied on referrals from ward staff. Participants felt that they also frequently relied on referrals from other members of the team to see CYP as outpatients and that the occurrence with which these referrals were received depended greatly on the member of staff making them. Although NHS England (2013) states that all members of the MDT should be responsible for providing psychosocial support to burn patients, psychologists in the current study felt that certain members of the team were more psychologically-minded than others. It was thought that staff members who had received psychosocial training were more receptive to the idea of psychological services. The charity Changing Faces and the London and South East Burn Network have worked together to develop a training pack for health professionals caring for CYP with burn injuries and their families, to provide them with a better understanding of the psychosocial aspects associated with burn injuries (Changing Faces, 2016c). Such psychosocial training for all ward staff could help them recognise and refer those in need of support, when making both inpatient and outpatient referrals.

Once psychologists had screened patients or received a referral, the initial assessment of patients' needs was far more thorough and considered a wide range of issues. There were individual differences between the assessment procedures used by psychologists, but this tended to relate to the individual preferences of the psychologists, and the need to effectively address the specific issues with which each patient presented. The necessity of considering issues specific to each

individual client continued throughout the interviews in the current study, as participants recognised that the complex nature of a burn injury meant that therapy should be tailored to meet the individual needs of the family. It was also considered important to take into account the needs of different members within each family, which was often addressed by speaking to family members both separately and together. This is in keeping with previous research which has suggested that each member of the family should be supported individually, as well as helping them to support the other members (Blakeney et al, 1998; Rizzone et al, 1994). Many participants felt that CYP were often very protective of their parents and found it hard to talk candidly within sessions for fear of upsetting them. Concern for parents has been reported in previous burns research, such as Mancuso et al's (2013) finding that siblings may try to do better in school after their brother or sister's injury, to prevent their parents worrying. Therefore, speaking to CYP on their own may provide them with an important opportunity to express any worries freely.

Psychological support was also found to differ depending on the different stages of the injury. While inpatient work focused mainly on reducing pain and normalising initial reactions to the injury, outpatient work involved a greater variety of challenges associated with adjustment to the injury. These findings reflect those of Arceneaux and Meyer (2009) and Blakeney et al (2008), who reported that inpatient support related to pain management, anxiety reduction and symptoms of ASD, whereas outpatient support was associated with a range of issues such as body image, bullying and the reactions of others, and the emergence of PTSD. The need to remain flexible continued as psychologists discussed the different therapeutic techniques they used to treat families. In keeping with the previous research outlined above in section 7.1, the most commonly used approaches were CBT (including an element of SIST) and family systemic therapy. Participants felt that systemic practices were inherently involved when working with families, and recognised that while they might not be providing specific family therapy, all of their work would involve underlying systemic principles. In accordance with Corey (1996), for example, many participants talked about observing and assessing the interactions between family members, and recognising that the whole family is affected by a burn injury. Rivett (2012) states that change is more likely to occur for an individual when the entire system (family) is helped to change, and the participants in the current study recognised the importance of including the whole family in a CYP's treatment (recommended by Blakeney et al, 1998).

The majority of participants also felt that they tended to approach sessions within a CBT framework initially, but with an awareness that they could adapt their techniques throughout therapy sessions. Cognitive-behavioural therapy was felt to be very effective to treat both trauma symptoms and appearance concerns, however many participants felt that they relied on CBT

principles as this was the approach in which they had received the most training. Psychologists who had received training in additional techniques often favoured these over CBT. For example, while most participants said that they would use CBT to treat symptoms of trauma, those who had received training in EMDR tended to favour this method. One of the psychologists felt that EMDR was as effective as CBT, but produced a positive result in a shorter length of time. This finding has been replicated elsewhere in the literature as de Roos, Greenwald, den Hollander-Gijsman et al, (2011) compared EMDR and CBT to treat trauma in children and adolescents who had been exposed to an explosion in a factory. De Roos et al found that both treatments were extremely effective in reducing trauma symptoms, but that EMDR achieved results in fewer sessions (a mean number of three EMDR session compared to four of CBT).

This finding is important because time is an issue for psychologists working in the NHS. The majority of participants said that one of the most significant barriers to their role was simply a lack of time and a feeling that they were spread too thinly across their service. Psychologists talked about needing to prioritise what they can and cannot do at times when they are very busy, which they feel can be detrimental to the overall service provided. Therefore, although many participants reported that they do not have access to funding to attend training on additional techniques, it could be that additional techniques could actually be more time- and cost-effective in the long run.

Participants in the current study recognised that although they usually provided one-to-one support to individuals with the highest level of psychosocial need, this type of therapy does not suit everybody. Several participants discussed examples of CYP who did not want to try, or had not benefitted from, one-to-one support, but found lower-level interventions such as burn camps far more effective. Conversely, other CYP had needed some one-to-one support to help them feel ready to attend a burn camp. Furthermore, some CYP may find the idea of both camp and one-to-one therapy daunting, and prefer to access support on an online basis. This highlights the importance of using an appropriate therapy for clients' psychosocial needs, and is in keeping with both National Burn Care Standards (National Network for Burn Care, 2013) and the CAR framework of appearance-related interventions, which both recommend a tiered approach to care based on individual need. This finding also lends support to the fluid nature of the CAR framework, which allows people to move from one level to another (in either direction) as their needs change, rather than needing to move through each of the levels in turn.

7.4.1 Limitations and future research

A limitation of this study is that the potential pool of participants was small, as there are few psychologists working within paediatric burns across the UK, and most of the participants were known to each other through the British Burn Association (BBA) Psychosocial Special Interest Group (SIG). As the psychologists meet regularly and discuss their services, they may have demonstrated social desirability bias within the interviews, choosing to over-represent aspects of their roles that have been discussed in a favourable light within SIG meetings. Furthermore, while every step was taken to ensure that participants were aware of the steps taken to ensure confidentiality and anonymity, they may still have been guarded in some of their responses due to concerns other members of the SIG could identify them in any publication of results.

The limited number of potential participants for the current study may also have had implications during the initial discussions of the study, as some of those contributing to these discussions also took part in the study as participants. This increases the chance that interview topics were suggested which would be more likely to, again, favour them in a positive light. Many of the psychologists, however, felt that it was important to ask questions relating to areas of burns services which were not working as well as they could be. Furthermore, while topics suggested within the discussions were incorporated into the interview schedule, the final decision lay with the researcher who aimed to ensure questions provided as comprehensive an overview as possible.

While the majority of participants in this study said that they mainly used CBT (including elements of other techniques such as SIST) and family systemic therapy, a number said that the reason for this was because these two approaches had the best evidence base. While these techniques are most commonly used because the most research has been conducted in them, it is also possible that research focuses on them because they are the most commonly used. The aforementioned research into EMDR and trauma in other populations indicates that it can be an effective treatment, and further research into alternative techniques such as this could help to widen the therapeutic options available to CYP with burns and their families.

7.5 CONCLUSION

The overarching conclusion from this study was that clinical psychologists needed to work flexibly to identify and meet the complex range of psychosocial needs of CYP with burn injuries and their families. While there were inconsistencies between the extensiveness of screening procedures

described by participants, all reported a comprehensive, yet variable, assessment process to identify psychosocial needs. The current study has offered an insight into how clinical psychologists tailor therapy sessions to individual clients in practice, using a range of therapeutic techniques to try to most effectively meet the individual needs of CYP with burn injuries and their families. However, participants tended to favour CBT and family systemic therapy. Future research could examine whether additional techniques could improve the range of therapeutic tools available to clinical psychologists working in paediatric burns. While CBT and systemic therapy provide effective outcomes, it is possible that additional methods such as EMDR may produce similar results in a more time-effective, and therefore potentially economical, way. Other techniques such as mindfulness, hypnosis and Acceptance and Commitment Therapy (ACT) may also benefit from further exploration.

This study complements the first three studies in the thesis, by demonstrating how psychologists can support those with the highest level of psychosocial needs, completing an overview of the ways in which different levels of intervention may suit different people. However, it also makes an additional contribution by revealing how crucial it is that the needs of CYP with burn injuries and their families are addressed in a flexible manner, and establishing how interventions can be used fluidly to support individual needs at specific times. A consideration of the findings from these studies, and their clinical and research implications, is provided in the next chapter.

CHAPTER 8. CONCLUSIONS AND IMPLICATIONS OF THE RESEARCH

This chapter draws on the findings from the four studies undertaken within this thesis to summarise interventions designed for individuals with varying levels of psychosocial need. It begins with a summary of the findings from each study and a reflection on the methodology. Clinical implications from the research are then discussed, relating to screening and selection procedures, the CAR framework of appearance-related interventions and support for the family. The chapter ends with a consideration of the strengths and limitation of the current research and suggestions for future research.

8.1 SUMMARY OF FINDINGS AND DISSEMINATION TO DATE

The findings from study 1A relate to various models of adjustment to a visible difference. For example, the specific finding that camp had helped to make a positive experience from a negative one may be explained by the cognitive-behavioural model outlined in section 2.2, as it appears that it helped to restructure some of the families' previously-held negative associations into more positive ones. CYP reported that camp provided them with a chance to enjoy themselves without worrying about their scars, as they felt accepted knowing that others had been through similar experiences. This is consistent with a number of the theories described in section 2.1. For example, one CYP in particular had previously refused to go swimming because she felt that people were staring at her, which resulted in her feeling stigmatised (Goffman, 1963) and employing a fear avoidance strategy to avoid negative evaluations from others (Newell, 1999). Members of the general public were also present at the swimming pool at camp; therefore it seems that the presence of other CYP with scars did not reduce the possibility of staring, but rather CYP's *interpretation* of the situation from a cognitive-behavioural perspective (Moss & Carr, 2004).

Parents/carers described how camp had promoted a forum for discussion with families of other children with burn injuries, and that the support received from these families had helped them to let go of feelings of guilt and blame. This provides support to Bonanno and Esmaeli's (2012) claim that families of those with a visible difference can also experience stigma, not only from other people but relating to their own feelings, and that these feelings can be very isolating and lead to a desire to meet others who have been through something similar (Carnevale, 2007).

Findings from this study were emailed to the participants (Appendix 10). The findings from this study were also fed back to the FAB committee group by the researcher, who recommended that

it would be beneficial for families to have a way of contacting others who had been through a similar experience after the burn injury. Since this time FAB have set up a Facebook page, and plans are underway for the psychology service associated with FAB to encompass parent groups. This is an example of how research can be translated directly into clinical practice, and it is encouraging that the findings from study 1A apply to the service in this way. Raising awareness of the benefits of peer support within burns services may help with the design of these services, for example, parents may find it helpful to have a place on the ward where they can meet others, or a forum for communicating with other parents once they leave the ward. Previous research and additional clinical implications surrounding peer support are discussed further in section 8.2.2.

The quantitative results from study 1B indicated that parents rated their children's behaviour and emotions as worse after the camp than they had before, however as discussed in section 5.4 this may not necessarily be construed as a negative finding. CYP's quantitative responses indicated that they felt more comfortable in social situations and experienced fewer stigmatizing behaviours (relating to both Goffman's (1963) model of stigma and Newell's (1999) model of social anxiety) at the end of camp than before, but this effect was only maintained for the reduction in stigmatizing behaviours at the follow-up. Quantitative results also showed that CYP felt more satisfied with their appearance at the end of camp when compared to the pre-camp measure, and that this effect was improved again at the follow-up. CYP's and parents' qualitative responses mainly referred to confidence, perspective and acceptance related to their appearance. These reported changes in outcomes may relate to the cognitive-behavioural model of body disturbance (Cash, 2012), which suggests that factors such as activating situations and events (burn camp) and interpersonal experiences (interactions with other CYP with burns) can affect the way in which a person thinks, feels and acts in relation to their body.

While the qualitative results indicated that a minority of parents had concerns about their children's behavioural conduct before the camp, none of the parents mentioned difficulties after the camp, instead referring to improvements in areas such as confidence, compassion and maturity. Qualitative responses from CYP and their parents mainly referred to friendship and the chance to spend time with other CYP who have been through similar experiences. Results from this study were provided to both the young people who attended the camp (Appendix 22) and their parents (Appendix 23). Findings from this study were fed back to the camp organisers via a presentation made by the researcher to the BBA Burn Camp Special Interest Group within which the study design was initially discussed. The SIG members suggested that the study findings indicated that the camp was meeting its objectives, and reported that findings from the CYP were as they might have expected from their own experiences of volunteering at the camp.

The psychologists in the YPF study found that recruitment was significantly more difficult than first expected, even though they felt that they exhausted all possible avenues to engage CYP into the study. They believed that this was due to a number of reasons, including a limited number of potential participants in the right age range, and a lack of appearance-related concerns among those who did fit the age criteria, as well as the difficulties of engaging families in therapy, or even contacting them in general. Even though recruitment was very limited, psychologists still thought that YPF has the potential to make a valuable contribution to burn care provision as it may be able to improve access to therapy, both for CYP who live far away and for those who struggle to engage with face-to-face support. It was suggested that YPF could be used flexibly within a tiered model of care to meet multiple levels of psychosocial need, ranging from a tool used within one-to-one therapy sessions to a preventative intervention. The CYP who did complete YPF sessions reported that they found it helpful to meet their individual needs even though they used it in different ways, lending support to the idea that it can be used in a flexible manner.

Findings from the interviews with clinical psychologists in study 3 revealed four main themes: the psychological complexities of the burn injury itself; differences between screening and assessment procedures; family support requires flexibility; a combination of therapeutic approaches to meet individual needs. Participants described a wide range of complex, often interlinked, psychosocial issues associated with a burn injury. Most CYP and their families experienced trauma symptoms and/or appearance concerns, but these often existed alongside other issues such as impaired self-esteem or pre-existing difficulties within the family. Psychologists from different burns services used a variety of techniques to screen inpatients for psychological concerns, and were often reliant on other members of the burn team to make referrals to psychological services for both inpatients and outpatients. There was an overwhelming consensus relating to the need to be flexible and adaptive when working with families, to ensure the different needs of each family member were recognised. Finally, while the majority of participants relied heavily on family systemic and CBT approaches, there was an agreement that a combination of different approaches and techniques was the most appropriate way to conduct therapy sessions, in keeping with Thompson's (2012) suggestion that one model or theory alone may be insufficient within the area of visible differences. The findings from this study were fed back to participants in writing (Appendix 39), but also presented verbally at the British Burn Association Annual Meeting (2016), which was attended by many of the psychologists who had been involved in the study, as well as a range of other burn care professionals.

8.1.1. Reflection on the methodology

A pragmatic, mixed methods approach was used for the studies in this thesis, focusing on the most appropriate method of answering each research question (Johnson & Onwuegbuzie, 2004). It has been suggested that mixed methods can offer a range of benefits (Doyle, Brady & Byrne, 2009) including triangulation (corroboration between qualitative and quantitative results), completeness (combining approaches to provide a more comprehensive representation of the phenomenon studied), and explanation of findings (using one approach to explain the findings from the other). However, there is a great deal of debate within the research community about the suitability of mixed methods, with a number of criticisms being levelled at the approach.

The main concern directed towards mixed methods research relates to a perceived incompatibility between quantitative and qualitative techniques. As discussed in section 3.1, the approaches differ drastically in terms of ontological, epistemological and methodological assumptions and methodological purists state that this prevents harmonisation between qualitative and quantitative research. Sale, Lohfeld and Brazil (2002) go so far as to suggest that mixing research methods reduces the value of both methods. The lack of clearly defined epistemology and ontology within mixed methods may be viewed as a limitation of the approach; however Onwuegbuzie (2002) suggests that rather than being viewed as incompatible opposites, epistemological and ontological considerations belong on a continuum, with mixed methods falling between positivism and constructivism. Moreover, further deliberation may suggest that the two approaches may already involve a degree of overlap. Advocates for the positivist approach often overlook the fact that solely quantitative research cannot escape a degree of subjectivity, as the researcher makes a number of choices such as deciding upon the research question, selecting appropriate outcome measures to help them arrive at their conclusions, and subsequently interpreting the data collected.

A number of researchers (e.g. Johnson, Onwuegbuzie & Turner, 2007; Greene, 2006) believe that the deviation from a specific philosophical standing should be welcomed as an essential part of the mixed methods paradigm. However, Johnson et al (2007) also emphasize the importance of understanding the strengths and weaknesses of qualitative, quantitative and mixed research, and recognising that each approach is significant in varying circumstances. Quantitative or positivist research is considered by many to be the 'gold standard' (Doyle et al, 2009), suggesting from an ontological and epistemological perspective that there is a 'single truth' in the world, which can only be uncovered by objective measures of confirmation (Johnson & Onwuegbuzie, 2004). While quantitative techniques may be very effective for a number of research questions, such as

comparing scores on outcome measures at different time points, they may be considered limiting when used as the sole technique within psychosocial research such as that included within this thesis. Stubbornly rejecting the qualitative (or constructivist) view that reality is created by the participants involved in the research, and uncovered through the researcher's interaction with these participants (Creswell, 1994), means that the researcher is likely to prevent themselves from reaching a true understanding of the social and cultural contexts of the research question.

The research within this thesis was therefore approached with a degree of intersubjectivity, accepting that while there may be a single truth, or 'real world', individuals may differ greatly in their unique perceptions of that world. For example, while the interventions within this thesis may have had a clear, measurable effect on participants in terms of psychosocial outcomes, it also aimed to gain a deeper understanding on the way in which participants interpreted their experiences. This pragmatic approach may lend itself to answering 'real world' questions in a practical way, reducing restrictions imposed by a strict adherence to the principles of positivism or constructivism (Feilzer, 2010). However, it is important to recognise the limitations of the approach.

Employing a variety of research methods may be more difficult and time-consuming; however careful planning and time management within the current studies ensured that the researcher could dedicate sufficient attention to each stage of the research. It is recognised that a definitive pragmatic technique by which to conduct mixed methods research has not yet been reached by methodologists (Johnson & Onwuegbuzie, 2004) although this in itself should not disqualify the approach as a paradigm within research; indeed it is accepted that other research paradigms will demonstrate their own inconsistencies (Denscombe, 2008). Mixed methods should be viewed as a way of combing approaches to ensure the best chance of answering specific research questions (Doyle et al, 2009), and each study within the thesis utilised a different approach, with a mixture of both quantitative and qualitative techniques as deemed appropriate.

Triangulation of findings requires researchers to compare the qualitative and quantitative findings to determine convergence (agreement), or dissonance (disagreement) between the two techniques (O'Cathain, Murphy & Nicholl, 2010). Convergence of results between the two techniques occurred within the current thesis which lends greater credibility to the findings (Fetters, Curry & Creswell, 2013), but it is important to acknowledge that this will not always be the case in research. While it is recognised that findings do not necessarily have to be "neatly consistent to have meaning and to have the capacity to explain" (Mason, 2006, p20), the sources

of the differences should be explored where dissonance does occur (Farmer, Robinson, Elliott et al, 2006).

Slonim-Nevo and Nevo (2009) discuss two different approaches to dissonance of findings: the complementary approach and the non- complementary approach. The non- complementary approach states that conflicting results are mutually exclusive and one must therefore be rejected, whereas the complementary approach believes that conflicting findings may still be integrated to explain different aspects of a phenomenon. For example, rather than assuming one of the techniques must be incorrect, the complementary approach taken by Slonim-Nevo and Nevo (2009) accepts the concept that inconsistencies simply relate to the way in which objective outcome measures evaluate performance or functioning, whereas qualitative techniques explore personal, subjective views.

Slonim-Nevo and Nevo's (2009) complementary approach may reduce a need for further exploration of dissonance when studying attitudes or behaviours, but becomes problematic when research findings are used to influence changes to practice or policy recommendations. For example, in the case of presenting research relating to the efficacy of interventions to commissioners, inconsistencies would reduce the impact of these findings. In cases which necessitate further exploration of dissonance, a number of strategies may be employed, such as considering potential sample biases or the possibility that qualitative material was interpreted incorrectly or inappropriate statistical models used (Erzerberger & Prein, 1997).

Although dissonance was not present within the current research, the potential for it to occur was acknowledged, and strategies planned to address it if necessary. For example, Moffat, White, Mackintosh et al (2006) concluded that the outcome measures they used in a mixed methods study were not appropriate to the population included, tying in with previous burn camp research (e.g. Gaskell, 2007) which suggested that the discrepancy between findings related to the generic nature of the outcome measures utilised. Biases can occur when a participant gives the response they think a researcher wants to hear (Helitzer-Allen & Kendall, 1992) and it was acknowledged within the current research that this could have been an undesirable effect of the researcher attending the burn camps as a volunteer (see appendix 2). If dissonance had occurred within the current research, a number of strategies could have been considered, such as repeating certain parts of the study (Erzerberger & Prein, 1997) or re-analysing existing data (Fetters et al, 2013). Previous studies have addressed dissonance by conducting follow-up focus groups (Wagner, Davidson, Pollini et al, 2012) or ethnographic interviews (Helitzer-Allen & Kendall, 1992) to seek explanations surrounding the inconsistencies from the participants themselves.

Overall, the use of mixed methods worked well throughout the thesis, to answer the specific research questions within each study. Two of the studies employed solely qualitative techniques to conduct exploratory research about poorly understood phenomena, and both studies generated an ample range of rich data. The remaining studies used mixed methods, one employing qualitative and quantitative techniques together to answer the same research questions (Study 1A), and the other using the two techniques to answer different aspects of the research question (Study 2). However, a consensus was found between the qualitative and quantitative techniques in both studies, lending strength to the findings. It is recommended that future research into psychosocial interventions within paediatric burns continues to employ mixed methods to address specific research questions as appropriate.

8.2 CLINICAL IMPLICATIONS

Clinical implications from the research relate to screening and selection procedures, the provision of tiered care according to the CAR framework of appearance-related interventions, and support for all the family.

8.2.1 Screening and assessment tools

The National Burn Care Review (NBCR, 2001) and Burn Care Standards (National Network for Burn Care, 2013) recognised that early psychosocial screening is needed to help identify patients who are at the highest risk of complications and to contribute to the provision of appropriate interventions. However, despite many attempts by the Burns Psychosocial SIG (BBA), it has not been possible to apply a standardised system of screening (Gaskell, Hodgetts, Mason, et al, 2008). Study 3 revealed that, although outpatients tend to be regularly assessed by psychologists, inpatient screening can be patchier. Psychologists felt that asking ward staff to screen patients would allow them to dedicate more time to treatment, although this was met by reluctance in some services. It was the psychologists' opinion that many ward staff either felt that it was not their responsibility to take psychological concerns into consideration or did not have the confidence or experience to conduct screening activities.

A general lack of cohesion between psychologists and other staff has been reported elsewhere in the literature. Peck and Norman (1999) suggest that nurses, occupational therapists and social workers experience envy about psychologists' comparative autonomy and status, and may therefore attempt to exert their own clinical autonomy as a defence mechanism (Byrne, 2006).

Activities considered outside the remit of a role can be perceived as a threat to one's professional identity and integrity (Donnison, Thompson & Turpin, 2009) and may be translated into a reluctance to work collaboratively. It has been suggested that increased supervision within MDTs may be the key to improving team cohesion (Jasper, Wilberforce, Verbeek, et al, 2016) which could include the use of a dedicated team co-ordinator (Collins & Byrne, 2011). However NHS budget constraints mean that the value of this notion would need to be convincingly demonstrated to turn the idea into practice.

While it is possible that a lack of psychological expertise may result in ward staff either overlooking or underestimating psychological difficulties, it is important to remember that the findings from this study were based on the views of the clinical psychologists who took part in the study and did not provide objective results relating to the training or experience of ward staff. Ward staff in a number of the sites had received the Changing Faces training and psychologists from other Trusts discussed setting up additional psychosocial training, so ward staff may indeed be appropriately suited to conduct and interpret screening. Psychologists in services where ward staff have received psychosocial training believed that it had helped the team to be more psychologically-minded and understand that the responsibility of providing psychosocial support should be shared across the team. Therefore, psychosocial training as standard could help ensure that staff accept the overlapping of roles which is often unavoidable in the area of mental health (Donnison, Thompson & Turpin, 2009).

Screening methods also varied across services, ranging from a yes/no tick box approach asking whether there were any concerns, to the implementation of outcome measures. While there is little published research into psychosocial screening procedures in paediatric burns, several recent studies have been conducted with paediatric cancer services. Di Battista, Hancock, Cataudella et al (2015) assessed health professionals' views of two psychosocial screening tools in paediatric cancer departments. It was suggested that social workers found the tools to be least useful as their role already required them to obtain an understanding of a family's psychosocial needs, whereas nurses found them most useful because they have the greatest contact with patients and therefore find it useful to be able to determine psychosocial concerns.

Di Battista et al (2015) suggested that the implementation of screening tools would improve nurses' knowledge of patients' psychosocial wellbeing and would help them communicate any concerns to the rest of the team. However, there are also disadvantages to using this method. Administering and interpreting outcome measures requires time and knowledge, and psychologists noted that burn staff were very time-limited in their role. Furthermore, the

complexities of a burn injury and the lack of suitable burn-specific measures (Griffiths et al, 2015) means that a number of different outcome measures would need to be employed to fully screen for the wide range of potential difficulties experienced by CYP. Burns-specific measures developed in UK-burn settings with patient involvement may improve the likelihood that the majority of possible psychosocial concerns could be captured, streamlining the screening process.

While ward staff may be able to administer screening tools to patients, it is important to consider what happens to the data obtained from this method. The psychologists in study 3 frequently referred to time constraints preventing them from carrying out their role as fully as they would like, and often do not feel able to analyse and interpret data from a battery of outcome measures. An obvious solution to this issue would be to employ more psychologists within burns services, which is unlikely given the present economic climate. There is a lack of research into the cost-effectiveness of screening within psychosocial conditions, but studies in other areas such as HIV (Sanders, Bayoumi, Sundaram et al, 2005) and cancer (Frazier, Colditz, Fuchs & Kuntz, 2000) have found screening to be cost-effective as issues can be identified and treated in their early stages. This may also be applicable to burns, as targeting psychosocial difficulties as early as possible may prevent them from developing into more complicated problems later on. In addition, analysis of screening measures could be conducted by an assistant psychologist, who could be employed at a lower cost than a clinical psychologist. Indeed, one of the psychologists in study 3 suggested that an assistant psychologist would greatly reduce the burden on her caseload and allow her to focus more on delivering support.

8.2.2 CAR framework of appearance-related interventions

The findings from the studies in this thesis lend support to the fact that individual psychosocial needs can differ greatly, and that interventions should be targeted towards meeting these needs. The CAR framework outlines appropriate interventions for different levels of need and recognises that people may move fluidly between the interventions as needed. However, it was felt that revising the framework may better represent the way in which young people and their families can move fluidly between different levels of interventions according to their changing needs. The pyramid framework was thus reworked into a wheel framework (Figure 20). This new framework retains the key features of the pyramid framework (e.g., the locations of various interventions according to psychosocial need and the way in which the number of people requiring the intervention decreases as the intensity of the intervention increases). It demonstrates how a person may move fluidly from one level to any of the others to suit their current level of

psychosocial need. It also reflects the way in which psychosocial needs can constantly change and require an ongoing assessment to ensure that the most appropriate level of support is provided.
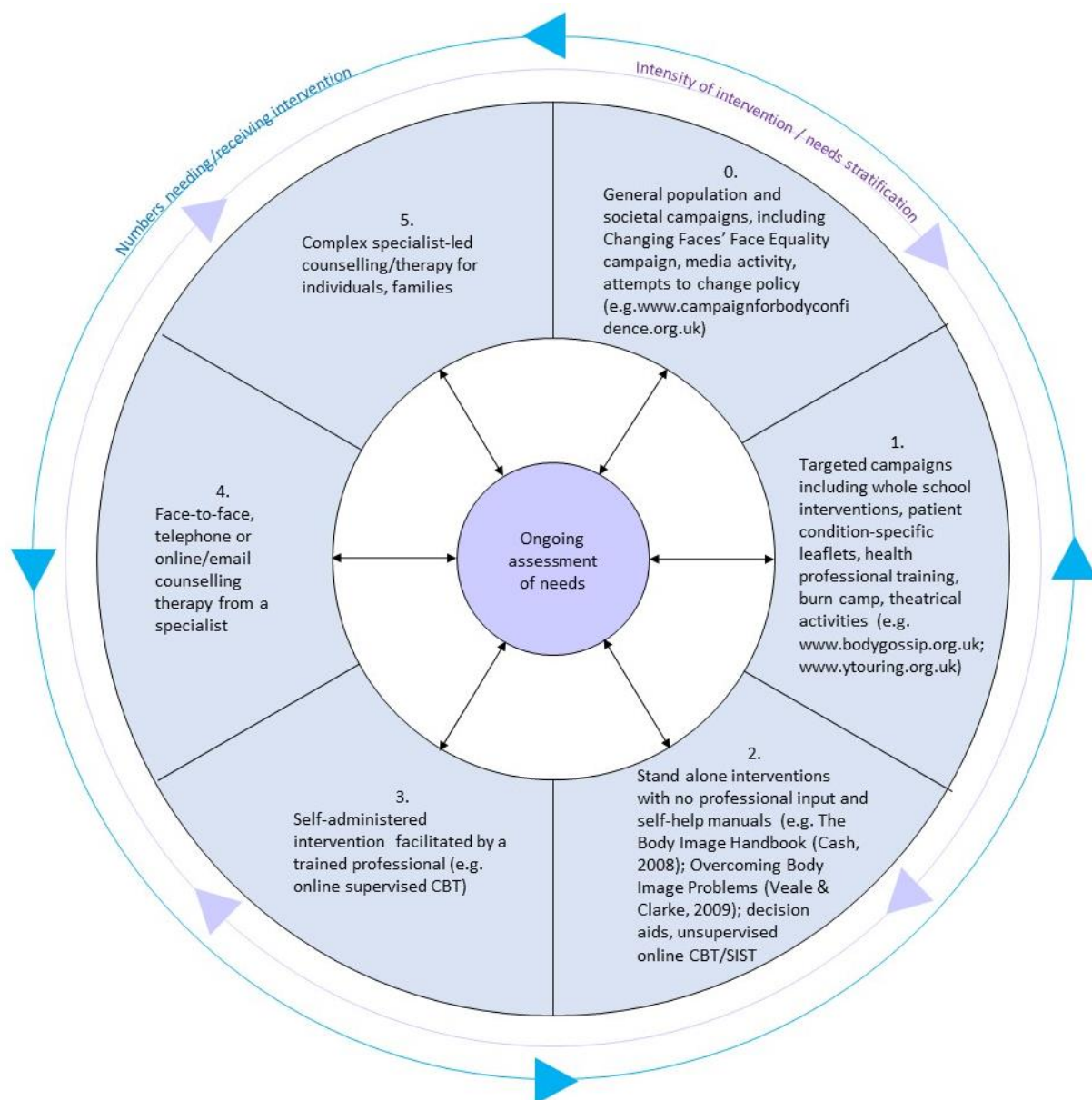

Figure 20 CAR Wheel of Appearance Related Interventions

The studies in this thesis consider a range of interventions from different levels of the framework; however there are a wide range of other potential interventions which could prove helpful to CYP with burn injuries and their families. For example, while the majority of psychologists in study 3 preferred to use CBT and systemic approaches several alluded to a number of other techniques such as mindfulness, hypnosis, or acceptance and commitment therapy (ACT). All three techniques have been found to improve a large number of issues including depression, anxiety, stress and pain (Keng, Smoski & Robins, 2011; Hayes, Luoma, Bond, et al, 2006; Schoenberger, 2000). These techniques were discussed in the context of level 4/5 interventions in study 3, but could also be used to inform interventions at lower levels of the framework. For example, ACT

could be used to inform self-help materials at level 2, or a supervised online intervention at level 3.

Mindfulness is intended to reduce psychological distress by helping individuals to focus on the present moment (Baer & Krietemeyer, 2006), aiming to result in a way to watch experiences as they unfold without evaluating or judging them (McCracken, 2007). A survey of health professionals in both the US and the UK by Lawrence, Qadri, Cadogan and Harcourt (2016) found that mindfulness was most commonly used to treat chronic pain after discharge and depression. While there is little research into the effects of mindfulness in burns, research in other conditions lends support to its use. Igna et al (2014) compared mindfulness-based CBT (MCBT, VR-enhanced CBT) and treatment as usual in adults with chronic back pain. While both types of CBT reduced levels of pain, only MCBT also reduced levels of depression, leading the authors to conclude that this type of intervention may be of help for both pain and its associated emotional difficulties. While this study involved back pain, it may be suggested tentatively that MCBT could also be of benefit to levels of pain and depression associated with a burn injury. However, it has been suggested that better quality studies into mindfulness for pain are required, employing more rigorous measures of change (Bawa, Mercer, Atherton et al, 2015).

Lawrence et al's (2016) survey found that hypnosis was most commonly used to treat procedural pain. This is supported by a number of studies which have indicated that hypnosis can be effective for procedural pain, such as that experienced during wound debridement (Sliwinski, Fisher, Johnson & Elkins, 2013; Tefikow, Barth, Maichrowitz et al, 2013). Hypnosis is a well-established technique, with studies as far back as the 1800s reporting on its effectiveness as the sole anaesthesia for major surgeries (Hammond, 2008). More contemporary research has focused on alternative methods of distraction such as virtual reality, and it is now considered possible to combine the two techniques. Patterson, Jensen, Wiechman et al (2010) assessed a programme of hypnosis delivered by specialised virtual reality software, which demonstrated reduced pain intensity compared to virtual reality alone. This has important clinical implications for the thinly-stretched NHS as it suggests that a computer can deliver the therapeutic benefits of hypnosis without requiring a clinician, saving both time and money.

ACT is based on the principles of CBT, but with an increased focus on mindfulness, acceptance and flexibility (Arch, Eifert, Davies et al, 2012). Research into ACT within paediatric burns is scarce; however Sveen, Andersson, Ekselious et al (2015) recognised the extent to which a child's burn injury can be stressful for parents, and developed an online intervention based on the principles of CBT and ACT. The intervention was developed from consultations with health professionals and

interviews with parents, and it incorporated techniques such as validation, visualization, mindfulness, acceptance strategies and exposure training. The paper does not include an evaluation of the intervention but the authors state their intention to formally evaluate it over a 12-month period. The results from this study may have important implications for the use of both ACT and online interventions for parents of CYP with burns.

As discussed throughout this thesis, it is recommended that psychologists train in a number of different approaches to provide them with a toolbox of strategies to best treat their patients. However, as revealed in study 3 in this thesis, top-tier support may not be suitable for a number of CYP who struggle to express themselves in a one-to-one situation. While level 3 interventions such as online CBT are designed for CYP whose needs are not great enough to require one-to-one support, they may also be a preferable option for those who struggle to speak to a psychologist face-to-face. There are also a number of practical barriers to therapy for many people as burn services often cover such a large geographical area, so it can be difficult for CYP and families to attend regular therapy sessions. Online support interventions, such as YPF in study 2, may therefore help to make support more accessible for those who live far away.

A number of psychologists in study 3 felt that there was only so much support they could provide to CYP when they had not experienced a burn injury themselves, and in some cases it was far more effective for CYP to talk to others who had been through a similar situation themselves. In these cases burn camps may be a more appropriate option, however many burn camps only run once a year so additional support may also be beneficial. The benefits of spending time with other children can be considered in the context of peer support, which could occur more frequently than camps, particularly if taking place online.

Peer support groups allow those who have been through similar experiences to meet and discuss their feelings in a safe environment, and are thought to promote a sense of community and acceptance (Ussher, Kirsten, Butow, et al, 2006). Studies of peer support suggest that it may facilitate improvement of symptoms and quality of life, while increasing social networks (Davidson, Chinman, Kloos et al, 1999), and this seems to be the case for a range of issues including HIV (Funck-Brentano, Dalban, Veber et al, 2005), bullying (Naylor & Cowie, 1999), and weight-related self-esteem (McVey, Lieberman, Voorberg, et al, 2003). However, the success of support groups in other populations does not appear to be replicated among those with burn injuries. While research has demonstrated the reported value of peer support to people with burn injuries in other countries such as the USA (Badger & Royse, 2010a & 2010b), there appears to be a general lack of engagement with peer support in the UK.

Batchelor and Williams (2013) were commissioned by the charity Dan's Fund for Burns to produce a report examining adult group-based burns support in the UK. Health professionals suggested a range of potential reasons for a lack of motivation to attend support groups, such as being unable to travel long distances or being unaware that such groups exist. It is also possible that support groups are presented differently in other countries, as it tends to be offered as a standard part of care to families on admission to the burns service and then repeatedly throughout their treatment (Batchelor & Williams, 2013). The majority of psychologists within study 3 emphasised the importance of ensuring that families did not feel singled out when offered psychology, so presenting support groups in a similar way may help them to feel more approachable. The health professionals in Batchelor and Williams' report also suggested that people with burns may not feel that their injury is severe enough to warrant help, which was a concern expressed by one of the participants in study 1A. The psychologists in study 3 also described how they routinely explained to families how it is not the size or severity of the injury that affects feelings towards it, so it may also be essential to emphasize this when offering ongoing support such as peer groups.

Batchelor and Williams (2013) also spoke to adults who had sustained burn injuries who had differing views on who should facilitate support groups. Some felt that these should be peer-led, while others felt that they would only attend if they were guided by a professional. The term 'support group' was felt to be off-putting, with participants suggesting the group should have more of a social focus. This is a strategy employed within burn camps which are viewed favourably by CYP, their parents and the camp volunteers (see section 5.1). Therefore, continued support groups could be presented in a similar vein, and could involve family fun days or social outings. However, an ongoing challenge to this notion is a lack of available funding and difficulty travelling potentially long distances. One potential solution could be to intersperse physical activities with online peer support. Online peer support has again proven very effective in other conditions such as depression (Eysenbach, Powell, Englesakis et al, 2004) or cancer (Shaw, McTavish, Hawkins, et al, 2000) but far less is known about the effectiveness within burns. The charity Dan's Fund for Burns is in the process of launching Adult Burn Support UK (www.adultburnsupportuk.org), an online support resource for adults, which could be researched using the methods suggested below in section 8.4.

It was suggested by Batchelor and Williams (2013) that some people may not want to identify as 'someone with a burn injury'. However, this is not to say that peer support cannot still be of benefit. An alternative technique was evaluated in a study by Clark, Ichinose, Meseck-Bushey et al (1992), where CYP with cancer and those from the general population took part in activities

together. The children with cancer felt that the group had helped them to manage their condition and improve their overall quality of life, while the other children reported that the group had improved their perceptions of, and behaviour towards, children with a chronic condition. This has interesting implications for whole school interventions as discussed in section 2.2, as it could improve attitudes of those with classmates who have sustained burn injuries, without such a strong focus on the burn injury itself.

Peer support may be suitable for the majority of CYP with burns and their families (e.g. those at level 1 of the framework); however other types of support group may provide help to those requiring a more intensive level of intervention. A 'Living Well with Burns' group could incorporate aspects of peer support with more targeted interventional components. For example, a nine-week "Living Well with Dementia" (LivDem) group included educational materials for people living with dementia and their carers (such as an external speaker providing an overview of dementia from a medical perspective or an Occupational Therapist discussing living skills for daily life), followed by a therapeutic discussion of the material. Significant improvements were observed in quality of life, depression and family communication following the intervention (Marshall, Spreadbury, Cheston, et al, 2015). It has been suggested that groups such as LivDem should aim to provide guided self-help rather than active intervention from therapists, such as suggesting strategies that may be of benefit (Cheston & Howells, 2015). It is possible that a similar group may be of benefit to those with burns and their families, providing a self-help style of intervention located at level 2 of the framework.

8.2.3 Support for the family

The current research also highlighted the way in which other family members may be affected by a burn injury and benefit from psychosocial support. Although the CAR framework was designed to represent the needs of those with appearance-altering conditions, it may also be used to help determine the psychosocial needs and most appropriate level of intervention for family members. This can be considered an original contribution based on the development of the framework throughout this thesis. While a limited amount of research has investigated the effects of a child's burn injury on other family members (see section 1.4), there is a distinct lack of published research into appropriate interventions for those other than the CYP with the burn. While previous literature has shown that any member of a family can experience psychosocial difficulties after a burn injury, study 3 revealed that clinical psychologists reported that this was also the case within their clinical work.

In certain cases (often when a child is burned at a very young age) the CYP with the burn injuries themselves may not need specialist support and it is other family members who experience problems. The majority of paediatric burn injuries occur in children under three (Pope et al, 2007), and many participants in study 3 reported that work with parents and other family members therefore makes up the majority of their caseload. The importance of including the whole family in a patient's treatment has been suggested previously (Blakeney et al, 1998) but little has been written about the ways in which the different individual needs of family members may be identified and treated.

Psychosocial support available to family members of CYP with burn injuries tends to be mainly one-to-one support provided by a clinical psychologist as described in study 3. However, similarly to support for CYP there are a number of issues relating to this method which need to be considered. For example, psychosocial support for family members at the inpatient stage can be reliant on screening techniques, which may be affected by a number of factors as discussed in section 7.3.2. As follow-up procedures tend to consist of an open invitation to return if problems arise, support for other family members after the child has been discharged often relies on the parent contacting the burns service and asking for support. While it might be expected that adults would be better at identifying and conveying any concerns to a health professional, the psychologists in study 3 suggested that parents often felt their concerns were not significant enough to warrant requesting psychosocial support.

Therefore, unless routine follow-up appointments with other members of the MDT generate concerns, it is possible that some family members who might benefit from support will not receive it. As discussed above, less psychologically-minded staff may not have the confidence or skills to identify issues which warrant concern and therefore psychosocial training may also help MDT members to refer other family members who may benefit from support. However, a child may be accompanied to follow-up appointments with a parent who is coping quite well, meaning that if other family members who are not coping so well do not attend the appointments, then it is not possible for MDT members to identify potential concerns. Comparably to follow-up measures for CYP with burn injuries, routine follow-up procedures for other family members could therefore help ensure that psychosocial concerns are not overlooked, although the practical limitations of this are recognised.

Another important factor to consider is that, like the individual needs of CYP, the psychosocial needs of other family members may also vary between individual and/or over time. One-to-one support was not found to be suitable for all CYP, and it is likely that other family members may

also benefit from the most appropriate level of intervention according to their level of need. For example, the parents in study 1A found it hugely beneficial to speak to other parents who had been through similar experiences to themselves. They felt that while health professionals may have tried to reassure them at the time of injury that the burn was not their fault, it was far more powerful to hear this from another parent who had been in a similar situation. In many cases this was the first time that parents had been able to let go of feelings of guilt and blame in the years since the injury had occurred. This suggests that for these parents, the peer support experienced during the burn camp may have been a more effective intervention than speaking to a health professional on a one-to-one basis.

However, akin to CYP, it is possible that some parents may not feel comfortable talking about their feelings face-to-face, and may prefer to seek out information online. The internet is believed to be a particularly popular method of seeking information and social support for those who have fewer friends and feel socially isolated (Plantin & Danebak, 2009). As discussed in study 1A, parents of CYP with burn injuries can feel very alone, so may find online support beneficial as a way of reaching out to others in similar situations. A number of studies have demonstrated the benefit of online support for parents of children with a range of other conditions, such as clubfoot (Oprescu, Campo, Lowe, et al, 2013), cancer (Han & Belcher, 2001), diabetes (Merkel & Wright, 2012) and cystic fibrosis (Kirk & Milnes, 2016). The positive effects from groups such as these are thought to stem mainly from the chance to discuss experiences with others who have been through something similar, both in terms of specific advice relating to the condition, as well as more generalised peer support (Suzuki & Kato, 2003).

Plantin and Daneback (2009) discovered that the internet is used less frequently by those with a lower socio-economic status (SES), which relates to the availability of resources rather than differences in help-seeking behaviour. This is prudent as it is well-known that burn injuries happen more regularly in lower SES families (see section 1.2), so it is important to consider how online support could be made available to those who struggle to access the internet. While public internet access has improved greatly since Plantin and Daneback's study, young people may not feel uncomfortable accessing support in public place. It is possible that burns charities who provide financial support to families affected by paediatric burns may consider funding internet-capable devices in the future if this method of support can be shown to be beneficial.

8.4 SUGGESTIONS FOR FUTURE RESEARCH

The research in this thesis provide an overview of the way in which the needs of CYP with burn injuries and their families can be met by using a range of different interventions. However, additional research using the CAR framework could help to strengthen the research questions outlined in the thesis. The first research question asks how the psychosocial needs of CYP with burn injuries and their families are assessed, and study 3 identified this as something which needs more attention within burn services. As discussed in section 8.2.1, a more comprehensive and consistent screening method could help health professionals identify psychosocial needs, and the development of burns-specific measures could aid in this process. Refining the screening process could make an important contribution, not just as a method to improve current care provision, but as a way of further testing the CAR framework. While the studies in the current thesis suggest that the framework can effectively represent interventions at different levels of intensity, there is currently no definitive technique to identify the type and level of intervention that might most appropriately and effectively meet an individual's needs. A standardised screening approach could be tested in conjunction with interventions on the framework, to determine whether a screening tool can help to identify appropriate interventions according to levels of need.

The second and third research questions in the thesis ask how psychosocial needs can be addressed using a range of psychosocial interventions and whether these interventions can be represented by the levels of the CAR framework. The studies in the thesis consider a range of interventions in the context of these questions; however it is also acknowledged that the complex nature of burn injuries means that CYP and families should be offered a toolbox of different types of support to address their needs at any one time. Therefore the research in this thesis could be strengthened further by testing additional interventions located at different levels on the framework. For those with lower levels of psychosocial need, studies 1A and 1B demonstrated that burn camps may provide a range of benefits to attendees, such as improving feelings about appearance, social challenges and behavioural/emotional functioning. Parents in study 1A reported that talking about their child's burn injury with other families helped them to address their own feelings towards the injury; however the opportunity was only available to parents who had been invited to burn camp. Therefore, future research could explore different mediums of peer support which are more accessible to parents of children with burns, such as local or online peer support groups.

It has been suggested that the array of available online support groups warrants detailed evaluation to determine exactly what components are most helpful and to whom (Eysenbach,

Powell, Englesakis, et al, 2004). While the findings from studies of other support groups have indicated that it is the opportunity to discuss specific conditions with others in similar situations which is beneficial, there are specific aspects to burns which may not be relevant across other populations. For example, parents may be unable to let go of feelings of guilt and blame stemming from the injury until they have discussed their feelings with other parents of CYP with burns (see study 1A). Therefore, it would be worthwhile to examine whether the same effect is obtained via the internet. As online support groups specifically for families affected by burns is a little know topic, the mixed methods approach employed to evaluate YPF in this thesis could also be employed to examine the feasibility and acceptability of this type of support. Based on the results from the studies outlined in section 8.2.2 above, pre-post quantitative measures could be used to determine the whether the programme improved constructs such as social isolation, depression and quality of life, whereas qualitative interviews could explore in more depth whether families found the group to be of help.

In contrast to studies 1A and 1B which involved an evaluation of a well-established intervention, study 2 focused on a newly-developed intervention, YPF. While this intervention had been piloted with a sample of CYP with a variety of visible differences, this study aimed to explore whether it would be feasible to use YPF to support CYP with burn injuries being treated within secondary care. Few CYP opted to participate in this study; however it was suggested that this may be due to a variety of reasons as outlined in section 6.3.2, although it was found to be acceptable for those who did take part. Study 2 aimed to recruit CYP to complete YPF under the supervision of a health professional, however it was suggested that the programme could actually be used in a wide range of different ways in an attempt to address differing levels of individual needs. Future research could explore the feasibility of using YPF in a number of different ways, such as offering the first session as standard to CYP coming through the wards as a preventative intervention/method of information provision.

The final study in the thesis was exploratory in nature, as little is known about the ways in which health professionals identify and treat families with the highest levels of psychosocial needs using top-tier interventions. This study therefore made a contribution to the existing research literature as it revealed current practices used by clinical psychologists working in paediatric burns. The study emphasised the need for flexibility and adaptability when screening, assessing and treating CYP with burn injuries and their families. It also provided a better understanding of the different types of techniques which are employed by psychologists, which were selected either according to the presenting difficulty, the technique with the strongest evidence base at the time, or simply the psychologists' preferences. Future research could therefore evaluate the different approaches

used and their effectiveness in treating various psychosocial issues. Additionally, now that a fundamental understanding of the practices used by clinical psychologists has been reached, future research could explore the experiences of CYP and their families who have received top tier support, with a particular focus on whether this level of intervention addressed their particular levels of psychosocial needs. The pre-post measures routinely completed by CYP and their families in a number of Trusts could be used to provide an indication of the usefulness of different techniques, while interviews may lend weight to exactly which components were of the greatest help.

As discussed, the majority of previous research has focused on burn camps for CYP, whereas the studies in this thesis showed that a variety of psychosocial support is available and should be tailored to meet the individual needs of CYP and their families. Although the CAR framework this provides a useful guide for considering interventions at different levels, further research is needed to determine the best way to screen CYP and their families to identify firstly whether they would benefit from support, and secondly their level of psychosocial need. While study 3 revealed that families are screened within hospitals, the methods used to achieve this vary greatly. Future research could compare different screening techniques, to determine whether the methods currently used by burns services are effective at identifying areas of concern. This could be achieved by conducting diagnostic interviews alongside the implementation of the proposed screening measures to determine the extent to which each measure identified the relevant psychosocial concerns (e.g. Simon & Bogels, 2009; Ruggiero & McLeer, 2000).

The finding within this thesis that lower-level interventions (such as burn camps) often have no formal selection procedures in place means that such interventions are not necessarily targeting those who may find them to be the most beneficial. Similarly to above, the development of burn-specific measures and psychosocial training could help facilitators to establish the psychosocial needs of CYP and families before they begin an intervention. While this should not be implemented as a method of denying care, it may help facilitators deliver interventions more successfully, and may also help them identify CYP who would benefit from interventions at a higher intensity. Future research could evaluate whether the implementation of outcome measures and psychosocial training improved facilitators' awareness of psychosocial issues, and could examine the acceptability of requiring such selection procedures to be in place before any intervention commences.

There were a number of overall strengths and weaknesses within the current research. One such strength relates to the use of mixed methods within the thesis, as the concurrence between the

two techniques as described in section 8.2 suggests that this is an appropriate method for conducting research within paediatric burns. While only one camp was included in studies 1A and 1B, the CYP attending the National Camp came from burn clubs all over the country and included those from a wide range of different backgrounds (see demographic information in section 5.2.2). Similarly, nine different NHS Trusts were included in the YPF study, and while it is acknowledged that few CYP completed the programme, this did mean that the experiences of psychologists from sites with varied procedures were considered.

While limitations within the thesis may relate to small sample sizes and poor recruitment rates, these are often expected within burns research (McQuaid, Barton & Campbell, 2003). A greater limitation relates to the fact that only those participants who had agreed to participate in interventions were included in the studies. It would have been interesting to speak to families who turned down support, to determine the reasons for this and try to gauge whether their needs are also being met. However, this creates a number of challenges, relating firstly to access as it is unclear how such families could be contacted if they are choose not to participate in research. It may be possible to link in with other members of the burn team and ask them to promote future studies, although participants in study 3 suggested that some ward staff are very resistant to psychology, and busy staff may resent being asked to take on additional responsibilities. However, it is worth noting that this was a perception of some of the psychologists in the study, and not based on reports from ward staff themselves. Another potential technique is to send out study invitation letters to all families who have been treated for a burn injury in the hospital. It is acknowledged that identifying participants through clinicians and mailouts produced a very poor return rate in the YPF study; however the psychologists in the study believed that a longer recruitment window may have produced more positive results, so these methods should not be automatically disqualified from use in the future.

In addition, only those families who spoke fluent English were included within the studies in this thesis. It was suggested in study 3 that many families affected by burn injuries may be asylum seekers, or those with a poor grasp of English, and that the psychologists often require the use of an interpreter. An interpreter was considered beyond the remit of the studies in the current thesis, but future research could examine ways to ensure that families who do not speak English as a first language are provided with the same opportunities for support as those who do.

Possible research questions for the future may involve:
1.	How can face-to-face or online support groups benefit CYP with burn injuries and their families?

2. What are the different ways in which an online support programme such as YPF can be implemented to best support CYP with burns?

3. Could a similar programme of online support be of benefit to the families of CYP with burn injuries and their families?

4. What are the most useful approaches for psychologists to use in a toolbox to address concerns, and which techniques are most effective for specific concerns?

5. How can screening tools and outcome measures improve the likelihood of CYP and families receiving the most effective treatment for their level of concern?

6. How can health professionals ensure that the needs of those who opt-out of psychosocial support are met?

8.5 CONCLUSION

The research questions for the thesis were:
1. How are the psychosocial needs of CYP with burn injuries and their families assessed?
2. How can these needs be addressed using a range of psychosocial interventions?
3. Can these interventions be represented by the levels of the CAR pyramid framework?

The studies in this thesis have identified that a wide range of assessment methods are used to gauge the psychosocial needs of CYP with burn injuries and their families, and has revealed a need to improve these assessment techniques. While it is widely recognised that early psychosocial screening is important to identify those at greatest risk of difficulties and facilitate the provision of interventions, there is no clear guidance on the most appropriate way to conduct these assessments. A lack of suitable outcome measures coupled with varied screening methods in different burns services has resulted in an inconsistent approach to assessment. The development of relevant outcome measures and a set of nationally-recognised guidelines could help to streamline the assessment process, improving both outcomes and time-efficiency.

This thesis has also made an original contribution to the existing literature surrounding psychosocial interventions for CYP with burn injuries and their families. While one of the interventions in this thesis (children's-only burn camps) had been previously evaluated, the study in this thesis sought to improve on past methods by using outcome measures designed specifically for those with burn injuries. This resulted in a recognisable link between the qualitative and quantitative findings relating to the camp, and to-date is the first study to achieve this. The next studies in the thesis were also innovative, as they explored an existing, yet previously unevaluated intervention (family burn camp), and a newly-developed intervention (YP Face IT). The

techniques used by the psychologists in the final study are well-known, but this study promoted a deeper understanding of them specifically in the context of paediatric burns, revealing the importance of considering different levels of intervention to suit a range of psychosocial needs. While these studies successfully demonstrated a number of benefits within the different interventions, they also exposed a need to clarify the relative efficacy of various components of interventions.

Results from the studies in this thesis have demonstrated the utility of considering interventions within a framework. The CAR framework is a useful starting point for illustrating psychosocial support at varying intensities, however the breadth and fluctuation of potential difficulties reported within this thesis prompts a consideration of how to match the level of need of the patients and the intensity of the intervention. Improvements to assessment methods and further evaluation of interventions as described above will be fundamental in informing future clinical practice.

In addition to answering the research questions outlined above, the studies in the thesis have also demonstrated the utility of employing a range of methodologies in improving our understanding of the area. As discussed above, the use of mixed methods has led to richer and more meaningful findings in the current research, particularly as corroboration has been demonstrated between the qualitative and quantitative findings in the various studies. This contributes to the ongoing debate about the two methodologies and lends support to the notion that mixed methods can indeed be used successfully within health psychology research. This is particularly useful in a field such as burns research in which solely quantitative approaches are challenging, due to sample sizes and the population involved.

Finally, in an area where attention is dedicated primarily to those who have sustained the burn injury, this thesis has promoted the voice of not just CYP with burns, but also family members and health professionals. This has helped to shape the future research agenda, by emphasizing the need to learn more about the factors contributing to risk and resilience in CYP, families and health professionals affected by burns, and to generate knowledge about the ways in which collaborative efforts can promote healthy adjustment to a burn injury in all those affected by it.

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Appendix 1 Glossary of terms

Body image

A person's perceptions, thoughts and feelings about his or her body.

Burn Injury

A burn is an injury to the skin tissue encompassing scalds, thermal, chemical or electrical injuries.

Burn Services

Burn services provide specialist care to people with a burn injury, using a tiered model of care where those with the most severe burns are treated within burn centres and those with more minor burns are treated within a facility or unit as follows:

Burn Facilities

Burn Facilities provide acute care for people with less complex burns (in line with National Burn Care Referral Guidance). Burn Facilities refer patients to Burn Units and Centres for the treatment of more complex injuries.

Burn Units

Burn Units provide care for patients with a burn of moderate size and/or moderate severity (in line with National Burn Care Referral Guidance). These services treat patients across a wider area than Burn Facilities and provide treatment for patients requiring critical care.

Burn Centres

Burn Centres provide care for patients with the most severe injuries and for those requiring the highest level of critical care (in line with National Burn Care Referral Guidance).

Cognitive-behavioural therapy (CBT)

A type of talking therapy based on the notion that thoughts, feelings and physical sensations are interlinked, and aiming to break cycles of negative and/or irrational thoughts and feelings.

Debridement

The removal of dead or damaged tissue to improve the healing process of the remaining healthy tissue.

Eye Movement Desensitisation and Reprocessing (EMDR)

A therapy used to treat trauma and anxiety using a patient's own rapid, rhythmic eye movements to reduce emotional arousal.

Family systemic therapy

A therapeutic approach which focuses on the systems of interaction between family members, encouraging family members to support and empathise with each other.

Fluid resuscitation

The replacement of bodily fluids depleted by a burn injury to prevent shock.

Mortality rate

The number of deaths in a particular population or from a specific cause.

Narrative therapy

A form of therapy that attempts to separate the person from the problem using personal stories to give meaning and shape a person's identify.

Psychosocial

A combination of social factors and individual thought and behaviour.

Psychosocial interventions

Activities used to facilitate change, such as a person's behaviour, emotional state, or feelings.

Visible difference

A difference from a culturally defined norm which is visible to others.

Appendix 2 Reflexive account of the research

<u>Reflection on Study 1A</u>

This was the first study I completed due to the aforementioned difficulties with NHS ethics, and I was slightly apprehensive about attending the FAB family camp as I had no idea what it would entail. Although I attended the FAB camp in May, I knew that the family camp would be very different as the whole family would attend. I had been told that this camp would be less structured, as the volunteers did not tend to look after the children and follow set activities. I was also slightly concerned as I hadn't received a single consent form back prior to the camp. Whilst I knew that this was probably due to the families simply being too busy as they prepared for camp, I had a slight worry that it might indicate a lack of interest to take part in the study.

After checking in I met the other volunteers. I had only met Karen previously, but all of the others were incredibly friendly and immediately made me feel very welcome. Quite soon after sitting down with the other volunteers, we were joined by one of the families, and it was suggested that I approach them at that point to talk about my study. Although I was a bit nervous, I knew it would be a good idea to start getting to know the families as soon as possible, so I introduced myself. The family were lovely, and as soon as I mentioned my study they knew who I was and said that they had brought the forms to the camp but had just been too busy to send them before leaving. This made me feel far more at ease, and I explained my study to them in more detail and gave them the camera. I ensured they knew how to use the camera, and what the study would entail, and they all seemed very enthusiastic about the idea.

We then went to dinner, and as the families were spread across several tables I did not have the opportunity to speak to them all during the meal. However, immediately after the meal we all went to play bowling as a group, and this gave me the chance to speak to each family. The families I spoke to had received the information I sent them, so were all aware of the study to some degree. It was good to discover this as it confirmed that nothing had gone wrong when actually sending out the information. The second family declined to take part in the study, and stated that they didn't feel they could make a useful contribution to the research. I made sure they knew that this was absolutely fine, although it did make me wonder whether the other families would also decline to take part. However, all of the other families were very keen to take part in the study. The children became very excited when they saw the cameras, and most of the families immediately started taking pictures, which was really nice to see.

During the second day, we all had breakfast together so this gave me a chance to have a chat to all of the families again. I discussed the activities they had planned for the day, and was told that they were looking forward to getting some good pictures. Some of the families had even brought their cameras to the breakfast table. After breakfast, the adults had a session with Julia, so the rest of the volunteers looked after the children. This gave me a really good chance to get to know the children better, and take part in some fun activities with them, such as bowling and crafts. I felt that this also helped them to feel more relaxed around me.

Throughout the rest of the day, the families did their own activities, but I ensured that I continued to engage with them when I got the opportunity. I wanted to make sure that I was visible, and got to know the families as well as I could, but also ensure that they could relax and spend quality

time with each other. After dinner, the whole group spent the evening together and the children enjoyed a disco, which gave me a chance to speak to the adults separately. I feel that getting to spend time with the children and adults separately, as well as together, gave me the best opportunity to speak to everyone.

On the Sunday we had breakfast together and I reminded the families that I would be collecting the cameras after lunch. I think this was really helpful as it reminded them to use their cameras throughout the morning, and ensured they brought them to lunch. After the meal, I collected all of the cameras and this gave me the chance to speak to the families individually about the next stage of the study. I explained that I would be getting the photographs developed and made a note of convenient times to call them about setting up an interview. I also asked if they had any questions about the study, and made sure they felt happy to continue taking part.

I feel that attending the camp was very beneficial for the study. I felt like I knew all of the families quite well by the time I left, and couldn't imagine trying to set up interviews to discuss the weekend had I not been there and met them all. I think it helped them to feel more at ease too, as it also gave them the chance to get to know me, rather than a stranger requesting to interview them. This was certainly apparent when I arrived at the interviews and they greeted me more like a friend, and we spent some time catching up before the interviews which promoted a positive atmosphere within the focus groups.

However, I was aware that there may also have been a downside to attending the camp with the families when it came to the interviews. Although I felt as though I knew the families quite well, I recognised the importance of striking a balance between friendliness and maintaining some sense of professional detachment. For example, had a family member become upset about any issues during the interview, it could have been more difficult to react accordingly than with someone I had no relationship with at all. However, I felt very well supported by my supervisors throughout this study, including one who is a clinical psychologist working in paediatric burns. In addition, as stated on my ethics form I knew that if a participant became upset I would reassure them and direct them to my supervisor who would be the relevant clinical psychologist to support them in this instance.

Overall, while I was aware that previous contact with the families may have made things more difficult if distress had occurred, I strongly feel that it was essential in promoting engagement in the interviews. Furthermore, as I did not receive any consent forms back before the camp, had I not attended I would most likely have had no participants in the study.

Reflection on Study 1B

I originally planned to conduct study 1B during the first year of my PhD and believed that I would not need to apply for NHS ethics as the camp was run by an independent charity. Therefore, I applied for UWE ethics which I received back quickly, and started preparing the questionnaire packs for the study and making arrangement with the organisers to attend the camp. However, further examination of the process used by the organisers to invite young people to camp started to flag up potential problems. From the original discussions I was under the impression that the burn camp organisers directly contacted young people to invite them to camp, but it emerged

that the organisers contacted individual burn clubs who then selected children from their own club to attend.

At this stage I was unsure of the individual burn clubs' affiliations with the NHS, so I realised that I needed to confirm this before commencing the study. Unfortunately, this process took a lot longer than anticipated as the contact list the burn club organisers had was out of date, and it took a long time to track down up-to-date contacts for each of the individual clubs. While I was in the process of doing this, I was also trying to determine whether I would need to apply for NHS ethics if I found that the clubs were run as part of the NHS trusts. I found this very challenging, as I was completely new to NHS ethics and wasn't which department I needed to contact. I spoke to a number of different departments who seemed unable to provide any insight, but eventually I was referred to the manager of the South West NRES Committee. She suggested that the best course of action would be to wait until the camp organisers had confirmed attendees with the individual clubs and then ask the organisers to send out the information packs for the study directly to attendees, and that I would not need NHS ethics to do this.

This meant that the burn clubs affiliation with the NHS did not affect whether I needed ethics after all, however I do not feel that I wasted my time looking into this, as it allowed me to make contact with the organisers of the individual clubs. This proved beneficial, as before I started the study I attended a meeting run by the camp organisers to discuss the upcoming camp with the individual club leaders, and this allowed me to discuss the study with them and make sure everybody was on board. As I had already spoken to the club leaders they were aware of the study, and had prepared some questions about it which I think made the meeting more productive than if I was introducing the study from scratch.

Unfortunately the whole process of contacting club leaders and NHS departments took so long that I was unable to conduct the study during the first year of my PhD. This was very disappointing but I do feel that there were some positive outcomes, such as starting to form working relationships with the club leaders and becoming far more aware of the complexities of the NHs ethics process. I also felt that when the camp ran in the second year of my PhD, I was far better prepared to attend and conduct the research, as I had a much better understanding of paediatric burns research and what I was trying to achieve with my own research.

In general I think the camp study went quite well. Recruitment was difficult as less than half of campers responded to the invitation to participate, however I feel that this was due to a number of factors. As discussed in chapter 3, people with burn injuries are typically difficult to recruit to research, and evidence has shown that postal questionnaires tend to lead to poor response rates. However, sending out the information packs and questionnaires in the post was unavoidable as camp was attended by over fifty children from all over the country. Therefore it would have been unfeasible to visit them all in person. I did attend the entire camp in person, both to collect data on the last day of camp, and in an attempt to boost follow-up responses which also had to be sent in the post.

The data collection on the last day was very challenging. Preferably, I would have liked to have carried out the data collection in a classroom style environment, but I had to be respectful of the camp organisers' wishes, who did not want the data collection to interfere with the activities. Therefore, we arrived at a compromise whereby I would ask the young people to complete the

questionnaires during the archery session on the last day. Since only three young people could take part in the archery at a time, the idea was that the remaining young people would complete the questionnaires while waiting for their turn. The main difficulty was keeping the young people focused, as it was quite distracting for them trying to complete the questionnaires while others were doing archery nearby. Although it was quite chaotic, I did manage to keep them focused and ensured they finished their questionnaires, however this method was far from ideal. I would recommend that future research should take part in a more controlled environment, but as the research took part with the support of the organisers, it was essential to take their wishes into account.

In terms of the effect my attendance had on the follow-up packs, I felt that attending the entire camp as a volunteer and getting to know the children would encourage them to respond better than if they just received the packs in the post from a stranger. Follow-up responses were disappointing, but comparable to a similar study conducted at a UK burn camp previously, so overall I think I achieved the best results possible.

Reflection on study 2

This study was the most challenging study within my thesis, without a doubt. The first major challenge related to the NHS approval process. This was completely new to me and so I felt like I had no idea what I was doing at the beginning. I did read through the guides provided by the Health Research Authority but I didn't find these particularly helpful. There was so much information provided that I felt completely overwhelmed by it all, and I also found that the relevant information was located in numerous different places, and it was never immediately obvious what I needed to read and where I could find it. I eventually got my head around the process for the main REC approval and while the ethics form wasn't particularly difficult to understand, it required a huge amount of information and took a really long time to complete. I also had to get the form signed by a number of different people and was told that I had to coordinate the signatures to ensure I obtained them all on the same day that I booked the REC meeting, which was a bit stressful. I understood the process for the REC form, but also had to fill out an R&D form which I didn't really understand. I spoke to my main R&D office about it and was told that I had to complete and submit the form, but that it wasn't actually approved by anyone. Therefore I felt like this was a bit pointless and also took up more of my time.

I submitted the REC form and attended a committee meeting where I had to answer questions about the study, but it was approved with only a few minor comments. Although the REC approval process was quite lengthy, the main problems emerged when I applied for site approval. I had decided to recruit from five NHS sites and had psychologists lined up to be my principal investigators, so thought this process would be quite straightforward. However, this was not the case as each site had completely different requirements, which all seemed to take an excessive amount of time to complete. I was really surprised by the lack of consistency between the sites as I naively assumed that all of the sites would approve studies in a similar way. There was also a huge difference in terms of the people working in the R&D offices, as some were incredibly helpful and approved the study quite quickly, whereas others had to be reminded constantly about the study and took months to approve it.

The second main issue related to recruitment. Before I applied for ethics I spoke to the psychologists at the five sites to ask how many participants they thought they would be able to recruit for the study, and all said between 5-6. However, once the study had been approved and recruitment began, it became apparent that it was going to be a lot more difficult than first thought. The psychologists discovered that they actually had far fewer eligible patients than they first thought, and the few patients who were eligible did not want to take part in the study. After several months of recruitment with very little success, I decided to expand the study to include more sites and also visit the current psychologists to talk about alternative methods of recruitment.

During the meetings, the psychologists felt that the main thing putting off participants was the length of the study, which is when it was decided that it might be more appropriate to use the programme flexibly to make it more relevant to participants' individual needs. We also discussed alternative recruitment strategies, such as recruiting through burn camps or reviewing the database for potentially eligible participants. The meetings went really well and the psychologists were all very positive and enthusiastic about the new ideas, so I left feeling hopeful that recruitment would improve.

I contacted psychologists from other NHS sites around the country and a further five said that they would like to take part, although one subsequently left the service with no imminent replacement. Before I applied for ethics approval I asked them to think of a list of specific patients who they thought might want to participate in the study, rather than assume they had eligible patients and then realise after ethics approval that they did not. I thought that as I had already completed site approvals for five sites I might have a better idea of what to expect this time, but the new R&D departments turned out to be even more difficult than the original five. They had many additional requirements which took even longer than before, such as some requiring a contract to be drawn up between the trust and the university, or needing a cost analysis to be completed. The process was far more complicated and required a lot more liaison with different people, which again took a long time.

I think it's a real shame that the NHS approval process is so complex and time-consuming as I feel like I spent a huge amount of my time chasing up R&D departments, which is time that I could certainly have used more productively. It also took so long to obtain approvals from some sites that it really ate into the psychologists' recruitment time, which was also detrimental to the study. I know that there are plans to make the NHS ethics process far more streamlined in the future, by asking researchers to complete a single form which R&D departments will all use to provide site approval. While this will not benefit my PhD, I think that it will be of enormous benefit to those conducting NHS–related research in the future.

Reflection on study 3

This study has felt very different to my earlier studies for a number of reasons. Probably the main difference relates to recruitment, as this is something I have really struggled with in the other studies. Recruitment for this study has been very easy in comparison, partly because it was much easier for me to contact potential participants. I recruited some participants from the SIG, and then I created a list of all the other burn services in the country and contacted them directly to ask whether they had a psychologist, and then contacted the psychologists to introduce my study

and invite them to take part. While it took some time to put the list together, the actual recruitment went very well as the psychologists were really interested in the study and nearly all of them wanted to take part, meaning I had a much better response rate than the other studies.

The interviews themselves also felt very different. In the previous studies, some of the children have been very quiet so it was quite challenging to engage them in the questions and try and encourage them to answer, and many answers were quite brief. I often found myself rewording questions to ensure that they understood what I was asking, and to try and prompt them to provide a bit more information. In contrast to this, the psychologists in my final study answered each question in depth and I found that I had to prompt them much less as they provided so much detail in each answer. I think this was partly because they have so much knowledge in their area, but also partly because they have all conducted research themselves, so have more experience in taking part in interviews than most young people will have. The participants also seemed to enjoy talking about their work very much, which was a nice reaction as it showed how passionate they all are about their jobs. It was also positive to feel like they were enjoying the interviews as I know how busy they all are, so was slightly concerned that they might not want to take too much time away from their work to talk to me.

Excerpts from my reflexive journal

Study 1A, interview 1

[Before the interview]

I feel quite nervous about this interview at it's my first one and I don't really know what to expect. I am really glad that I went to the camp and spent the weekend getting to know the family as I think it will make the interview much for comfortable for both me and the family, compared to if we were meeting for the first time at the interview. I do feel that I have prepared for the interview well by listening to some of my colleagues' interviews with young people and making notes of my observations from this. I have also read through literature on interviewing families as a group, which I found to be invaluable. I initially thought that interviewing a family would be similar to a focus group, and while there are certain similarities, differences also emerged from the literature I read.

I don't think there is any further preparation I could have done before this interview, so although I feel nervous I also feel that I can approach the interview feeling as ready as possible. I am also looking forward to seeing the family again and talking about their pictures, and finding out what they thought of the camp, so am also very excited about the interview. I also feel that once I've finished this first interview I will have a much better idea about what to expect for the remainder of the interview, and will hopefully be able to learn from the experience and apply this to the other interviews.

[After the interview]

I wasn't sure what to expect in this interview but it went very well. Although I was nervous at the start, I found that I relaxed into it quickly and was able to enjoy it. I did feel that I was able to pick out important points from the conversation which I then ensured I followed up on once the

participants had finished their current line of discussion. I also wanted to make sure that all of the participants were given the opportunity to have an equal voice. While the parents were very forthcoming, Andrew was very quiet, so I did find it quite tricky at times to elicit responses from him. I made sure that I referred back to him for the points discussed, and took the time to follow up on his responses to make sure that he said everything that he wanted to say.

I found the photos to be a really useful prompt, and although the most salient points that emerged from the interview weren't directly related to the photos as such, they definitely provided a good starting point. I also felt that they helped to keep Andrew focused on the interview as an eight-year-old child may find an hour-long interview quite intensive or boring. However, he stayed focus for the duration and talking about the photos which he had taken brought him out of his shell at times.

It was really helpful to have Julia at the interview as she was able to provide feedback afterwards. She said that overall it went very well – that I listened carefully and followed up on important points, and made sure that Andrew had a voice. She said that the things I could try and improve on were to ensure that I spoke slowly and used age-appropriate language throughout. These were both things that I was aware of which stemmed from nerves, which I think improved as the interview went on, and are points that I will concentrate on next time. It was really good to hear her opinion of the interview as I was quite involved in the interview, so although I thought it went well it was useful to hear the thoughts of someone else.

I'm also really glad that I did the background reading on interviewing families. While there was no conflict between participants, there were several interruptions such as the dog barking or the phone ringing. As I went into the interview fully expecting distractions I didn't find these to be an issue and was easily able to pick up the conversation once the distracting event had occurred. Overall I think the interview went very well, and I was really pleased with it as my first interview in particular. I found that I was able to expand well on all of the points discussed and actually find out lots of information that wasn't related directly to the camp but was very interesting. However, I am still very aware that other interviews may not go as well so I don't feel that I have become complacent, and will still approach the next interview with the same considerations in the front of my mind.

Study 2, interview 1

[Before the interview]

Preparing for this interview has made me think about the first interviews I conducted for my PhD. I remember feeling very nervous about those ones as I had very little experience of interviewing at that stage, and didn't really know what to expect. Overall I feel more confident about interviewing now, but while the interviews from study 1A all took place in person, this interview will be conducted on the phone. Therefore, I imagine it will be harder to read responses than in face-to-face interviews as I won't be able to see facial expressions or body language etc., so I am going to have to pay careful attention to what the participants say and the tone of voice that they use. The other difference between this interview and the previous interviews is that I am going to speak to a young person and her guardian one at a time, whereas the previous interviews were focus groups. Therefore, while the focus groups flowed very well as different family members

joined in, I feel like I will have to work harder in these individual interviews to ensure the questions flow well.

When I rang the young person's guardian I was under the assumption that she was expecting my call, which she wasn't, so it did throw me slightly. However, I quickly recovered and introduced myself and the study properly. She was very interested and was happy for her and her niece to take part in the interview which we arranged. I feel that it was useful to have the chat on the phone to arrange the interview as it started to build some rapport, and I feel much more confident than if I was ringing her for the first time and conducting the interview immediately. I am also looking forward to this interview as I am so interested to hear what the participants have to say, rather than it being overshadowed by nerves.

[After the interview]

The interview went really well, even better than I thought it would. I spoke to the young person first and was slightly more apprehensive about this as I have less experience of speaking to young people than adults. However, it was absolutely fine. I think she was a little bit nervous about speaking to me so I chatted with her for a few minutes before the interview and she seemed to relax. I also reassured her that there were no right or wrong answers and that she could say anything she wanted about her experience with the programme, good or bad.

As this was the first interview of the study and I was less familiar with the questions than if I'd asked them many times, I think the flow of the interview was pretty good. I think even the practice from the previous study had improved my interview technique, so I was able to divert from the list of questions to ask follow-up questions and additional questions which occurred to me from her responses. As I felt comfortable conducting the interview I felt like I could take my time with it, and it felt very natural and like a conversation which was positive, as I had worried that a phone interview might be a bit stilted. At the end of the interview I made sure that I took the time to let the young person know how much I had appreciated her taking part in the study, so that she felt like her responses were valued. Her feedback from the interview was so positive which was lovely to hear, as recruitment has been so difficult for this study, and it has made me even more keen to recruit more participants as I feel like the programme could be so beneficial to them.

Study 3, interview 13

[Before the interview]

I am feeling pretty confident about this interview as I have now conducted twelve others with clinical psychologists and they have all gone very smoothly. The participant in this interview is someone I have met quite a few times and feel like I know better than most of the other participants. This makes me feel more comfortable when approaching the interview, but at the same time I think I need to be careful to conduct the interview in the same way as I have with those I know less well, and make sure I still ask the same questions even though I am already a bit more familiar with her role.

[After the interview]

This interview didn't quite go to plan! I had arranged to ring the participant for the interview at a certain time, but when I rang the receptionist said she was in a meeting and she wasn't sure when she would be out, but suggested I call back in ten minutes. This is quite normal from my experience of calling psychologists as they have hectic schedules so I wasn't worried. When I called back, she was still in the meeting and the receptionist suggested that I call back in another fifteen minutes, however after this time she was still busy. The receptionist took my number and said she would ask the psychologist to call me back. I had booked an interview room so didn't have access to my computer to work, which was a bit annoying, but luckily I had brought some papers to read as I was expecting a delay at the beginning, although not to this extent. After another twenty minutes I was starting to feel a bit concerned, and called back. The psychologist had literally just returned to her desk and apologised that she said she had been called away on an emergency. I said it was completely fine and that these things happen, and we decided that as she had another appointment coming up it would be better to postpone the interview rather than rush it, so we arranged another one for first thing in the morning when she said she wouldn't be interrupted.

Usually I am quite impatient, but I didn't feel frustrated that we'd missed the interview which surprised me, as I think it would have done in the past. I think having experience of conducting research with people has helped me to be more patient, although I am also very aware that the participants are giving up their time to take part in my research, so am grateful for that. I am also really glad that I took some work to do just in case there was a problem and I think shows that I have learnt how important it is to be prepared for different outcomes. The rescheduled interview went brilliantly, and the participant said she was actually really glad that we'd changed it to an earlier time, as she knew she didn't have to worry about appointments for a couple of hours afterwards so could give it her full attention.

Appendix 3 Study 1A Letter to participants

Hello,

My name is Laura Armstrong-James and I am a PhD student at the Centre for Appearance Research at the University of the West of England, Bristol. My research is funded by The Healing Foundation as part of the Children's Burns Research Centre and involves looking at the experiences of young people who have had a burn injury and the support that is available to them, in order to inform the provision of care for young people in the future.

As part of my research, I am interested in talking to children and their families to find out their views about burn camp. I am conducting this research with the support of the organisers of FAB club, and I am supervised by Professor Nichola Rumsey and Professor Diana Harcourt from the Centre for Appearance Research, and Dr Julia Cadogan from the Paediatric Burn Service at Frenchay Hospital in Bristol. My supervisors' details can be found below.

If you and your family are interested in taking part, please read the information sheet in this pack which tells you how you can join in.

Thank you for reading this letter, I look forward to hearing from you!

Laura

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Children's Burns Research Centre
http://www.bristol.ac.uk/social-community-medicine/childrens-burns/

Centre for Appearance Research
http://www1.uwe.ac.uk/hls/research/appearanceresearch/

UWE
BRISTOL
University of the
West of England

Information sheet for young people!

Hello, my name is Laura. I am doing a study to find out what sorts of things help young people who have had a burn. Please look at this sheet and talk about it with your family and then decide if you would like to take part in my study.

If you have questions please ask me .Thank you for reading this.

What is this about?

I am looking at the different sorts of help there is for young people who have had a burn. This is so we can decide what sorts of help work best. In this study, I want to hear from young people who are going to a burns camp with their family.

Why have you given this to me?

You have been chosen because you are between 8 and 18 years old and you are going to burns camp with your family.

You are very important; with your help we can learn more about what is important to young people with burns and how we can best help them.

What will happen if I take part?

I will give you and your family a disposable camera (one you can throw away). You will be asked to take photographs of anything you want during your time at camp and then talk to me about them after camp once you are at home.

What if I change my mind about taking part?

You can decide not to take part at any time, even if you have already started. You do not have to say why you have stopped. You will not get into trouble if you change your mind.

Will the things I tell you be kept secret?

I will be telling people what I find out in my study, but I won't tell them who has taken part so they won't know who has said what.

But, if you tell me something that sounds like you or someone else needs help then I may need to tell someone else to keep you safe.

Because you are under 18 your parent or carer will need to say agree for you to take part.

Please tell your parent or carer if you are happy to take part, and ask them to contact me.

PARENT/CARER INFORMATION SHEET

Study title: **Using photographs to explore the experiences of young people with a burn injury and their families at a family burn camp**

You and your family are being invited to take part in a research study. Before you decide if you would like to take part, it is important for you to know why the research is being done and what it will involve. Please read the information below carefully and discuss it with others if you wish. Ask me if anything is unclear or if you would like to know more. Take time to decide whether or not you and your family would like to take part.

1.   Why is the research taking place?

A burns injury can impact on a young person's life in many ways. In order to provide them with the most appropriate levels of care and support, it is important for health professionals such as doctors, nurses, psychologists, occupational therapists and physiotherapists to know what types of support are best for young people who have had a burn injury.

Burns camps are one type of support offered to young people. This study will be looking at the experience of going to a burn camp from both the child and the family's perspective. The results of this study will help us plan future research aiming to provide the best possible care and support for young people affected by burns, and their families.

2.   Why have we been chosen?

Your child is being asked to take part because they have been treated for a burn injury in the past and is attending the FAB family burn camp on 15-17 November 2013. I would also like to hear from the families attending camp; which is why I am inviting you and your family to take part.

3.   Do I have to agree for me and my family to take part?

No, it's your choice. If you do decide you would like for you and your family to take part you will be given this information sheet to keep. You will also be asked to sign a consent form to show that you agree for you and your family to take part. You are free to change your mind about taking part at any time and without giving a reason. This will not affect your time at this, or any future, camp.

4.   What will happen to us if we take part?

Families who take part will be provided with a disposable camera on the first day of camp and asked to take photographs of their experiences at camp. On the last day of camp I will collect the cameras and have the photographs developed and send your photographs out to you. This will give you the chance to look at the photographs and decide whether there are any you would like to remove before you next meet with me. I will then ask your family to take part in an interview

to discuss the photographs and your experiences of camp. This interview will take place at a time and place that is convenient for you and your family.

5.   What do I have to do if I want to take part?

If you want to take part, please simply complete the consent form included in this pack and return to me in the pre-paid envelope included. If some of your family want to take part but not others, then you decide whether you want some of you to still take part, or whether none of you will take part.

6.   Will it cost me anything?

No, nothing at all. I will provide the cameras and pay for the photos to be developed, and I will travel to a location of your choosing to carry out the interviews.

7.   What are the possible risks of taking part?

We are always required to tell you about any possible risks of taking part in research. However, in this instance we are not aware of there being any such risks to you or your family. However, if at any point you or your family no longer want to take part in the research you may withdraw at any time and without needing to give a reason.

8.   What are the possible benefits of taking part?

The information we get from this study will help us inform how burns camps offered to young people with burns are provided in the future.

9.   Will our responses in this study be shown to anyone?

The information you provide and the photos you take will not be shown to anyone outside the research team and will only be used for research purposes. Your and your family's names and any identifying information will never be revealed. You will be able to choose which, if any, of the photos are used in the study.

10.   What will happen to the results of the research study?

A summary of what I find will be sent to everyone who takes part. The results will also be shared with other researchers and health professionals but you will not be identified in any summary, report or paper that is produced. You may decide on the consent form whether you are happy for your photos to be used in their original format or pixelated/blurred, or you may opt out of them being used at all and they will be destroyed after the study.

11.   Who is running and funding the research?

This research is being funded by The Healing Foundation Centre (registered charity no. 1078666) as part of its support of the Children's Burns Research Centre, which is part of the Burns Collective:

It is being run by Laura Armstrong-James at the Centre for Appearance Research at the University of the West of England, and supervised by Professor Diana Harcourt.

12. Who has reviewed the study?

This study has been reviewed and approved by the Faculty Research Ethics Committee at the University of the West of England, Bristol.

13. Contact for further Information

If you have any further questions about the study then please feel free to contact me on 0117 32 81892 or laura2.armstrong-james@uwe.ac.uk.

Or you can just complete the enclosed consent form. You may be sent one further letter to remind you about this study during the next few weeks.

Further support:
If you have any worries or concerns relating to your child's burn injury that you would like to talk to someone about, please contact the burns team that took care of your child.

These charities also provide support for people with burn injuries:

Changing Faces: www.changingfaces.com
Katie Piper Foundation: www.katiepiperfoundation.org.uk

Thank you for reading this information sheet.

Laura Armstrong-James
Laura2.armstrong-james@uwe.ac.uk
0117 3281892

CONSENT FORM

Study title: Using photographs to explore the experiences of young people with a burn injury and their families at a family burn camp

> **Please read the questions in the boxes below and tick if you agree.**

1. Have you read the information sheet explaining the study? ☐

2. Have you had enough information about the study? ☐

3. Do you understand that you and your family can ask questions about the study at any time? ☐

4. Do you understand that you are all free to withdraw from the study at any time without having to give a reason? ☐

5. Do you agree to yourself and your child taking part in the study? ☐

> **Are you happy for me to use your photographs to present my findings in journal articles and conferences? Please tick one of the following boxes.**

Yes – in their original format ☐

Yes – if the faces are pixelated/blurred ☐

No, not at all – please destroy the photographs after the study ☐

PLEASE TURN OVER

Please fill out the relevant sections below for each family member that is going to the FAB family camp on 15-17 November 2013 and would like to take part in the study:

Parent/carer's name…………………………………………………..
    Signature………………………………………………

Parent/carer's name…………………………………………………..
    Signature………………………………………………

Name of child with a burn injury
……………………………………Age…………Signature…………………………...

Other family members

Name……………………………………………… Age (if under 18)………….
Signature…………………………………………..

Name……………………………………………… Age (if under 18)………….
Signature…………………………………………..

Name……………………………………………… Age (if under 18)………….
Signature…………………………………………..

Name……………………………………………… Age (if under 18)………….
Signature…………………………………………..

Name……………………………………………… Age (if under 18)………….
Signature…………………………………………..

If you would like to be sent information about our future research into ways of helping young people who have had a burn (with no obligation to participate) please indicate your preferred method of contact and fill out your details in the space below:

☐   Telephone (day):

☐   Telephone (evening):

☐   Email:

☐   Postal address:

Appendix 7 Study 1A Interview schedule

<u>For each picture discussed</u>

What is in this picture?

Why did you decide to take this picture?

Why is this picture important?

What does this picture say about your time at camp?

How does this picture make you feel?

<u>Follow up picture questions</u>

Are there any pictures that you wished you had taken but didn't? What are they?

Which picture shows the most important part of camp and why?

Which is your favourite picture and why?

<u>Follow up general questions</u>

Have you been to camp before? If so, how did this camp compare?

Is there anything you would change about camp?

How did you find using the camera to take pictures of your time at camp?

Do you think that these photographs would help to tell other families what it's like to attend camp?

Is there anything else you would like to say about camp?

Appendix 8 Study 1A Worked example of thematic analysis

Ni	I found that that session that we had in the morning was...it just took all of the barriers away. Because everyone was on the same page in terms of why we were there, obviously it was an emotional experience for some in terms of maybe it's the first time they'd shared that feeling, I don't know. But it was a safe environment because everyone was in the same position really, and I felt that that really set the scene for some very easy going chat and getting to know each other and communicating outside of there because that obstacle had already been overcome. We'd already set the scene really, in terms of common ground.	Felt like the group session removed barriers Found it emotional to share experiences May have been the first time parents/carers had discussed their reactions to the burn The group was a safe environment Everyone was in the same boat Paved the way for further communication between families
	So would you say it was good to have that parent group in the morning on the Saturday rather than the Sunday?	
Na	Oh no, I think it was much better because then everybody has a rough idea. Because I suppose it's only a natural curiosity that once you've found out who is there, you start to think "ok, has anybody got any scars, I wonder what happened to their child, which child it's happened to". I mean I shared the story with James, with the firework on his leg, so we told Andrew about that one. So yeah, there were some moving stories there and I guess everybody's feeling guilty in a way where it was indirect parent involvement but I guess it's nice to know that actually everyone has similar feelings and everybody was reassuring each other that even though they feel guilty they can see from the other parents that actually it's nothing to feel guilty about, because you're not responsible for that directly. If you hear that from somebody else who felt that way then I think it's quite different.	Natural curiosity about other families Families shared their own experiences with others Feelings of guilt towards the burn injury Reassurance from other families helped parents/carers realise they weren't directly responsible Hearing from others who have been through a similar experience is more powerful than hearing it from others who have not

Appendix 9 Study 1A participant photographs

Appendix 10 Study 1A participant feedback

SUMMARY OF FINDINGS FROM THE PHOTOGRAPHY STUDY
AT THE FAB FAMILY CAMP 15-17 NOVEMBER 2013

The interviews about burn camp revealed three main themes: New activities and experiences; having fun without feeling different and support from those who understand.

1. New activities and experiences

For many of the families, spending time together was the best part of the weekend. The families felt that camp had been suitable for all members of the family, regardless of the different ages of the children. The variety of activities on offer helped provide something for every individual member of the family to enjoy.

Camp also provided the families with the chance to try out new activities. Some of the activities hadn't been tried before and some of the children found them to be quite challenging. However, once the children had practised the activities and had the chance to improve they reported enjoying themselves more. Interestingly, while many of the children reported that the activities were their favourite part of the weekend, several of them picked out photographs showing their family together when asked to select their favourite picture.

One of the outcomes mentioned by several of the participants is that camp helped the families to make a positive out of a negative, providing some happy memories to associate with the burn injury.

2. Having fun without feeling different

While the siblings mainly focused on the chance to have fun and try out new activities, a theme that emerged from the children with burn injuries was the chance to have fun with other children who had been through a similar experience without having to worry about feeling different. Spending time with other children who had been through the same experience helped the children to feel like they all had something in common.

Many of the children said they did not speak to their usual friends about their burns, but found that they could open up to the other children at camp as they could relate to each other. Although the majority of the children did not report feeling self-conscious about their scars before camp, some of them did say that they worried about them in certain situations such as swimming, where they were visible to the general public. However, these children felt more confident to try these activities at camp, since being around other children with scars made them feel more comfortable.

3. Support from those who understand

The adults at camp mainly referred to the chance to speak to other parents who had been through a similar experience, and receive support from those who understand each other's

feelings. Many referred to the group held on the second day which allowed parents to discuss their experiences in a safe environment. For most of the adults, camp was the first time that they'd spoken to anyone else who'd been through something similar. They said they found it hugely beneficial to hear how other families had dealt with the burn injury and helped them realise that they were not alone.

Camp gave parents the chance to talk about feelings which some of them admitted to holding inside for a very long time. Many parents blamed themselves for the burn injury, and said that the chance to talk to other families helped them to let go of feelings of blame and guilt, and realise that accidents do happen. For some families for which the injury was still quite new, hearing from other families for which the injury had occurred some time ago also inspired hope.

It was also suggested that it would be helpful to have a chance to speak to other families on a regular basis, to share stories from supportive individuals who understood what each other was going through. This highlights how helpful the parents found the group session to be, and suggests that regular support groups might be helpful for some. Finally, all of the families mentioned the possibility of staying in touch with the others. Some of the families had kept in touch since camp and already discussed meeting up with each other.

Thank you again for your participation in the study.

Appendix 11 Study 1B Letter to participants

University of the West of England
BRISTOL

Hello,

My name is Laura Armstrong-James and I am a PhD student at the Centre for Appearance Research at the University of the West of England, Bristol. My research is funded by The Healing Foundation as part of the Children's Burns Research Centre and involves looking at the experiences of young people who have had a burn injury and the support that is available to them, in order to inform the provision of care for young people in the future.

As part of my research, I am interested in the views of children who go to camp, as well as their parents' opinions.

I am conducting this research with the support of the organisers of burns camps in the UK, and I am supervised by Professor Nichola Rumsey, Professor Diana Harcourt and Dr Heidi Williamson from the Centre for Appearance Research, and Dr Julia Cadogan from the Paediatric Burn Service at Frenchay Hospital in Bristol. My supervisors' details can be found below.

If you and your child are interested in taking part, please read the information sheet in this pack which tells you how you can join in.

Thank you for reading this letter, I look forward to hearing from you!

Laura

Laura Armstrong-James
Laura2.armstrong-james@uwe.ac.uk
0117 32 81892

Supervisory team:

Professor Diana Harcourt   Professor Nichola Rumsey
Diana2.Harcourt@uwe.ac.uk   Nichola.Rumsey@uwe.ac.uk
0117 3282192   0117 3283989

Dr Heidi Williamson   Dr Julia Cadogan
Heidi3.Williamson@uwe.ac.uk   Julia.Cadogan@nbt.nhs.uk
0117 3281572   0117 3402903

Children's Burns Research Centre
http://www.bristol.ac.uk/social-community-medicine/childrens-burns/

Centre for Appearance Research
http://www1.uwe.ac.uk/hls/research/appearanceresearch/

University of the
West of England
BRISTOL
UWE

Information sheet for young people!

Hello, my name is Laura. I am doing a study to find out what sorts of things help young people who have had a burn. Please look at this sheet and talk about it with your parent/carer and then decide if you would like to take part in my study.

You can ask me if you have any questions. Thank you for reading this.

What is this about?

> I am looking at the different sorts of help available for young people who have had a burn. This is so we can decide what sorts of help work best. In this study, I want to hear from young people who are going to a burns camp.

Why have you given this to me?

> You have been chosen because you are between 8 and 18 years old, you have had a burn in the past.
>
> You are very important; with your help we can learn more about what is important to young people with burns and how we can best help them.

What will happen if I take part?

> You will be asked to answer 3 sets of questions – 1 month before camp, on the final day of camp, and 3 months after camp.

What if I change my mind about taking part?

You can decide not to finish the questions at any time, even if you have already answered some. You do not have to say why you have stopped. You will not get into trouble if you change your mind.

Will the things I tell you be kept secret?

I will be telling people what I find out in my study, but I won't tell them who has taken part so they won't know who has said what.

But, if you tell me something that sounds like you or someone else is in danger then I may need to tell someone else to keep you safe.

Because you are under 18 your parent or carer will need to agree for you to take part.

Please tell your parent or carer if you are happy to take part, and ask them to contact me.

University of the
West of England
UWE
BRISTOL

PARENT/CARER INFORMATION SHEET

Study title: **Helping young people with burns: experiences of attending burns camps**

You and your child are being invited to take part in a research study. Before you decide if you would like to take part, it is important for you to know why the research is being done and what it will involve. Please read the information below carefully and discuss it with others if you wish. Ask me if anything is unclear or if you would like to know more. Take time to decide whether or not you and your child would like to take part.

Thank you for reading this.

**1.	Why is the research taking place?**

A burns injury can impact on a person's life in many ways. In order to provide them with the most appropriate levels of care and support, it is important for health professionals such as doctors, nurses, psychologists and physiotherapists to know what types of support are best for young people who have had a burn injury.

Burns camps are one type of support offered to young people. This study will be looking at the experience of going to a burn camp from both the children's and parent's perspective. The results of this study will help us plan future research aiming to provide the best possible care and support for young people affected by burns, and their families.

**2.	Why have we been chosen?**

Your child is being asked to take part because they have been treated for a burn injury in the past. I would like to hear from children who attend burn camps and their parents.

**3.	Do I have to agree for me and my child to take part?**

No, it's your choice. If you do decide you would like for you and your child to take part you will be given this information sheet to keep. You will also be asked to sign a consent form to show that you agree for you and your child to take part. You are free to change your mind about taking part at any time and without giving a reason.

**4.	What will happen to us if we take part?**

Children who take part will be asked to complete a questionnaire at three points in time over 3 months. Parents/guardians will be asked to complete a questionnaire at two points in time over 3 months.

5.   What do I have to do if I want to take part?

If you want to take part, please simply complete the questionnaires included in this pack, and return them to me using the pre-paid envelope provided. Or you can complete the questionnaires online if you would prefer. If you would prefer to complete the questionnaires online please indicate this on the consent form and I will email you with a link. It is a secure website so your information will be confidential.

6.   What are the possible risks of taking part?

We are always required to tell you about any possible risks of taking part in research. However, in this instance we are not aware of there being any such risks to you or your child. However, if at any point you or your child no longer want to take part in the research you may withdraw at any time and without needing to give a reason.

7.   What are the possible benefits of taking part?

The information we get from this study will help us inform the care that is available to young people with burns in the future.

8.   Will our responses in this study be shown to anyone?

The information you provide will not be shown to anyone outside the research team and will only be used for research purposes. Your and your child's names and any identifying information will never be revealed.

9.   What will happen to the results of the research study?

A summary of what I find will be sent to everyone who takes part. The results will also be shared with other researchers and health professionals but you will not be identified in any summary, report or paper that is produced.

10.   Who is running and funding the research?

This research is being funded by The Healing Foundation Centre (registered charity no. 1078666) as part of its support of the Children's Burns Research Centre:

http://www.thehealingfoundation.org.uk/thf2008/hfcburninjuryI.htm

It is being run by Laura Armstrong-James at the Centre for Appearance Research at the University of the West of England, and supervised by Professor Diana Harcourt.

11.   Who has reviewed the study?

This study has been reviewed and approved by the Faculty Research Ethics Committee at the University of the West of England, Bristol.

12.   Contact for further Information

If you have any further questions about the study then please feel free to contact me on 0117 32 81892 or laura2.armstrong-james@uwe.ac.uk.

Or you can just complete the enclosed questionnaires and consent form. You may be sent one further letter to remind you about this study during the next few weeks.

Further support:
If you have any worries or concerns relating to your child's burn injury that you would like to talk to someone about, please contact the burns team that took care of your child.

These charities also provide support for people with burn injuries:

Changing Faces: www.changingfaces.com

Katie Piper Foundation: www.katiepiperfoundation.org.uk

Thank you for reading this information sheet.

Laura Armstrong-James
Laura2.armstrong-james@uwe.ac.uk
0117 32 81892

CONSENT FORM

University of the
West of England
BRISTOL

Study title: Helping young people with burns: experiences of attending burns camps

Please read the questions in the arrows below and tick the boxes if you agree.

1. Have you read the information sheet explaining the study?

2. Have you had enough information about the study?

3. Do you understand that you and your child can ask questions about the study at any time?

4. Do you understand that you are both free to withdraw from the study at any time without having to give a reason?

5. Do you agree to yourself and your child taking part in the study?

Please turn over

Would you like to complete the questionnaires on paper ☐ **OR online?** ☐

If online please state your email address………………………………………………………………………….

Child's name: ………………………………………………….

Date: ………………………………………………
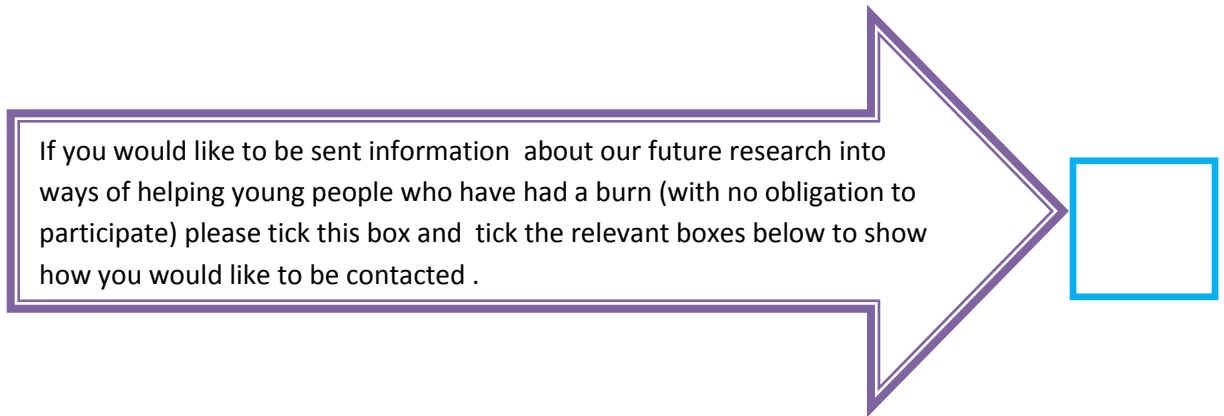
Child's Signature: ……………………………………………………………

Name of Parent/carer: ………………………………………………

Date: …………………………………………….

Parent's Signature: ……………………………………………….

If you would like to be sent information about our future research into ways of helping young people who have had a burn (with no obligation to participate) please tick this box and tick the relevant boxes below to show how you would like to be contacted . ☐

☐   Phone – if so, please enter number here: ……………………………………………………………

☐   Email – if so, please enter email here: ………………………………………………………………..

☐   Letter – if so, please enter address here:
………

………

1. YOUNG PEOPLE'S PRE-CAMP QUESTIONNAIRE

The Burns Collective
Leading Children's Burns Research
A Healing Foundation Initiative

UWE BRISTOL
University of the West of England

Thank you for taking part in this study

To create your ID code, please enter the last three letters of your surname and the day of the month you were born.

For example, if your surname is Smith and you were born on 28th September you would enter ITH28.

Please enter your code in the box below.

INFORMATION ABOUT YOU

Age………………………………………………………………….

Are you male or female?

☐Male   ☐Female

How would you describe your ethnic group?

☐ White

☐ Asian / Asian British

☐ Black / African / Caribbean / Black British

☐ Mixed / multiple ethnic groups

☐ Other Ethnic Group

Have you been to burn camp before?

☐Yes   ☐No

If so, how many times?...

How old were you when you got your burn?

………………..Years   …………………Months

This is a practice question. Please draw a circle around the number that shows whether you agree with the statement or not.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
	😞	😟	😕	😐	🙂	😊	😄
I enjoy maths lessons	1	2	3	4	5	6	7

So if you really enjoy maths lessons then you would circle the number 7 but if you really don't like maths lessons you would circle the number 1.

Remember that there are no right or wrong answers – I would just like to find out what you think.
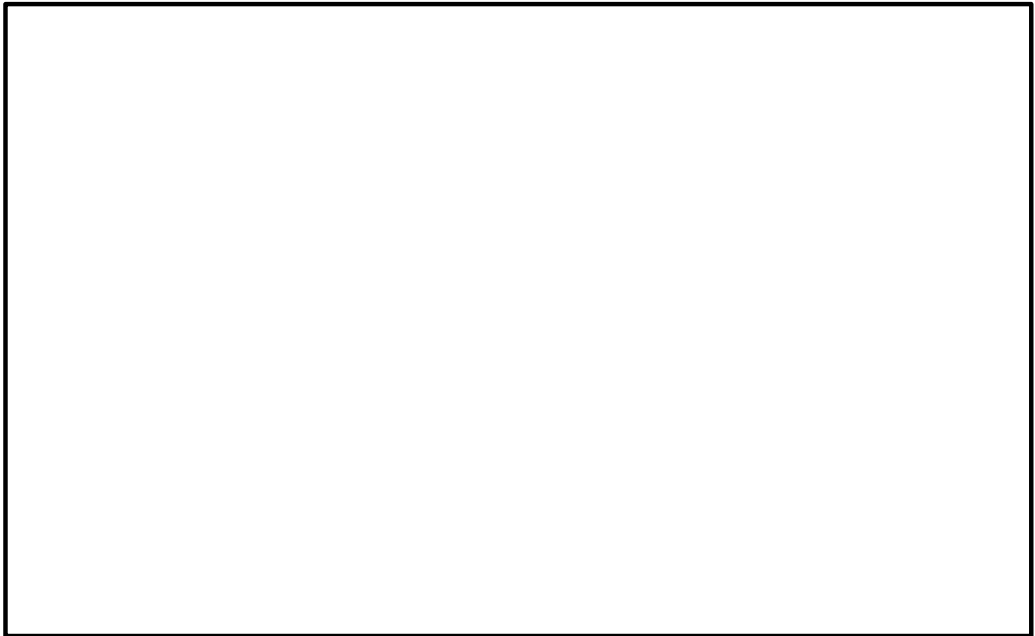
Please complete the following questions in the same way

	Never	Almost never	Sometimes	Often	Always
	😞	😕	😐	🙂	😊
1. I feel like I fit in with most groups.	1	2	3	4	5
2. No one can understand me.	1	2	3	4	5
3. I would rather be by myself than with other people.	1	2	3	4	5
4. I like meeting new people.	1	2	3	4	5
5. It is easy for me to talk to other people my age.	1	2	3	4	5
6. I feel comfortable in a crowd.	1	2	3	4	5
7. I feel like I don't fit in with other people.	1	2	3	4	5
8. It is easy for me to blend in with other people.	1	2	3	4	5
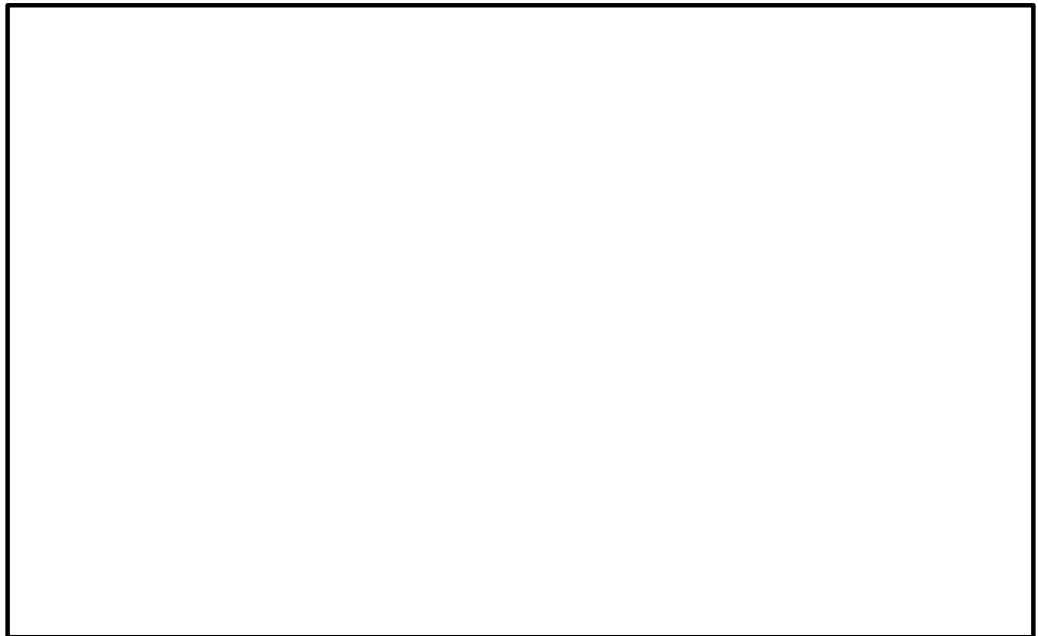
	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
	☹	☹	☹	😐	🙂	🙂	😊
1. Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my family.	1	2	3	4	5	6	7
2. Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my friends	1	2	3	4	5	6	7
3. Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of strangers	1	2	3	4	5	6	7
4. I am satisfied with my overall appearance	1	2	3	4	5	6	7
5. I am satisfied with the appearance of my scalp	1	2	3	4	5	6	7
6. I am satisfied with the appearance of my face	1	2	3	4	5	6	7
7. I am satisfied with the appearance of my neck	1	2	3	4	5	6	7
8. I am satisfied with the appearance of my hands.	1	2	3	4	5	6	7
9. I am satisfied with the appearance of my arms.	1	2	3	4	5	6	7
10. I am satisfied with the appearance of my legs.	1	2	3	4	5	6	7
11. I am satisfied with the appearance of my chest.	1	2	3	4	5	6	7
12. Changes in my appearance have interfered with my relationships.	1	2	3	4	5	6	7
13. I feel that my burn is unattractive to others.	1	2	3	4	5	6	7
14. I don't think people would want to touch me.	1	2	3	4	5	6	7

	Never	Almost never	Sometimes	Often	Always
	🙁	🙁	😐	🙂	😊
1. People are friendly with me.	1	2	3	4	5
2. People call me names.	1	2	3	4	5
3. People avoid looking at me.	1	2	3	4	5
4. People I don't know act surprised or startled when they see me.	1	2	3	4	5
5. People are nice to me.	1	2	3	4	5
6. People don't know what to say to me.	1	2	3	4	5
7. People I don't know say "Hi" to me.	1	2	3	4	5
8. People laugh at me.	1	2	3	4	5
9. People are relaxed around me.	1	2	3	4	5
10. People feel sorry for me.	1	2	3	4	5
11. People pick on me.	1	2	3	4	5
12. People I don't know smile at me in a friendly way.	1	2	3	4	5
13. People don't know how to act around me.	1	2	3	4	5
14. People do "double takes" or turn around to look at me.	1	2	3	4	5
15. People are kind to me.	1	2	3	4	5
16. People bully me.	1	2	3	4	5
17. Strangers are polite to me.	1	2	3	4	5
18. People make fun of me.	1	2	3	4	5
19. People I don't know stare at me.	1	2	3	4	5
20. People treat me with respect.	1	2	3	4	5
21. People seem embarrassed by my looks.	1	2	3	4	5

1. What are you looking forward to about camp?

2. Is there anything about camp you are worried about?

3. Is there anything else you would like to add?

Thank you for your participation.

Please return the questionnaires and the consent form in the pre-paid envelope provided.

If you would like to contact the researcher my details are:

Laura Armstrong-James

Telephone: 0117 23 81892

Email: laura2.armstrong-James@uwe.ac.uk

Address:
Centre for Appearance Research
Room 2L15
University of the West of England
Coldharbour Lane
Bristol
BS16 1QY

1. What did you enjoy most about camp?

2. What did you enjoy least about camp?
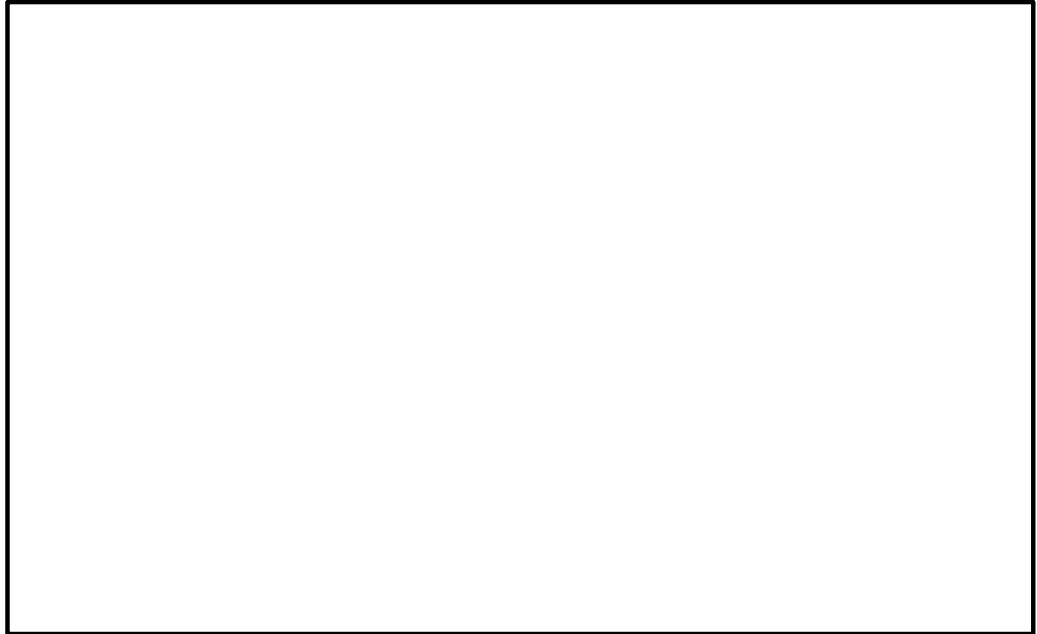
3. Has being at camp helped you? If so, how?
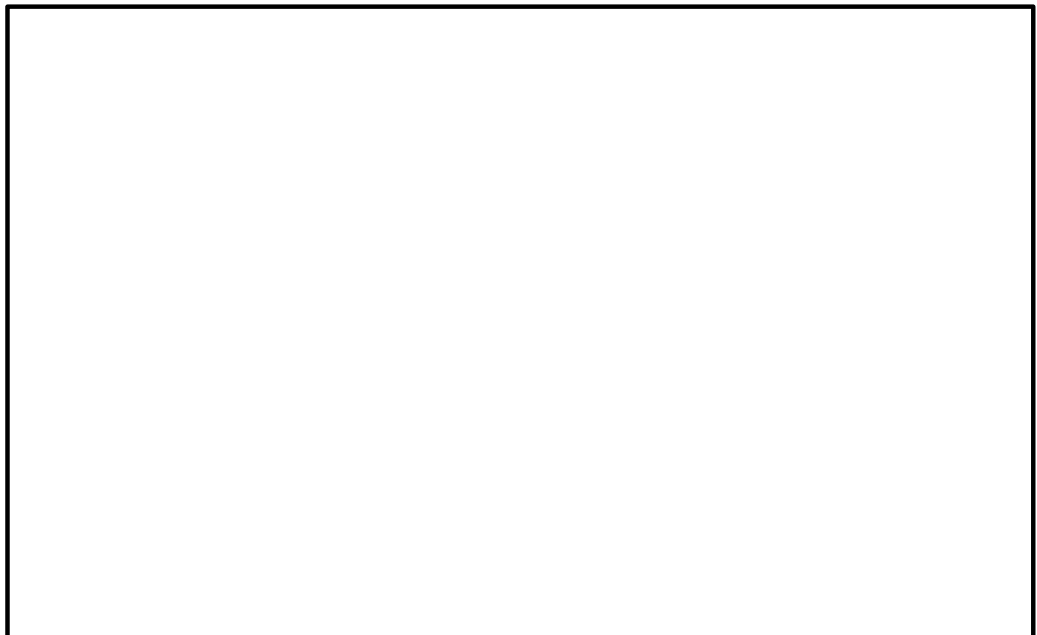
4. What have you learned while you have been at camp?

5. How could we make camp better?

6. Is there anything else you would like to tell us about your time at camp?

1. PARENTS' PRE-CAMP QUESTIONNAIRE

Thank you for taking part in this study.

You and you child may withdraw from the study up to four weeks after you have completed the questions, without needing to provide a reason. If you do decide to withdraw you will need to inform me by email laura2.armstrong-james@uwe.ac.uk, quoting your unique ID code.

To create your ID code, please enter the last three letters of your child's surname and the day of the month they were born.

For example, if your child's surname is Smith and they were born on 28th September you would enter ITH28

INFORMATION ABOUT YOU

These questions will be used for statistical purposes only and will not be used to identify you. All responses are anonymous and all questions are optional.

Are you male or female?

☐ Male ☐ Female

What is your age range?

☐ 24 years or younger

☐ 25-34 years old

☐ 35-44 years old

☐ 45-54 years old

☐ 55-64 years old

☐ 65-74 years old

☐ 75 years or older

How would you describe your ethnic group?

☐ White

☐ Asian / Asian British

☐ Black / African / Caribbean / Black British

☐ Mixed / multiple ethnic groups

☐ Other Ethnic Group

What is your marital status?

☐ Single, never married

☐ Married or domestic partnership

☐ Widowed

☐ Divorced

☐ Separated

What is your relationship to the child attending camp?

☐ Parent

☐ Other relative (please state)…………………………………….

☐ Carer

☐ Other (please state)……………………………………………………….
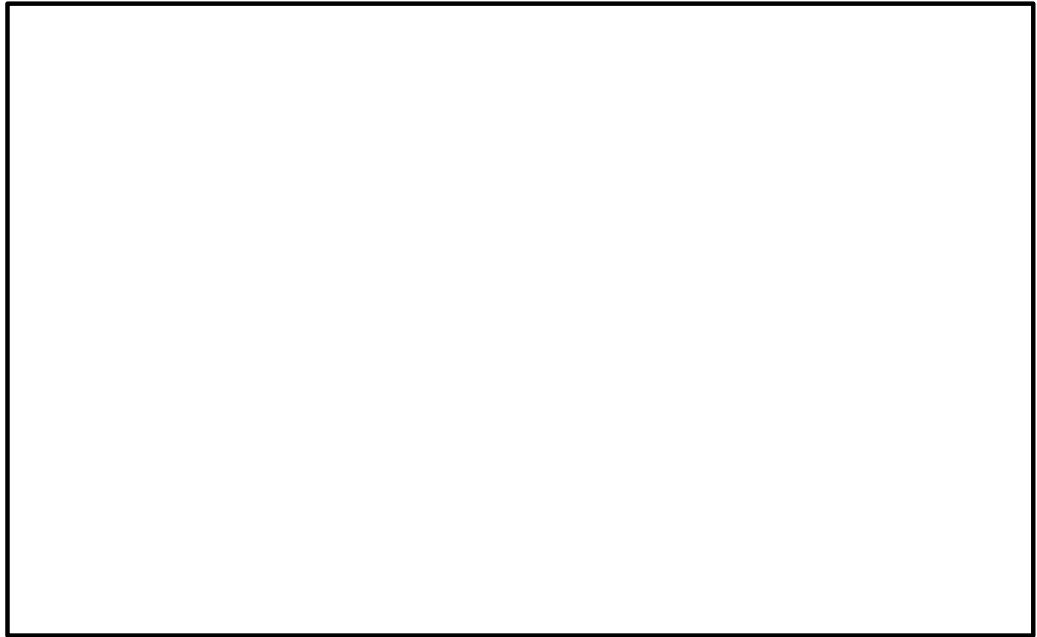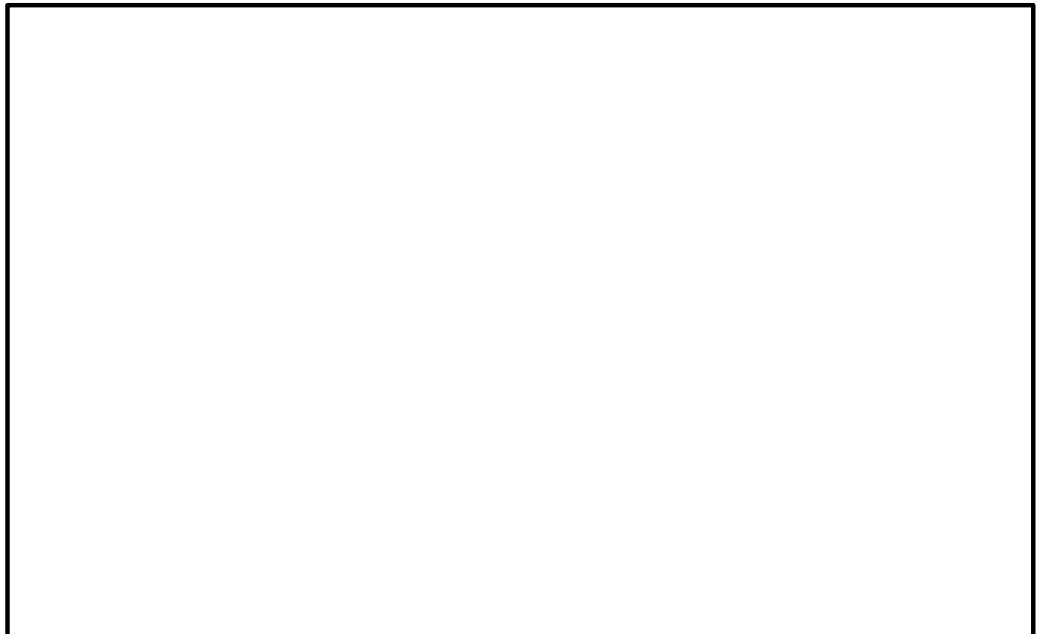
For each item, please mark the box for Not True, Somewhat True or Certainly True that is relevant to how you would describe your child's behaviour. Please give your answers on the basis of the child's behaviour over the last six months or this school year.

	Not True	Somewhat True	Certainly True
1. Considerate of other people's feelings	1	2	3
2. Restless, overactive, cannot stay still for long	1	2	3
3. Often complains of headaches, stomach-aches or sickness	1	2	3
4. Shares readily with other children (treats, toys, pencils etc.)	1	2	3
5. Often has temper tantrums or hot tempers	1	2	3
6. Rather solitary, tends to play alone	1	2	3
7. Generally obedient, usually does what adults request	1	2	3
8. Many worries, often seems worried	1	2	3
9. Helpful if someone is hurt, upset or feeling ill	1	2	3
10. Constantly fidgeting or squirming	1	2	3
11. Has at least one good friend	1	2	3
12. Often fights with other children or bullies them	1	2	3
13. Often unhappy, down-hearted or tearful	1	2	3
14. Generally liked by other children	1	2	3
15. Easily distracted, concentration wanders	1	2	3
16. Nervous or clingy in new situations, easily loses confidence	1	2	3
17. Kind to younger children	1	2	3
18. Often lies or cheats	1	2	3
19. Picked on or bullied by other children	1	2	3
20. Often volunteers to help others (parents, teachers, other children)	1	2	3
21. Thinks things out before acting	1	2	3
22. Steals from home, school or elsewhere	1	2	3
23. Gets on better with adults than with other children	1	2	3
24. Many fears, easily scared	1	2	3
25. Sees tasks through to the end, good attention span	1	2	3

1. What do you hope your child will gain from camp?

2. Is there anything about camp you are worried about?

3. Is there anything else you would like to add?

Thank you for your participation.

Please return the questionnaires and the consent form in the pre-paid envelope provided.

If you would like to contact the researcher my details are:

Laura Armstrong-James

Telephone: 0117 23 81892
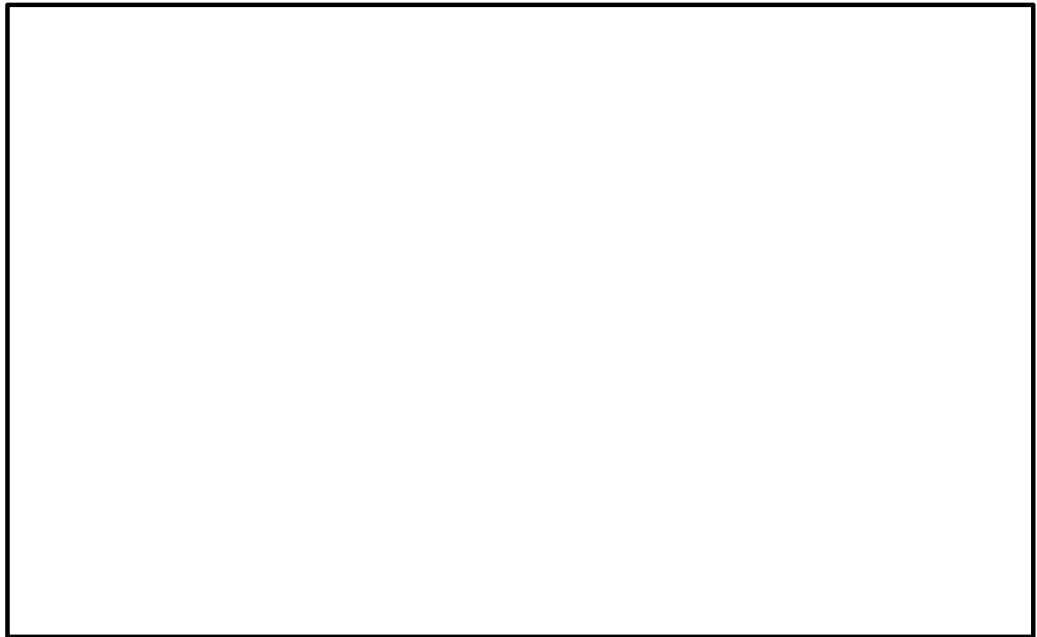
Email: laura2.armstrong-James@uwe.ac.uk

Address:
Centre for Appearance Research
Room 2L15
University of the West of England
Coldharbour Lane
Bristol
BS16 1QY
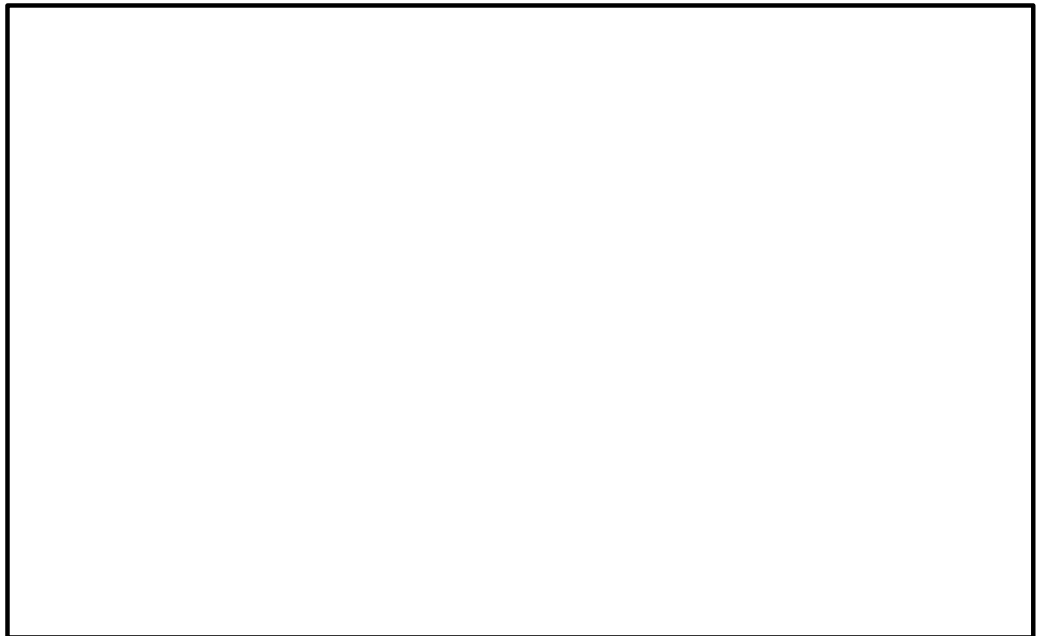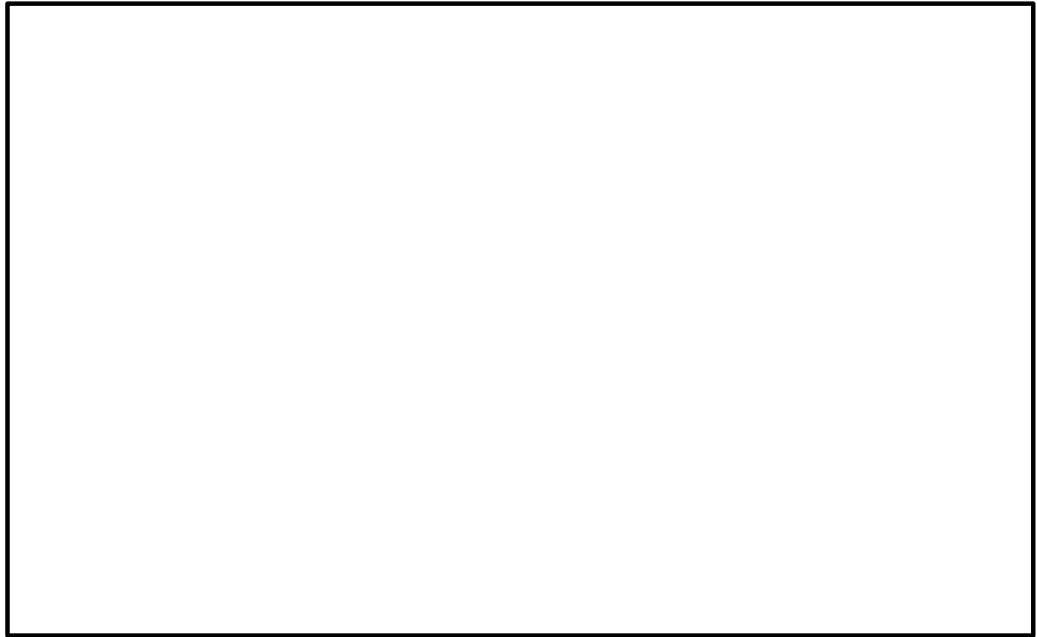
1. Did you feel your child gained anything from Camp? If so, what?
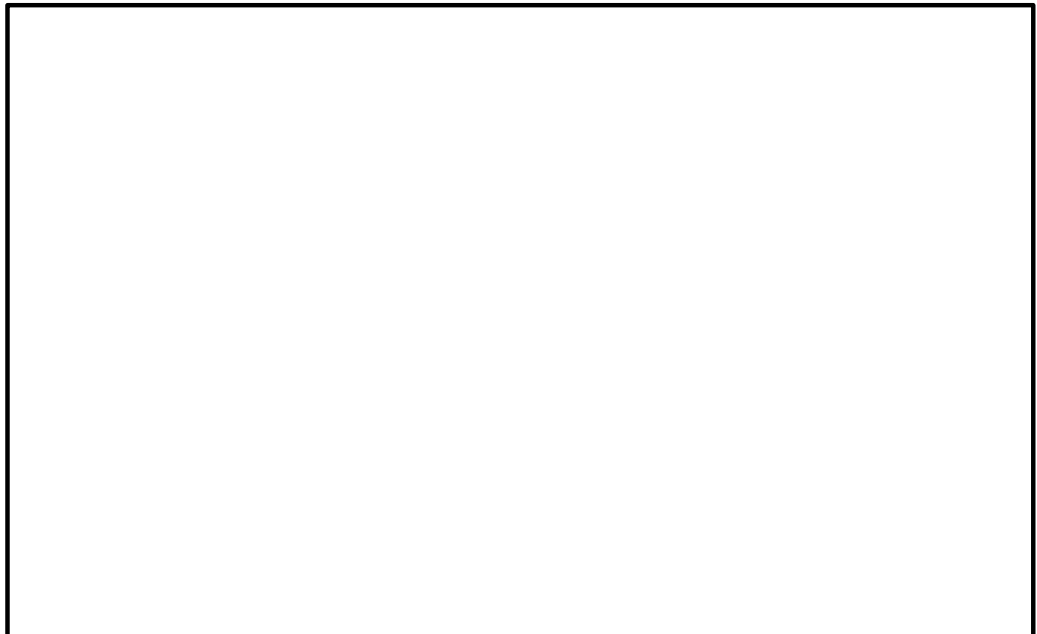
2. What do you think are the good things about Burns Camp?

3. Do you think Camp could be improved in any way? If so, how?

4. Is there anything else you would like to add?

Appendix 19 Categorising SDQ Scores for parent-completed measure (SDQ Info, 2016)

	Original three-band categorisation			Newer four-band categorisation			
	Normal	Borderline	Abnormal	Close to average	Slightly raised (/Slightly lowered)	High(/Low)	Very high (/Very low)
Total difficulties score	0-13	14-16	17-40	0-13	14-16	17-19	20-40
Emotional problems score	0-3	4	5-10	0-3	4	5-6	7-10
Conduct problems score	0-2	3	4-10	0-2	3	4-5	6-10
Hyperactivity score	0-5	6	7-10	0-5	6-7	8	9-10
Peer problems score	0-2	3	4-10	0-2	3	4	5-10
Prosocial score	6-10	5	0-4	8-10	7	6	0-5

Appendix 20 Study 1B Skewness and kurtosis of data

Young Person Data

	N	Skewness		Kurtosis	
	Statistic	Statistic	Std. Error	Statistic	Std. Error
SCQ_T1_T2diff	21	.746	.501	.045	.972
SCQ_T2_T3diff	12	.410	.637	-.141	1.232
SCQ_T1_T3diff	12	.128	.637	.365	1.232
SWAP_T1_T2diff	20	-.085	.512	-1.075	.992
SWAP_T2_T3diff	11	1.342	.661	3.129	1.279
SWAP_T1_T3diff	11	-.384	.661	1.022	1.279
PSQabsence_T1_T2diff	20	.359	.512	-.111	.992
PSQabsence_T2_T3diff	13	1.418	.616	5.308	1.191
PSQabsence_T1_T3diff	13	.676	.616	.906	1.191
PSQconfused_T1_T2diff	20	.439	.512	.785	.992
PSQconfused_T2_T3diff	13	-.409	.616	1.190	1.191
PSQconfused_T1_T3diff	13	-.155	.616	-.520	1.191
PSQhostile_T1_T2diff	13	.684	.616	-.340	1.191
PSQhostile_T2_T3diff	13	-.391	.616	2.480	1.191
PSQhostile_T1_T3diff	13	.684	.616	-.340	1.191
PSQtotal_T1_T2diff	20	1.110	.512	1.387	.992
PSQtotal_T2_T3diff	13	-.462	.616	.104	1.191
PSQtotal_T1_T3diff	13	.684	.616	-.340	1.191
Valid N (listwise)	10				

Parent Data

	N	Skewness		Kurtosis	
	Statistic	Statistic	Std. Error	Statistic	Std. Error
Diff_Em	12	-.864	.637	.319	1.232
Diff_Con	12	-.508	.637	.511	1.232
Diff_Hyp	12	-.490	.637	-.444	1.232
Diff_Peer	12	-1.283	.637	1.117	1.232
Diff_Tot	12	-.479	.637	-1.841	1.232
Diff_Pro	12	1.382	.637	2.279	1.232
Valid N (listwise)	12				

Appendix 21 Study 1B Wilcoxon signed ranks test

Perceived Stigmatization Questionnaire

Descriptive Statistics

	N	Mean	Std. Deviation	Minimum	Maximum
PSQ_absence_time1	22	2.1159	.62167	1.25	3.38
PSQ_absence_time2	21	1.9605	.59158	1.00	2.88
PSQ_confused_time1	22	2.0473	.83740	1.00	4.25
PSQ_confused_time2	21	1.8952	.64647	1.00	3.50
PSQ_hostile_time1	22	1.7000	.79222	1.00	3.20
PSQ_hostile_time2	21	1.6571	.72977	.80	3.20
PSQ_total_time1	22	1.9891	.60492	1.29	3.19
PSQ_total_time2	21	1.8610	.54779	1.00	2.95
PSQ_absence_time3	13	1.9823	.59168	1.00	2.88
PSQ_confused_time3	13	1.8477	.76464	1.00	3.63
PSQ_hostile_time3	13	1.6769	.70493	1.00	2.80
PSQ_total_time3	13	1.8577	.52242	1.29	2.95

Test Statistics[a]

	PSQ_absence_time2 - PSQ_absence_time1	PSQ_absence_time3 - PSQ_absence_time2	PSQ_absence_time3 - PSQ_absence_time1	PSQ_confused_time2 - PSQ_confused_time1	PSQ_confused_time3 - PSQ_confused_time2	PSQ_confused_time3 - PSQ_confused_time1	PSQ_hostile_time2 - PSQ_hostile_time1	PSQ_hostile_time3 - PSQ_hostile_time2	PSQ_hostile_time3 - PSQ_hostile_time1	PSQ_total_time2 - PSQ_total_time1	PSQ_total_time3 - PSQ_total_time2	PSQ_total_time3 - PSQ_total_time1
Z	-.855[b]	-.669[c]	-.035[c]	-1.113[b]	-.224[b]	-1.730[b]	-.212[c]	.000[d]	-1.294[b]	-1.003[b]	-.275[b]	-2.315[b]
Asymp. Sig. (2-tailed)	.393	.504	.972	.266	.823	.084	.832	1.000	.196	.316	.783	.021

a. Wilcoxon Signed Ranks Test
b. Based on positive ranks.
c. Based on negative ranks.
d. The sum of negative ranks equals the sum of positive ranks.

Social Comfort Questionnaire

Descriptive Statistics

	N	Mean	Std. Deviation	Minimum	Maximum
SCQ_time1	23	3.9426	.64764	2.75	4.88
SCQ_time2	21	3.9724	.73988	2.00	5.00
SCQ_time3	12	3.9283	.63793	2.88	5.00

Test Statistics[a]

	SCQ_time2 - SCQ_time1	SCQ_time3 - SCQ_time2	SCQ_time3 - SCQ_time1
Z	-.237[b]	-1.687[c]	-.510[c]
Asymp. Sig. (2-tailed)	.813	.092	.610

a. Wilcoxon Signed Ranks Test
b. Based on negative ranks.
c. Based on positive ranks.

Satisfaction with Appearance Questionnaire (SWAP)

Descriptive Statistics

	N	Mean	Std. Deviation	Minimum	Maximum
SWAP_time1	22	20.0455	9.11554	3.00	41.00
SWAP_time2	20	17.8000	9.92392	.00	35.00
SWAP_time3	11	13.1818	9.97816	.00	31.00

Test Statistics[a]

	SWAP_time2 - SWAP_time1	SWAP_time3 - SWAP_time2	SWAP_time3 - SWAP_time1
Z	-.786[b]	-.153[b]	-2.143[b]
Asymp. Sig. (2-tailed)	.432	.878	.032

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.

Strengths and Difficulties Questionnaire

Descriptive Statistics

	N	Mean	Std. Deviation	Minimum	Maximum
SDQ_Emotional_time1	22	1.9545	2.19257	.00	8.00
SDQ_Conduct_time1	22	1.5455	1.43849	.00	5.00
SDQ_Hyperactivity_time1	22	3.1364	2.89984	.00	10.00
SDQ_Peer_time1	22	1.2727	1.90693	.00	7.00
SDQ_Total_time1	22	7.9091	6.86544	.00	28.00
SDQ_ProSocial_time1	22	8.7727	1.63100	5.00	10.00
SDQ_Emotional_time2	12	1.5000	1.67874	.00	5.00
SDQ_Conduct_time2	12	1.6667	1.30268	.00	5.00
SDQ_Hyperactivity_time2	12	3.5833	2.53909	1.00	8.00
SDQ_Peer_time2	12	2.3333	2.60536	.00	7.00
SDQ_Total_time2	12	9.0833	4.60155	3.00	17.00
SDQ_Prosocial_time2	12	7.8333	2.20880	5.00	10.00

Test Statistics[a]

	SDQ_Emotional_time2 - SDQ_Emotional_time1	SDQ_Conduct_time2 - SDQ_Conduct_time1	SDQ_Hyperactivity_time2 - SDQ_Hyperactivity_time1	SDQ_Peer_time2 - SDQ_Peer_time1	SDQ_Total_time2 - SDQ_Total_time1	SDQ_Prosocial_time2 - SDQ_ProSocial_time1
Z	-.966[b]	-.604[b]	-1.273[b]	-1.556[b]	-1.605[b]	-1.715[c]
Asymp. Sig. (2-tailed)	.334	.546	.203	.120	.108	.086

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

c. Based on positive ranks.

RESULTS FROM NATIONAL BURN CAMP STUDY

We asked you to answer questions before camp, on the last day of camp, and three months after camp. We asked you:

How do you feel about the way you look?

You felt happier about the way you look on the last day of camp than before camp, and happier again three months later.

How do you feel around other people?

You felt more comfortable around other people on the last day of camp than before camp or three months later.

How do you other people act towards you?

You felt that other people were friendlier and more relaxed towards you on the last day of camp than before camp or three months later.

You also told us:

You like making new friends at camp, and seeing old friends.
You think that the other people at camp understand what you are feeling.
You get lots of support at camp from the instructors and other young people.

You also enjoy all of the different activities that you do at camp.
You like the chance to try new things.
You feel that camp helps you to learn new skills.

You feel that camp helps you to be more confident.
Talking about your burns with other people makes you feel more comfortable with your scars.
You feel that camp gives you the chance to help other people.

Thank you for taking part! Any questions?

Laura Armstrong-James   0117 328 1892

Laura2.armstrong-james@uwe.ac.uk

Appendix 23 Study 1A parent feedback

RESULTS FROM NATIONAL BURN CAMP STUDY:

In the summer of 2014, I invited you and your child to take part in some research that was exploring experiences of attending national burn camp and, in particular, whether it affected young people's behaviour, and their thoughts and feelings about social situations and appearance. Parents/carers filled out questionnaires about their child's behaviour one month before camp, and three months later. Young people answered questions about how they felt in social situations and what they thought of their appearance before, during and after camp. Twenty two parents/carers and twenty three young people took part. Here is a brief summary of what this study found:

Results

Young people reported feeling more comfortable in social situations at the end of camp, than they did before camp or three months later. They also felt happier at the end of camp about their appearance and how other people react to them. Young people enjoyed making new friends at camp, catching up with old friends and the chance to speak to other young people who had experienced similar situations to them and could therefore understand their feelings:

"Meeting new people is great as they have been through what you have been through and are understanding of what burned people are going through - overall you get tremendous support from camp"

Young people described how camp helped them to be more confident and accepting towards themselves, and gave them the opportunity to help other people. Feeling that everyone at camp was in the same situation helped them to feel more comfortable with their scars.

"My confidence has improved so much. I used to be so shy and would have no confidence at all."

They enjoyed the range of activities at camp, which enabled them to overcome challenges and learn new skills.

"I enjoyed meeting up with everyone as well as going to the water park as I like to experience new things."

Parents/carers also thought that camp had helped their child to feel more confident and accepting towards themselves, to develop a sense of independence, and learn new skills such as communication, compassion and teamwork:

"To give him confidence and not feel he has to 'hide' his burn, be proud of who he is!"

Parents/carers thought that camp had given their child the chance to mix with lots of other children from different backgrounds and different ages. Parents/carers also felt that if young people had any concerns about their burns then they could discuss these with the volunteers at camp:

"The children can speak and see others which have gone through similar experiences and can talk about their fears and worries"

Overall, parents/carers thought the camps were very helpful for children, but suggested there could be a need for more support for parents/carers and older children:

"I think we could have a get together for the parents or share emails"

"Just to make sure there is still support for teenagers and upwards as this is the age they become more self-conscious".

Conclusion

This study found that attending burn camp can benefit young people by enabling them to spend time with others who have been through similar experiences to themselves, helping them to feel more confident in social situations and to be more accepting of their scars.

The results of this study will be submitted to an academic journal and published in a PhD thesis. I would like to thank all of the young people and parents/carers who took part, and Burns Camps UK without whom this research would not have been possible.

Laura Armstrong-James
Centre for Appearance Research, University of the West of England, Bristol
1st July 2015

If you have any questions or comments, please do not hesitate to contact me:
Laura2.armstrong-james@uwe.ac.uk
0117 328 1892

Thank you!

Appendix 24 Study 2 Letter to participants

University of the
West of England
BRISTOL

Hello,

My name is Laura Armstrong-James and I am a PhD student at the Centre for Appearance Research at the University of the West of England, Bristol. My research, which is part of the Children's Burns Research Centre, involves looking at the experiences of young people who have had a burn injury and the support that is available to them, in order to inform the provision of care for young people in the future.

As part of my research, I am evaluating a new online support programme for young people aged 11-18 who have concerns about their appearance. I am supervised by psychologists from the Centre for Appearance Research, and consultant clinical psychologist Dr Julia Cadogan from the Paediatric Burn Service at University Hospitals, Bristol. My supervisors' details can be found below.

If you and your child are interested in taking part, please read the information sheet in this pack which tells you how you can join in.

Thank you for reading this letter!

Laura

Laura Armstrong-James
Laura2.armstrong-james@uwe.ac.uk
0117 32 81892

Supervisory team:

Professor Diana Harcourt
Diana2.Harcourt@uwe.ac.uk
0117 3282192

Professor Nichola Rumsey
Nichola.Rumsey@uwe.ac.uk
0117 3283989

Dr Heidi Williamson
Heidi3.Williamson@uwe.ac.uk
0117 3281572

Dr Julia Cadogan
Julia.Cadogan@UHBristol.nhs.uk
0117 342 8168

Children's Burns Research Centre
http://www.bristol.ac.uk/social-community-medicine/childrens-burns/

Centre for Appearance Research
http://www1.uwe.ac.uk/hls/research/appearanceresearch/

Information sheet for young people

Hello, my name is Laura. I am doing a study to find out what helps young people who have had a burn. Please read this sheet and talk about it with your parent/carer if you would like to take part.
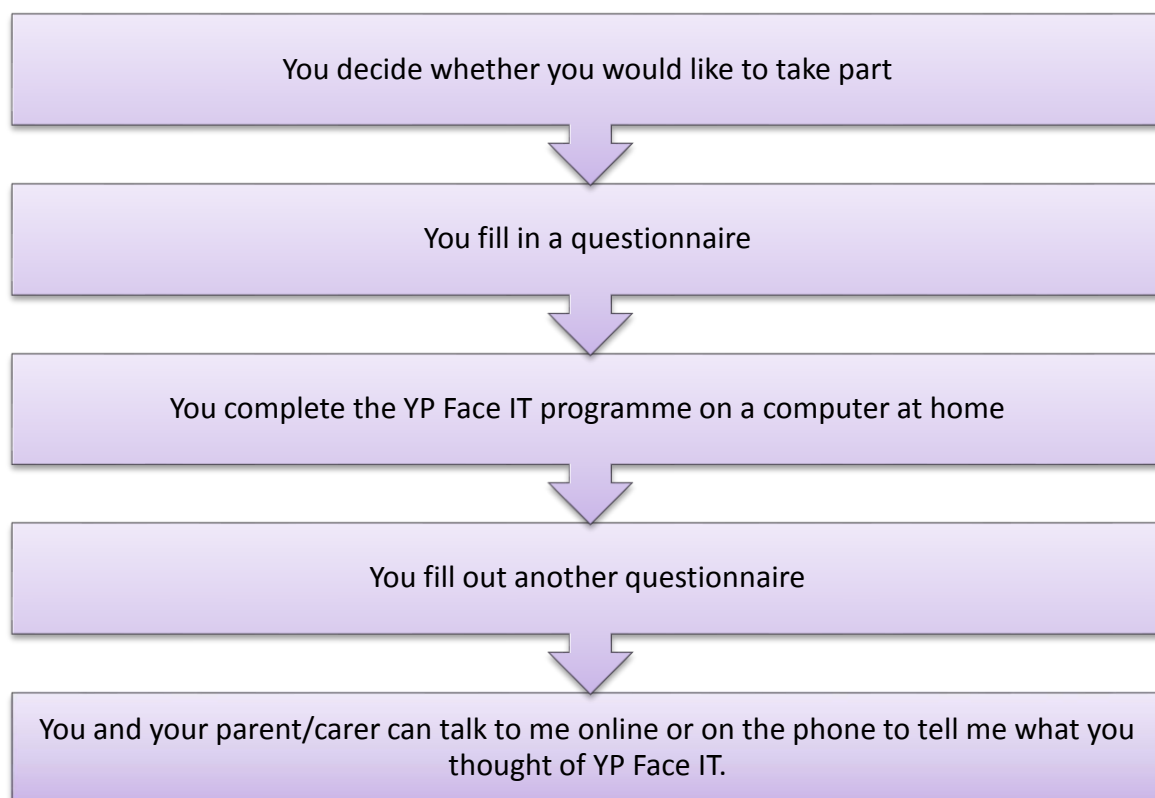
1. What is this about?

I am looking at the types of help available for young people who have had a burn. This is so we can decide what sorts of help work best. Some young people are worried about the way that they look, or might have difficulties with teasing or bullying. YP Face IT is an online programme designed by young people and experts, which can help young people feel better about the way they look. You can find out more about YP Face IT in the YP Face IT leaflet.

2. Why have you given this to me?

You have been chosen because you are between 11 and 18 years old, and you have had a burn in the past. You are very important; with your help we can learn more about what matters to young people with burns and how we can best help them.

3. What will happen if I take part?

You decide whether you would like to take part

You fill in a questionnaire

You complete the YP Face IT programme on a computer at home

You fill out another questionnaire

You and your parent/carer can talk to me online or on the phone to tell me what you thought of YP Face IT.

4. What if I change my mind?

You can stop taking part at any time, even if you have already started. You don't have to say why you have stopped. You won't get into trouble if you change your mind.

5. Will the things I tell you be kept secret?

I will tell people what I find out in my study, but I won't tell them who has said what. But, if you tell me something that sounds like you or someone else is in danger then I may need to tell someone to keep you safe.

6. Who will look after me during the study?

Your psychologist will speak to you once a week after you have completed each session of YP Face IT. This may be on the phone, over email, or in person. You will decide with your psychologist how you would like to speak to them each week.

7. Who has checked this study?

This study has been reviewed and approved by the South-West Central Bristol Research Ethics Committee.

If you would like to take part, please sign the form.
If you are under 16 your parent or carer will need to agree for you to take part. Please tell your parent or carer if you would like to take part.

Laura Armstrong-James   laura2.armstrong-james@uwe.ac.uk

Appendix 26 Study 2 Parent information sheet

UWE University of the
West of England
BRISTOL

PARENT/CARER INFORMATION SHEET

Study title: Evaluating attitudes towards an online support programme for young people with a burn injury

Your child is being invited to take part in a research study. Before you decide if you would like your child to take part, it is important for you to know why the research is being done and what it will involve. Please read the information below carefully and ask your child's psychologist or contact me if anything is unclear or if you would like to know more. Also included in this pack are an information sheet about the study for your child to read, and an information leaflet about the YP Face IT programme.

1.   Why is the research taking place?

A burn injury can affect a young person's life in many ways. In order to provide them with the best care, it is important for health professionals such as doctors, nurses and psychologists to know what types of support are best at meeting their needs. Some young people with a burn injury are worried about the way they look, which can sometimes make them feel worried or anxious in social situations. YP Face IT (www.ypfaceit.co.uk) is a new kind of online support to help young people with appearance-related concerns, by teaching them new skills to help them feel more confident.

2.   What is the study about?

The study will investigate whether young people, their parents and their psychologist feel that YP Face IT is a useful support tool for young people with a burn injury. This will help health professionals decide whether YP Face IT should be offered to young people with a burn injury in the future.

3.   What does the programme involve?

YP Face IT has seven sessions, one per week, each lasting around 45-60 minutes and containing different activities and exercises. There is also a 'homework' assignment each week, to help young people practice the skills they have learnt in the previous session. Six weeks after the final session they are asked to complete a 'booster quiz' to reinforce the skills they have learnt over the sessions. The programme uses text and email reminders to help young people remember to complete the activities

4.   Why has my child been chosen?

Your child has been asked to take part because they have been treated for a burn injury in the past and may be experiencing concerns about their appearance. The psychologist in their burns team thinks that they might be interested in using the YP Face IT programme. I would like to recruit around 35 young people to take part in the study.

5.   Do I have to agree for my child to take part?

No, it's your choice. If you do decide you would like your child to take part you will be given this information sheet to keep and you will be asked to sign a consent form. You are free to change your mind about taking part at any time and without giving a reason. This will not affect your child's care, now or in the future.

6.   What will the study involve?

Week number	Activity	Length of activity
0	Your child's psychologist will explain the YP Face IT programme to you and your child. If you would like your child to take part you will be asked to sign a consent form and your child's psychologist will set them up on the programme to start as soon as they are ready. Your child will complete one set of questionnaires before starting the programme.	20-30 minutes
1-7	Your child will be asked to complete one session of YP Face IT per week at home on a computer. After each session, your child's psychologist will contact them to discuss the session and provide support, which may be over the phone, online, or face-to-face.	45-60 minutes per session
13	Your child will be asked to complete the 'booster quiz' to help reinforce the skills they have learnt while using the programme, with support from their psychologist. Your child will then be asked to complete the set of questionnaires again.	45-60 minutes
14+	You and your child will be invited to discuss your experiences of using the YP Face IT programme with the researcher on the telephone or online, at a time that is convenient for you.	30-60 minutes

7.   What do I have to do if I want my child to take part?

If you would like your child to take part, simply complete the consent form included in this pack and hand it to your child's psychologist, who will explain how your child will be able to use the programme. They can then start using the programme as soon as they are ready.

8.   Will it cost anything to use the programme?

No, YP Face IT is free to use from any computer or tablet with internet access. YP Face IT is not currently available to access from mobile phones.

9.   What are the possible risks of taking part?

Some of the activities may require your child to reflect on challenging thoughts and behaviours, such as any worries about their appearance. However, they will be supervised by a clinical psychologist who will be able to provide support if your child finds any of the activities difficult.

10.   How will my child be supported during the research?

Your child's clinical psychologist will provide support to your child at least once a week when using the programme. The type of support given (e.g. face-to-face, telephone, email) will be agreed by you, your child and the psychologist before your child starts the programme. Your child's psychologist will be available to provide support during office hours (usually Mon-Fri, 9-5). If your child requires support outside of these times, there is a list of charities that provide support for young people with burn injuries at the end of this information sheet.

11.   What are the possible benefits of taking part?

Young people in previous studies have said that YP Face IT has helped them to feel more confident about their appearance. The information we get from this study will help us to inform the care that is available to young people with burns in the future.

12.   Will our responses in this study be shown to anyone?

The personal information you provide will not be shown to anyone outside the research team and the psychologist who referred them to YP Face IT, and will only be used for research purposes. Your names and any identifying information will never be revealed. However, if the researcher or your child's psychologist has any safety concerns during the study (e.g. possible harm to a child or others), then they will be required to report this to the relevant professionals.

13.   What will happen to the results of the research study?

A summary of the findings will be sent to everyone who takes part. I will aim to publish my findings from the study in academic journals and present them at academic conferences but you and your child will not be identified in any summary, report or paper that is produced.

14.   Who is running and funding the research?

This research is funded by The Healing Foundation (registered charity no. 1078666) as part of its support of the Children's Burns Research Centre:

http://www.bristol.ac.uk/social-community-medicine/childrens-burns/

I am running the study as part of my PhD, at the Centre for Appearance Research at the University of the West of England, and I am supervised by Professor Diana Harcourt, Professor Nichola Rumsey, Dr Heidi Williamson and Dr Julia Cadogan.

15.   Who has reviewed the study?

This study has been reviewed and approved by the South-West Central Bristol Research Ethics Committee, and the Faculty of Health and Applied Sciences Research Ethics Committee at the University of the West of England, Bristol.
Appendix 22

16.   Contact for further Information

If you have any further questions about the study then please feel free to contact me on 0117 32 81892 or laura2.armstrong-james@uwe.ac.uk.
Further support:

Changing Faces: www.changingfaces.com   0207 391 9270

The Katie Piper Foundation: www.katiepiperfoundation.org.uk

Children's Burns Trust: www.cbtrust.org.uk   020 7233 8333

Childline (provides 24-hour support): www.childline.org.uk   0800 1111

Thank you for reading this information sheet.

Laura Armstrong-James
Centre for Appearance Research
2L13
University of the West of England
Coldharbour Lane
Bristol
BS16 1QY

CONSENT FORM

University of the
West of England
BRISTOL

Study title: Evaluating attitudes towards an online support programme for young people with a burn injury

> **Please read the questions in the boxes below and initial if you agree.**

1. Have you read the information sheet explaining the study? ☐

2. Have you had enough information about the study? ☐

3. Do you understand that you can ask questions about the study at any stage? ☐

4. Do you understand that you are free to withdraw from the study at any time without having to give a reason? ☐

5. Do you agree to take part in the study? ☐

If you are happy to take part in the study please sign below:

Name of participant……………………………………………..

Signature……………………………………………………

Age of participant……………………………………………..

Phone number (for text reminders) ……………………………………………………….

Email address (for email reminders) ………………………………………………………

Parent's name……………………………………………………………

Signature……………………………………………………….

Date…………………………………………………………

Please turn over

We would like to let your doctor know that you are going to take part in this study in case you would like to speak to them about it in the future. If you are happy for us to do so, please provide your GP's contact details below.

Name of GP…….

GP's address……….

……

Phone number……

If you would like to be sent information about our future research into ways of helping young people who have had a burn (with no obligation to participate) please fill out your preferred method of contact and details in the space below:

Phone number…….

Email address………

Postal address………

……

Body-Esteem Scale for adolescents (BES) Mendleson & White (1997)

Place a tick in the box to show how much do you agree with the following statements?

	Not at all	A little	Sometimes	Most of the time	Always
I worry about the way I look	4	3	2	1	0
I like what I see when I look in the mirror	0	1	2	3	4
I wish I looked like someone else	4	3	2	1	0
I'm pretty happy about the way I look	0	1	2	3	4
I wish I looked better	4	3	2	1	0
There are lots of things I'd change about my looks if I could	4	3	2	1	0
I like what I look like in pictures	0	1	2	3	4
I'm looking as nice as I'd like to	0	1	2	3	4
I feel ashamed of how I look	4	3	2	1	0
My looks upset me	4	3	2	1	0

The Satisfaction with Appearance Scale (SWAP; Lawrence et al, 1998)

In each of the following statements, please circle the most correct responses for you according to the following scale.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my family.	1	2	3	4	5	6	7
Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my friends	1	2	3	4	5	6	7
Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of strangers	1	2	3	4	5	6	7
I am satisfied with my overall appearance	1	2	3	4	5	6	7
I am satisfied with the appearance of my scalp	1	2	3	4	5	6	7
I am satisfied with the appearance of my face	1	2	3	4	5	6	7
I am satisfied with the appearance of my neck	1	2	3	4	5	6	7
I am satisfied with the appearance of my hands.	1	2	3	4	5	6	7

I am satisfied with the appearance of my arms.	1	2	3	4	5	6	7
I am satisfied with the appearance of my legs.	1	2	3	4	5	6	7
I am satisfied with the appearance of my chest.	1	2	3	4	5	6	7
Changes in my appearance have interfered with my relationships.	1	2	3	4	5	6	7
I feel that my burn is unattractive to others.	1	2	3	4	5	6	7
I don't think people would want to touch me.	1	2	3	4	5	6	7

Social Anxiety Scale for adolescents (SAS-A) La Greca (1999)

Please read the following sentences and then tick the box to show how much you feel the following sentences are true for you.

	Never[1]	A little[2]	Sometimes [3]	Most of the time [4]	Always [5]
I worry about doing something new in front of others					
I like to do things with my friends					
I worry about being teased					
I feel shy around people I don't know					
I only talk to people I know really well					
I feel that peers talk about me behind my back					
I like to read					
I worry about what others think about me.					
I'm afraid that others will not like me					
I get nervous when I talk to peers I don't know very well					
I like to play sports					
I worry about what others say about me					
I get nervous when I meet new people					
I worry that others don't like me					
I'm quiet when I'm with a group of people					
I like to do things by myself					
I feel that others make fun of me					
If I get into an argument, I worry that the other person will not like me					
I'm afraid to invite others to do things with me because they might say no.					
I feel nervous when I'm around certain people					
I feel shy even with peers I know very well					
It's hard for me to ask others to do things with me					

Perceived Stigmatisation Questionnaire(PSQ) Lawrence et al, 2010)

During your normal day, you probably see and talk to many different people. We want to know how often people act in certain ways towards you. For each question, tick the box to show how often people do certain things **over the last year.**

	Never	Almost Never	Sometimes	Often	Always
People are friendly with me.	5	4	3	2	1
People call me names.	1	2	3	4	5
People avoid looking at me.	1	2	3	4	5
People I don't know act surprised or startled when they see me	1	2	3	4	5
People are nice to me.	5	4	3	2	1
People don't know what to say to me.	1	2	3	4	5
People I don't know say "Hi" to me	5	4	3	2	1
People laugh at me.	1	2	3	4	5
People are relaxed around me	5	4	3	2	1
People feel sorry for me.	1	2	3	4	5
People pick on me.	1	2	3	4	5
People I don't know smile at me in a friendly way.	5	4	3	2	1
People don't know how to act around me	1	2	3	4	5
People do "double takes" or turn around to look at me	1	2	3	4	5
People are kind to me	5	4	3	2	1
People bully me	1	2	3	4	5
Strangers are polite to me	5	4	3	2	1
People make fun of me.	1	2	3	4	5
People I don't know stare at me	1	2	3	4	5
People treat me with respect	5	4	3	2	1
People seem embarrassed by my looks	1	2	3	4	5

Harter's Self Perception Profile for Adolescents (SPPA) Harter et al (1988) Global self-worth and romantic appeal subscale

The following sentences are about two different types of teenagers. We want to see which type of teenager you're most like. Read the sample question below. It talks about two different types of teenager.

First, decide if you are **more like the teenager on the left or right**? Don't mark anything, just decide.

Second, decide whether this is only **sort of true** for you or **really true**. If it's 'sort of true' put a cross on that box, if it's really true put a cross on the 'really true' box.

Only mark one box for each sentence.

SAMPLE QUESTION

Really true for me	Sort of true for me	Some teenagers like to see films in their spare time	BUT	Other teenagers would rather go to sports events	Sort of true for me	Really true for me
☐	☒				☐	☐

NOW PLEASE COMPLETE THE FOLLOWING

Really true for me	Sort of true for me	Some teenagers are often disappointed with themselves	BUT	Other teenagers are pretty pleased with themselves	Sort of true for me	Really true for me
☐ 1	☐ 2				☐ 3	☐ 4
☐ 1	☐ 2	Some teenagers don't like the way they are leading their life	BUT	Other teenagers do like the way they are leading their life	☐ 3	☐ 4
☐ 4	☐ 3	Some teenagers are happy with themselves most of the time	BUT	Other teenagers are often not happy with themselves	☐ 2	☐ 1
☐ 4	☐ 3	Some teenagers like the kind of person they are	BUT	Other teenagers often wish they were someone else	☐ 2	☐ 1
Really true	Sort of	Some teenagers are really happy		Other teenagers wish they were	Sort of	Really true for

for me □4	true for me □3	**being the way they are**	**BUT**	**different**	true for me □2	me □1
Really true for me □4	Sort of true for me □3	**Some teenagers feel that if they are romantically interested in someone, that person will like them back**	**BUT**	**Other teenagers worry that when they like someone romantically, that person won't like them back**	Sort of true for me □2	Really true for me □1
Really true for me □1	Sort of true for me □2	**Some teenagers are not dating the people that they are really attracted to**	**BUT**	**Other teenagers are dating those people they are attracted to**	Sort of true for me □3	Really true for me □4
Really true for me □4	Sort of true for me □3	**Some teenagers feel that people their age will be romantically attracted to them**	**BUT**	**Other teenagers worry about whether people their age will be attracted to them**	Sort of true for me □2	Really true for me □1
Really true for me □4	Sort of true for me □3	**Some teenagers feel they are fun and interesting on a date**	**BUT**	**Other teenagers wonder about how fun and interesting they are on a date**	Sort of true for me □2	Really true for me □1
Really true for me □1	Sort of true for me □2	**Some teenagers usually don't go out with people they really like on a date**	**BUT**	**Other teenagers do go out with people they really want to date**	Sort of true for me □3	Really true for me □4

Social Skills Improvement System (SISS)
Gresham & Elliot (2008)

The following sentences are about things people your age may do.

Decide how true each sentence is for you. Cross the box to show us if it is **Not true, A little true, A lot true, Very True**

Now please complete the following

	Not true$_0$	A Little true$_1$	A lot true$_2$	Very true$_3$
I ask for information when I need it				
I pay attention when others present their ideas				
I try to forgive others when they say 'sorry'				
I'm careful when I use things that are not mine				
I stand up for others when they are not treated well				
I say 'please' when I ask for things				
I feel bad when others are sad				
I get along with other children / adolescents				
I ignore others who act up in class				
I take turns when I talk with others				
I show others how I feel				
I do what the teacher asks me to				
I try to make others feel better				
I do my part in a group				
I let people know when there's a problem				
I look at people when I talk to them				
I help my friends when they are having a problem				

I make friends easily				
I do my work without bothering others				
I am polite when I speak to others				
I stay calm when I am teased				
I follow school rules				
I ask others to do things with me				
I am well-behaved				
I say nice things about myself without bragging				
I stay calm when people point out my mistakes				
I try to think about how others feel				
I meet and greet new people on my own				
I do the right thing without being told				
I smile or wave at people when I see them				
I try to find a good way to end a disagreement				
I pay attention when the teacher talks to the class				
I play games with others				
I do my homework on time				
I tell others when I'm not treated well				
I stay calm when dealing with others				
I am nice to others when they are feeling bad				
I ask to join others when they are doing things that I like				
I keep my promises				
I say 'thank you' when someone helps me				
I stay calm when others bother me.				

I work well with my class mates				
I try to make new friends				
I tell people when I have made a mistake				
I ask for help when I need it				
I stay calm when I disagree with others				

Appendix 29 Study 2 Young person interview schedule

1. Who told you about YP Face IT?
   a. Did they tell you about it in person, on the phone etc.?
   b. Did they show you what the programme looked like before you used it? If so, what did you think at that stage? If not, what did you think when you first saw it?
   c. What did they say the programme was for?
   d. Why did they think you would find it helpful?
   e. What made you want to try out the programme?

2. Where did you log on to YP Face IT for the first time?
   a. How easy was it to log on to YP Face IT?
   b. How clear were the instructions when you logged on to YP Face IT for the first time?

3. Where did you work through the YP Face IT sessions?
   a. Did anyone help you work through the YP Face IT sessions? If so, who was it?
   b. Would you have liked any more help with the sessions?
   c. Would you have preferred to work through the sessions anywhere else?

4. How easy did you find YP Face IT to use?
   a. How easy di you find it to remember when to complete the sessions?
   b. Did you find the reminders helpful? If not, is there anything else that would've helped you remember?

5. What did you think of the YP Face IT programme overall?
   a. What did you particularly like about it?
   b. Is there anything you didn't like about it? If so, what?

6. What did you think of the sessions you completed overall?
   a. Is there anything you particularly liked about them? If so, what?
   b. Is there anything you didn't like about them? If so, what?

7. What did you think about completing the questionnaires at the beginning and end of the programme?
   a. Did you find the questionnaires easy to understand? If not, what did you find difficult to understand?
   b. How long did it take you to complete the questionnaires?
   c. Where did you complete the questionnaires?

8. How often did you speak to the person who showed you YP Face IT when you were using the programme?
   a. How did you speak to them? (phone, email etc.)
   b. Did you find this a helpful way of speaking to them? if so, what did you like about it? If not, how would you have preferred to speak to them?
   c. Did you speak to them enough about using YP Face IT? If not, how often would you have liked to speak to them?

9. How helpful did you find YP Face IT?
    a. What did you find particularly helpful?
    b. Is there anything you found unhelpful? Is so, what?
    c. Did you find it helpful for the reasons you thought it would be?
    d. Did you find it helpful for anything you hadn't expected? If so, what?

10. Would you use YP Face IT again if you needed help in the future?
    a. If so, what would you use it for?
    b. Would you want to use it in the same way in the future? If not, how would you use it?

11. If your friends asked you what YP Face IT is like, what would you tell them?

12. If another young person with a visible difference was interested in using YP Face IT, what would you tell them?

13. Do you have any else you would like to say about YP Face IT?

Appendix 30 Study 2 Parent/carer interview schedule

1. How did you hear about YP Face IT?
    a. How was the programme explained to you?
    b. When the YP Face IT programme was explained to you, what made you think it would be suitable for your child?
    c. Did you get a chance to look through the programme before deciding whether to take part in the study? If so, what did you think? If not, would you have preferred to look through it before making a decision?

2. What aspects of the programme did you think sounded most/least helpful?

3. Were there any aspects of the programme that you were concerned about?

4. What effect did you think that YP Face IT might have on your child?

5. Did your child's psychologist ask you to work through any of the programme with your child?
    a. Did your child need help logging onto the programme? If so, how easy did you find it to log on?
    b. Did your child involve you when they completed the YP Face IT programme, or ask you for help with any of the sessions? If so, what did they ask for help with?
    c. Would you have liked to be more involved when your child was completing the sessions?

6. Did you have to encourage your child to complete the sessions?
    a. If so, how likely do you think your child would have been to complete the sessions otherwise?
    b. Did you receive reminders when the next session was due? If so, how helpful did you find this service?

7. Do you know how your child's psychologists supported them while they were using the programme (phone, email etc.)?
    a. What do you think about this method of support?
    b. Do you feel that your child had enough support while they were completing the programme? If not, what support would you have liked for them?
    c. Did you need to speak to your child's psychologist during the programme? Do you feel like you had the opportunity to speak to your child's psychologist during the programme if necessary?

8. Did you talk to your child about any of the sessions when they were using the programme? If so, what did you discuss?

9. Did you child practice any skills or strategies that they had learnt from the sessions with you? If so, what skills or strategies did you practice?

10. Have you noticed any changes in your child's behaviour since completing the programme?

a. Do you think that YP Face IT has had any other effects on your child since completing the programme? If so, what?

b. Has your child talked about the programme with you since completing it, and anything they found helpful or unhelpful? If so, what did they say?

11. How well do you feel that the online programme works as an addition to face-to-face support from a psychologist?

12. Do you have any else you would like to say about YP Face IT?

Appendix 31 Study 2 Schedule for psychologists who were able to recruit participants

1. Can you tell me about your experience of recruiting young people to the study?
    a. How did you identify potential participants?
    b. How many patients did you ask?
    c. How did you contact potential participants?
    d. What criteria did you use? (explore in depth)
    e. Who do they think it is suitable for?
    f. How much supervision would you plan to give and how would they have chosen to stay in contact with YP? How would they have followed up patients?)

2. Were other members of the MDT aware of the study?
    a. Did you have much opportunity to discuss YP Face IT with other members of staff?
    b. At what events
    c. Did they give feedback about recruitment process?
    d. Did they help you with recruitment? If so how?

3. How did you introduce the programme to potential participants? Can you give me an example?
    a. How easy did you find it to explain the programme?
    b. How well do you think young people understood what the programme was for? Were there any concerns from YP?
    c. How many young people originally showed an interest in the programme? What did interested YP say?

4. How easy did you find it to use YP Face IT?
    a. Was there anything you found particularly difficult or easy?
    b. Did young people report finding anything difficult or easy?

5. How did you instruct your patients to use YP Face IT?

6. What type of support did you mainly offer to patients while using YP Face IT?
    a. What were your experiences of providing support in this way?
    b. Would you continue to provide support in this way if you were still using the programme?

7. How familiar are you with the programme?
    a. Would you find it easy to identify which areas would suit individual needs?
    b. Do you feel you need training to use programme?
    c. How useful was the training you received? Could it be improved?

8. How relevant was YP Face IT to your patients' needs?

9. Do you feel that YP Face IT helped your patients? If so how, give examples
    a. How did you assess whether it was helping your patients?

10. Do you feel that YP Face IT addressed the intended outcomes? If so how
    a. Do you think it addressed any outcomes which we did not discuss? If so expand

11. Do you feel that the outcome measures used accurately reflected any effects of the programme?
    a. If not, what outcome measures do you think would be more suitable?

12. In your opinion, why do you think recruitment was so difficult?
    a. If we could go back and do the study again, do you think you would do anything differently to try and recruit young people?
    b. Did parents give any feedback?

13. Do you feel that YP Face IT can help improve current care provision?
    a. In your opinion, what contribution can it make to current care provision?

14. Would you continue to use YP Face IT in the future?
    a. If so, what would you use it for? For whom?
    b. Would you use it in a different way?

15. How do you feel health professionals should use YP Face IT to best support their patients?

16. What do you consider to be the strengths of YP Face IT?
    a. Is there anything you think could be improved?

17. Do you have any other comments about YP Face IT?

Appendix 32 Study 2 Schedule for psychologists who were not able to recruit participants

1. Can you tell me about your experiences of trying to recruit young people to the study?
    a. How many patients did you ask?
    b. How did you identify potential participants?
    c. What criteria did you use? (explore in depth)
    d. How did you contact potential participants?

2. How did you introduce the programme to potential participants? Can you give me an example?
    a. How easy did you find it to explain the programme?
    b. How well do you think young people understood what the programme was for? Were there any concerns from YP?
    c. How many young people originally showed an interest in the programme? What did interested YP say?
    d. Have any young people given reasons why they might not want to use the programme? What were they?

3. In your opinion, why do you think recruitment was so difficult?
    a. If we could go back and do the study again, do you think you would do anything different to try and recruit young people?
    b. Did parents give feedback?

4. Do you have contact with other young people outside of therapy, e.g. through clubs or camp?
    a. How do you think recruiting through clubs or camp would compare with asking psychologists to contact young people directly?

5. Were other members of the MDT aware of the study?
    a. Did you have much opportunity to discuss YP Face IT with other members of staff?
    b. At what events?
    c. Did they give feedback about recruitment process?
    d. Did they help you with recruitment? If so how?

6. Who do you think YP Face IT is suitable for?

a. If you had managed to recruit participants, how would you have instructed them to use the programme?

b. How much supervision would you plan to give and how would you have chosen to stay in contact with YP? How would you have followed up patients?

7. How familiar are you with the programme?
   a. Would you find it easy to identify which areas would suit individual needs?
   b. Do you feel you need training to use programme?
   c. How useful was the training you received? Could it be improved?

8. Do you feel that YP Face IT can help improve current care provision?
   a. In your opinion, what contribution can it make to current care provision?

9. Would you continue to use YP Face IT in the future?
   a. If so, what would you use it for?
   b. Would you use it in a different way?

10. How do you feel health professionals should use YP Face IT to best support their patients?

11. What do you consider to be the strengths of YP Face IT?
    a. Is there anything you think could be improved?

12. Do you have any other comments about YP Face IT?

Appendix 33 Screenshots of YP Face IT

Session 4 > activities

Before the next session please keep a record of any experiences that have made you feel unhappy or anxious

Record any difficulty situations you have with other people (like staring, or comments or being left out), record what your feelings were at the time and any negative or positive thoughts you had about their behaviour. For each negative thought try to think what your best friend would say to make you feel better and challenge those negative thoughts?

If you're a bit stuck for ideas of what to write for this activity, take a look at the examples below.

1. Difficult situations with other people that I have experienced today:	2. What was I thinking at the time?	3. How did these thoughts make me feel?	4. What would my best friend say to challenge my negative thoughts and make me feel better?
View Example	View Example	View Example	View Example

dfsfsdffsfsd

Online support for young people with conditions or injuries affecting their appearance   Jo | change avatar

< back | home | session home | journal | forum

progress   100%

Journal

· Entries ·
view all entries
by date, time
and type

add
new

Date: 29/08/2016 Time: 10:46

Title:_____

Your diary is completely confidential, which means only you and the YP Face IT team can see what you write in it.

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Appendix 34 Study 2 Worked example of thematic analysis

L	That makes sense. And then with the others was it just a lack of contact after you first spoke to them?	
S	Um…yes, either the kind of…there was another boy who I'd been seeing for a long, long time and he got referred again because there was some teasing and bullying at school, so I thought "oh that'd be ideal, to just do one of the modules" and then he didn't attend for a while and then when he did come the situation had improved so then it didn't feel appropriate. So yeah, for each case it seemed to be a valid reason, if I knew about it then it was anyway.	• Young people may have already overcome difficulties • Sporadic attendance to therapy
L	Ok. Can we just talk about the two that originally consented a bit more then, can you tell me how you introduced the programme to them to begin with?	•
S	So one of them was a twelve year old boy, again I'd been seeing him on and off for about a year, so I knew the family quite well, so the point where I introduced it was actually when he'd attended clinic, sometimes I try and catch up with patients either before or after their appointment, so in the clinic I mentioned the programme and told him about it. The reason why it actually came up was because it was taking him so long to get to the hospital, it was taking him like two hours, so they'd managed to come and see [name of colleague], but they were struggling to come and see me separately. He did have quite significant appearance concerns. That's the point where I told them about the programme, and then I think the second time I saw them was when I showed them all the forms and went through all the paperwork, so they seemed quite happy with that, both mum and the boy consented. And then I think it was coming up to Christmas then I arranged another appointment in the new year for him to come back, to get him registered, do the password and questionnaires, but that was the point where he never came back, I never actually saw them again, so they dropped out of the service.	• Improving access to therapy • Those with appearance concerns • Young person disengaged from the service entirely
L	Do you know why they dropped out of the service?	•
S	People do now and again, so when we get DNAs we tend to write a letter, like an opt-in letter and if we don't hear anything in two weeks then we just close it.	• Young person disengaged from the service entirely
L	And the second young person that consented was, did you say, a young lady?	•
S	Yeah she was a young lady, she was fourteen then, she's probably about fifteen now, and she was the one who struggled to talk about feelings and how she was feeling about her body. There were some systemic issues as well, I was seeing mum as well with this family. I suppose there were lots of different things going on, she was lacking in motivation generally with the work, I think it was just…when she went away from here she didn't want to think about it, when she came here she could think about it, but it was just something that she wasn't able to do without support.	• Online aspect suits teenagers • Unwilling to complete sessions at home • Issues unrelated to the burn

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INFORMATION SHEET

Study title: Current practices in face-to-face psychosocial support for young burns survivors and their families

You are being invited to take part in a research study. Before you decide if you would like to take part, it is important for you to know why the research is being done and what it will involve. Please read the information below carefully and contact me if you would like to know more.

1.   Why is the research taking place?

The current study will explore health professionals' views on current care provision, to determine what is working well and what could be improved.

2.   Why have I been asked to take part?

You have been asked to take part because you are a health professional who provides face-to-face psychosocial support to young people with a burn injury and their families.

3.   What will the study involve?

If you would like to take part I will ask to you take part in an interview which can take place on the telephone or face-to-face according to your preference and will be recorded. The interview should last around an hour, during which I will ask you about your experiences of providing face-to-face psychosocial support to young people with a burn injury and their families.

4.   What do I have to do if I want to take part?

If you would like take part, please complete the consent form and return to me. I will then be in touch to arrange a convenient time to conduct the interview.

5.   What are the possible risks of taking part?

The study is not thought to pose a risk to participants. However, if at any stage you no longer want to be involved in the study you may withdraw without needing to give a reason.

6.   What are the possible benefits of taking part?

It is hoped that the information from this study will help to give us a better understanding of current psychosocial support for young people with a burn injury and their families, which may help to improve future care provision.

7.   What will happen to the results of the research study?

I will write up the findings in my PhD thesis, and aim to publish the findings in academic journals and present them at academic conferences. A summary of the findings will also be sent to everyone who takes part. However, the personal information you provide will not be shown to anyone outside the research team and you will not be identified in any summary, report or paper that is produced.

8.   Who is running and funding the research?

This research is funded by The Healing Foundation (registered charity no. 1078666) as part of its support of the Children's Burns Research Centre:

http://www.thehealingfoundation.org.uk/thf2008/hfcburninjuryl.htm

I am running the study as part of my PhD, at the Centre for Appearance Research at the University of the West of England, and I am supervised by Professor Diana Harcourt, Professor Nichola Rumsey, Dr Heidi Williamson and Dr Julia Cadogan.

9.   Who has reviewed the study?

This study has been reviewed and approved by the Faculty of Health and Applied Sciences Research Ethics Committee at the University of the West of England, Bristol.

10.   Contact for further Information

If you have any further questions about the study then please feel free to contact me. Thank you for reading this information sheet.

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CONSENT FORM

Study title: Current practices in face-to-face psychosocial support for young burns survivors and their families

Please read the questions in the boxes below and initial each box if you agree.

1. Have you read the information sheet explaining the study?

2. Have you had enough information about the study?

3. Do you understand that you can ask questions about the study at any stage?

4. Do you understand that you are free to withdraw from the study at any time without having to give a reason?

5. Do you agree to take part in the study?

If you are happy to take part in the study please sign below:

Name

Telephone number

Signature

Date

Appendix 37 Study 3 Interview schedule

1. Can you start by giving me a brief overview of your role within burns services?

2. How long have you been working in your current role? How long ago did you qualify?

3. In your experience, what are the most common psychological difficulties faced by young people and their families after a burn injury?

4. How do you decide which young people/families require psychological support after a burn injury?
   a. Do you face any difficult or sensitive issues when approaching potential patients and their families to offer assessment and support?

5. What proportion of your work focuses on appearance-related issues?
   a. How important do you feel appearance-related issues are within one-to-one support?
   b. How would you approach the issue of appearance-related issues within one-to-one support?
   c. How effective do you feel one-to-one support is to treat appearance-related issues?

6. What proportion of your work focuses on other psychosocial issues?
   a. What other issues do you treat in young people with a burn injury and their families?

7. How do you decide whether to see a patient individually or with their whole family?
   a. What are the differences for you when treating patients individually, with their family group, or just the family if that child is very young?

8. How do you carry out your initial assessment of their level of need?
   a. How do you use the results of this assessment to decide upon the most appropriate course of action?

9. Do you use a structured approach to therapy or tailor each session individually?
   a. If you structure therapy according to the age of the child, how do you determine the developmental age of the child?

10. The NHS website states that the types of therapy currently available on the NHS are: CBT, Psychodynamic, Cognitive Analytical Therapy, Interpersonal Psychotherapy, Humanistic Therapies and Family Systemic Therapy.
    a. Do you use any these approaches, and do you use any additional approaches?
    b. Do you prefer a particular approach or do you use a combination of different approaches?
    c. Would you use a different approach to treat appearance-related issues than other psychosocial issues?

d.   What effects do you think the different types of treatment you use have on your patients and their families?

11. Are you aware of any other approaches which you don't currently use with young burns patients?
    a.   If so, why don't you use them with this population?
    b.   Are there any approaches or techniques which you have used in the past but no longer use?

12. How receptive do you find families to be to the notion of one-to-one support?
    a.   Do you find that certain factors affect a family's decision to accept treatment?
    b.   What would happen if a family you feel would benefit from psychosocial support is reluctant to receive it? Do you provide them with other sources of support?

13. At what stage after the injury do you see patients/families?
    a.   Do needs differ at different stages of the injury?
    b.   Do you use different approaches at different stages of the injury?

14. What are your views on inpatient, outpatient or outreach support?
    a.   What do you think the benefits and limitations are across these different types of support?

15. Do you work collaboratively with other members of the burn team?
    a.   If so, what challenges might this create for you?
    b.   How well do you think the different members of the burn team work together?

16. Do you work collaboratively with other agencies such as social care and education within the families' life?
    a.   Does this create any challenges for you?
    b.   How well do you feel such collaborations are working?

17. How do you assess whether the psychological support provided is having an effect?
    a.   What would you do if you didn't feel like treatment was helping a patient or their family?
    b.   Have you ever felt like you weren't sure how to help a patient, or felt required to refer a patient elsewhere?
    c.   If so, what steps did you take following this?

18. Do you have a procedure for following-up with patients after support has ended?
    a.   How long would you follow up with a young person and their family after a burn injury?
    b.   How effective do you think follow up procedures are for ensuring the ongoing psychosocial wellbeing of patients?

19. What barriers do you face as a clinical psychologist when providing psychosocial support to young people with a burn injury and their families, and how do you overcome them?

20. Which parts of current psychosocial care provision do you feel are working well?

21. What are your views on the training and experience for those working at this level in psychosocial care?

22. What else do you think is needed in current psychosocial care provision?

23. Do you have any other comments on current psychosocial care provision for young people with a burn injury and their families?

Appendix 38 Study 3 Worked example of thematic analysis

L	And how effective do you think one-to-one support can be to treat appearance-related issues?	
R	I think it can be hugely effective, I think it can be really positive for a proportion of young people but I think there is also a proportion where thinking about different interventions, thinking about possibly groups, burn camps, school reintegration type interventions are really necessary alongside perhaps some one-to-one work as well. I think there is a proportion of children where one-to-one therapy is not the answer and perhaps also that they're willingness to engage and their ability to engage with one-to-one therapy means that it's not going to be effective, they find it incredibly difficult to sit in a room one-to-one and talk about difficult and sensitive issues and that's when the wider, more holistic and social-based interventions are crucial and certainly my experience of going on burn camps with young people is that I often think that can have, for some young people, just a bigger impact than eight sessions of therapy. I just think it's about assessment and knowing what's right for each person, and perhaps using them in conjunction as well.	- One-to-one work does produce positive outcomes - Combining different types of therapy - One-to-one support isn't for everyone - Most appropriate type of therapy may relate to individual differences rather than level of psychosocial need - Social groups can effectively bring young people with similar concerns together - Tailoring therapy to suit the individual
L	And how would you decide whether to see a patient individually or with their whole family?	
R	I think it would depend on a number of factors really, I think it would depend on age if I'm honest and that would go for pretty much all of my work in paediatric, I often feel that particularly when you're providing a psychological intervention for younger children it's so important to have the family and parents on board, and understanding what your aims are and what your goals are and helping them to be almost…I know people talk a little bit about parents as co-therapists and I'm not sure if that's necessarily the right description but I think it's so important to have that shared understanding of what you're doing in therapy sessions. So often with younger children I would spend a little bit of time with children on their own and then join the session up together. Age is definitely a key factor. I suppose the kind of opposite of that is with older young people I'd always want to give them the opportunity to have a bit of space and time on their own as well, so would try and facilitate that and that's the same across paediatrics I'd want to try and make sure that they had some space to talk about things away from their family as well. The type of intervention, the type of presenting difficulty I think, potential work around trauma I would be likely to provide that on a one-to-one basis and still…if that was with a younger child and we were doing some work around managing anxiety or trauma symptoms, I think it's often easier to do that on a one-to-one basis, but would want to include parents if that was appropriate. And complex families who might be seen and I	- Structure of therapy may differ according to the age of the child - Providing psychosocial support vicariously - Parents very involved with therapy for young children - Older children may benefit from time away from parents - Important to be able to give young people a voice - Useful to speak to the young person and family both together and separately - One-to-one work suited to trauma - Complex family situations may present additional challenges.

Appendix 39 Study 3 participant feedback

SUMMARY OF RESULTS FROM STUDY: CURRENT PRACTICES IN ONE-TO-ONE PSYCHOSOCIAL SUPPORT FOR YOUNG PEOPLE WITH BURN INJURIES AND THEIR FAMILIES

Fourteen clinical psychologists from ten NHS trusts took part in interviews about their experiences of working within paediatric burns. A thematic analysis revealed four main themes: the psychological complexities of a burn injury; differences between screening and assessment procedures; family support requires flexibility; a combination of therapeutic approaches to meet individual needs.

1. The psychological complexities of a burn injury

Most factors associated with a burn injury related to appearance, trauma or a combination of the two, although these issues can be very complex. While older children and adolescents often experience worries about appearance and reactions from others, younger children tend to cope quite well with the injury, and it is often the parents, and sometimes siblings, who present with difficulties. However, concerns often arise during the transition from primary school to secondary school, and the added development of body consciousness during adolescence can make this a particularly challenging time. While this may be a particularly salient time for support, it is possible that children burned at a very young age and discharged may have lost contact with psychological services by the time they reach adolescence.

2. Differences between screening and assessment procedures

Screening was carried out by a psychologist at four of the sites and ward staff at the remaining six. Some screening assessments were more comprehensive than others, with methods ranging from an adapted version of a standardised assessment tool to a simple tick box approach. A thorough assessment of individual needs was conducted by all psychologists, which involved a range of techniques intended to elicit a comprehensive picture of the families' individual needs and circumstances. Most psychologists used outcome measures such as the PedsQL or SDQ, but felt that these measures did not necessarily encapsulate the complexities of a burn injury. Many referred to the ongoing discussions by the BBA psychosocial SIG to agree on a set of appropriate outcome measures to be used across all services.

3. Family support requires flexibility

Participants agreed that therapy is not a 'one size fits all' method and discussed the importance of considering families' individual needs throughout therapy sessions. Participants felt that attempting to stick rigidly to a particular therapeutic approach was counterproductive, and instead described a more flexible, eclectic, semi-structured approach led primarily by the patient. Participants in the study also recognised the need to treat families flexibly according to the

different stages of an injury. Psychological issues may change as the recovery from the burn injury progresses, so assessment and therapy may also have to be adaptive depending on the stage of the injury. Concerns can also arise years after the injury, so psychological support may be required long after the involvement from the rest of the burn team has ended.

4. A combination of therapeutic approaches to meet individual needs

Most participants preferred CBT and systemic approaches, not only because of the usefulness of these approaches but also because they have received the most training in these methods. However, it was recognised that a combination of approaches was often the most effective way to address concerns. For example, a primarily CBT approach might also include elements of mindfulness to target anxiety or social skills to manage other people's reactions. Several participants had also completed additional training on techniques such as hypnosis for pain management and anxiety or EMDR for trauma. Participants recognised that one-to-one work can be effective for certain people, but perhaps not others. In certain cases, lower-level interventions such as burn camps are considered to be more effective than one-to-one therapy.

Conclusion

The overarching conclusion from this study was that clinical psychologists needed to work flexibly to identify and meet the complex range of psychosocial needs of young people with burn injuries and their families. While there were inconsistencies between the extensiveness of screening procedures used by participants, all used a comprehensive, yet variable, assessment process to identify psychosocial needs. The study revealed that therapy sessions were tailored to individual clients, using a range of therapeutic techniques to most effectively meet the individual needs of young people with burn injuries and their families.

Laura Armstrong-James 25th February 2016
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