

# **The Experiences of Older Adults Living with an Appearance Altering Burn Injury: An Exploratory Qualitative Study**

## **Abstract**

Semi-structured interviews were conducted with ten burn survivors aged 51-71 and transcripts analysed using Interpretive Phenomenological Analysis which resulted in four main themes: Time and adjusting to an altered appearance; Living with a visible difference in the eyes of others; Me, myself and I; The importance of maintaining appearance. Adjusting to the impact of the burn injury appeared to be a long process.

Participants identified a need for more information about how the ageing process may impact on burn injuries. Participants reported feelings of isolation and also discussed the importance of maintaining an appearance that is socially acceptable. Practical implications for care and participants are discussed.

## **Keywords**

Appearance, ageing, burn injury, qualitative

## **Introduction**

In 2007, Changing Faces (CF), a UK charity which supports people who have conditions or injuries that affect their appearance, estimated there were 60,000 people living in the UK with a disfigurement to the face or body which had been caused by a burn injury. As a result of advances in medical treatment (Klinge et al., 2009; Rossi et al., 2005; Thombs et al., 2007), mortality rates from burn injuries in Europe over the past 30 years have significantly reduced (Brusselaers et al., 2010). The number of people living with the physical and psychological consequences a burn injury has therefore increased and the provision of appropriate psychosocial care and interventions to support burn survivors with the challenges they may face during rehabilitation has become increasingly important (Klinge et al., 2009).

Looking in the mirror for the first time is thought to be a distressing experience with the most common emotional reactions being shock, sadness and anxiety (Shepherd, Tattersall & Buchanan, 2014). However, psychosocial distress goes beyond the acute recovery phase with burn survivors facing an array of rehabilitative challenges (Andrews et al., 2009). For instance, He et al. (2014) found in a sample of 246 burn patients (mean age=25.77 years), social support and optimism to be significantly correlated with depression. This association between social support and depression is not surprising considering that the face is central in social interactions (Tagkalakis & Demiri, 2009) and living with a visible difference

can be difficult in a society where a high premium is placed on physical appearance (Gilboa, 2001). Those who have a visible difference may experience stigmatising reactions and behaviour such as staring and unwanted questioning (Rumsey, 2002), which have been reported to be some of the most significant challenges facing people affected by a burn injury (Patterson et al., 1993; Rumsey & Harcourt, 2004) and can provoke social anxiety, social avoidance, fear of negative evaluation and lowered body-esteem (Rumsey & Harcourt, 2004).

Although adjustment (i.e. the process of adaption to a burn injury) takes time (Kornhaber et al., 2014a; 2014b; Thompson & Broom, 2009), some burn survivors report positive outcomes. Williams, Davey and Klock-Powell (2003) conducted a qualitative study with 8 burn survivors and found that participants, especially women, were able to reframe their losses as gains and define themselves more meaningfully as a consequence of their injury. Interestingly, they found adjustment to be positively influenced by time, memories of the accident and age when injured.

Post-traumatic growth (PTG), a concept which refers to an individual who exceeded pre-trauma levels of personal functioning and well-being (Tedeschi et al., 1998) has also been reported in some burn survivors (Baillie, Sellwood & Wisely, 2014). In this sample (mean age= 45.67), PTG was predicted by active coping (e.g. changing the way you think about a stressor); perceived social support and avoidance coping (e.g. diverting attention away from difficulties).

The conclusions drawn from the psychosocial burns literature are limited to children, adolescents, young or middle-aged adults. This is surprising given that western society considers older looking bodies, especially female bodies, as unattractive and unworthy of recognition (Hurd-Clarke, 2010). In one study, women aged between 50-70 discussed how ageing made them feel socially invisible and they reported engaging in appearance-enhancing strategies in response to this (e.g. hair-dye) which they felt increased their visibility and self-esteem (Hurd-Clarke & Griffin, 2008). At the same time older adults (aged 65-92) have also reported societal pressure to look age appropriate (Jankowski et al., 2014).

Nevertheless, the importance placed on physical appearance may reduce with age because body competence (e.g. physical coordination, agility and health) is considered more of a priority and concerns with these functional aspects of the body increase with age (Baker & Gringart, 2009; Jankowski et al. 2014).

Currently only one study (Hamlet & Harcourt, 2014) has explored the experiences of older adults living with a visible difference, in this instance cleft lip and/or palate. Hamlet and Harcourt found that whilst time appeared to have a positive effect by enabling individuals to incorporate the cleft into their identity, some participants were concerned about what would happen to their teeth as they aged and they were unsure how to obtain relevant information about this. As a consequence of these findings, the authors suggested that future research should explore the experiences and support

needs of older adults living with acquired (e.g. a burn injury), as opposed to congenital differences (e.g. cleft).

Globally, life expectancy is increasing (United Nations, 2013) and advances in burns medical treatment (Klinge et al., 2009; Rossi et al., 2005; Thombs et al., 2007) means that there are more people over the age of 50 living with a burn injury. The dearth of research with this population means that there is a lack of knowledge surrounding the experiences of burn survivors over the age of 50 and consequently the support needs of this population are not known. Burn survivors over the age of 50 may in fact have very specific needs (not seen in younger populations) considering that it is at this age when people start to experience the first signs of ageing (e.g. the menopause and greying of the hair). Additionally, listening to the experiences of burn survivors over the age of 50 could not only benefit similarly aged peers with a burn, but also younger burn survivors that are yet to reach this age.

Another limitation with this body of literature is that the majority of psychosocial research within the field of visible difference has adopted a quantitative methodology (Rumsey & Harcourt, 2004; Thompson & Kent, 2001; Thompson & Broom, 2009). Studies that employ the same quantitative measures (e.g. The Derriford Appearance Scale (Carr, Harris & James, 2001)) have enabled researchers to make meaningful comparison however, the extent to which quantitative measures can provide an in-depth understanding of psychosocial adjustment to visible difference has

been questioned (Rumsey & Harcourt, 2004). Additionally, even though some burn survivors report positive outcomes (Thompson & Broom, 2009; Williams, Davey & Klock-Powell 2003) the majority of quantitative psychosocial outcome measures focus on negative aspects (Fauerbach, Pruzinsky & Saxe, 2007). Therefore, more qualitative research is required in order to provide a more in-depth understanding of the experiences and needs of people living with a burn injury.

Therefore, to address the identified gaps within the existing literature a qualitative methodology was employed to:

1. Gain insight into the lived experience of burn survivors over the age of 50, with a focus on appearance and ageing.
2. Obtain an understanding of the support needs of burn survivors over the age of 50, whether these needs were adequately addressed and how support needs may have changed over time and if so, how?

## **Methods**

### *Research Design:*

Given the dearth of research with burn survivors over the age of 50, a qualitative inductive approach was adopted. Semi-structured interviews were conducted and to facilitate in-depth exploration of the participants' experiences, Interpretative Phenomenological Analysis (IPA) was chosen as the method of analysis since it views the participant as the expert (Reid, Flowers, & Larkin, 2005). IPA has been used within appearance-related

research, for instance to explore how people with a visible difference manage the reactions of others (Thompson & Broom, 2009) and to explore the experiences of older adults who are living with cleft lip and/or palate (Hamlet & Harcourt, 2014).

Ethical approval was granted from the first authors institution research committee.

#### *Participants and Recruitment:*

The study was advertised through four UK based charities: Changing Faces (CF), The Katie Piper Foundation (a charity that provides support to make it easier to live with burns and scars), Dan's Fund for Burns (a charity that provides practical help for burn survivors) and Age UK in Nottingham and Leicester. CF promoted the study via their website, Facebook page, Twitter account and in their newsletter. The Katie Piper Foundation and Dan's Fund for Burns advertised the study on their websites whilst Age UK Nottingham and Leicester, who helps everyone make the most of later life, placed posters and flyers around their day centres. The study was also promoted through local media. Adults over the age of 50 were invited to take part in the study.

In total, 10 participants aged 51-71 years (mean age=61) who were living with a burn injury were recruited, which is an acceptable sample size for IPA (Smith, Flowers & Larkin, 2013). Participants were asked to be 12 months post-burn because during the first 12 months, burn survivors are more likely to be suffering with post-traumatic stress disorder, which is

then likely to dissipate after a year (Ehde et al. 2000). Table 1 provides participants' demographic information; all pseudonyms were chosen by the participants.

## **INSERT TABLE 1 HERE**

### *Interviews:*

A semi-structured interview schedule was developed by consulting the burns, appearance and ageing literatures and also drawing on the appearance-related research experience of one of the co-author's. The schedule covered five topics: demographic information; experiences of living with a burn injury; attitudes towards appearance and ageing; coping with a burn injury and support needs.

All interviews were conducted by the first author, a female in her 20's with no personal experience of burn injuries who also kept a journal throughout the duration of the study to enable reflection on how her personal views and experiences may have influenced data collection and analysis.

Participants were offered the choice of a face-to-face, e-mail or telephone interview. Interviews conducted face-to-face (n = 1) and via telephone (n = 5) were audio recorded, transcribed verbatim and lasted between 30-80 minutes. Interviews conducted via email (n = 4) were 11-45 pages long.

### *Analysis:*

Interviews were analysed using IPA, following the guidelines suggested by (Smith, Flowers & Larkin, 2013). Transcripts were read twice the second

time making initial descriptive, linguistic and conceptual comments and by clustering these, emergent themes were developed. The first author then visually organised the emergent themes into superordinate and subordinate themes. Once this procedure had been completed for all 10 transcripts, patterns across cases were sought and the most prevalent themes were selected. These were reviewed and agreed by the two co-authors.

To ensure the validity of the themes, all participants were sent a summary of the themes and feedback was welcomed. Nine participants provided feedback that the themes were meaningful and comprehensible to them. Some participants also provided further insight into their experiences, which deepened the analysis.

## **Results**

Participants discussed their experiences of living with a burn injury and the subsequent four main themes were developed: (1) Time and adjusting to an altered appearance; (2) Living with a visible difference in the eyes of others; (3) Me, myself and I; (4) The importance of maintaining appearance.

### **(1) Time and adjusting to an altered appearance**

It became evident from the participants' discussions that time played a significant role in adjusting to their altered appearance. The 7 participants, who sustained a burn as a child, appeared to have become accepting of their visible difference over time. From the extract below, it is evident that whilst Lucy may not be satisfied with her external appearance, she has

come to the realisation that she will not be able to regain her lost looks and has accepted her scars are for life. Her final comment "Life goes on" may suggest that over time she has learnt that there is more to life than physical appearance:

*"I might not like how they look, the uneven pattern and different shades and that there are lumps and bumps but again, there's nothing that I can do about them. Life goes on."* (Lucy, aged 53)

It was also evident that some participants had integrated their appearance into their identity. Annid evidently has no memory of her appearance before the age of 6 and consequently does not have a pre-burn appearance to mourn:

*"Basically if I had a photograph before I was 6 could say oh well that's how I looked but I haven't seen a picture"* (Annid, age 51)

An accepting attitude was also evident through the way the participants focused on the positive aspects of their adversity. For example, Heidi spoke about how her experiences had been character building:

*"Something always comes out of the worst episode you learn more about yourself and your abilities to cope"* (Heidi, age 74)

Nevertheless, several participants who sustained a burn as children explained how the journey of adjustment was still ongoing and was not constant. John's discussion implies that there are still areas of his life that he is not completely satisfied with:

*"There is a part of me that hasn't quite made the hurdle to 100% adjustment. I'm comfortable at home and work, and among my circle of friends. Going out among strangers brings good and bad days."* (John, age 60)

Three participants sustained burns as adults. Gary had his accident just over a year before the interview and it was evident that he hadn't yet come to terms with his traumatic event:

*"I drink more alcohol than I did, but I think that blocks the realisation of what happened."* (Gary, age 62)

Both Venice and Gary appeared to be struggling to coming to terms with their altered appearance:

*"I've been faced with a burn on my face I look different I am different... your life changes therefore you are always trying to get your life back"*  
(Venice, age 71)

Venice's discussion portrays a sense of loss, perhaps she is grieving the person she once was. It appears she is holding onto her former self, which is preventing her from adapting and accepting to her altered appearance. However, Lousie had a near-death experience and it is evident from her discussion that her life has become enriched as a consequence of her accident. Perhaps it was her near-death experience that changed her outlook on life and reduced inhibitions she once had:

*"oh and public speaking is another thing I do which I would have never never have done"* (Louise, age 68)

## **(2) Living with a visible difference in the eyes of others**

All participants had a burn injury that they described as being visible to others and although those who sustained a burn during childhood appeared accepting of their visible difference, they all discussed how society was less accepting. All of the participants, apart from Louise, explained how they had been stigmatised (e.g. staring) and judged because they did not convey externally what is perceived as 'normal' in society. For example, Venice who sustained her burn aged 68, explains in the quote below how she avoids social interaction (which may be perceived as an unhelpful coping mechanism by professionals) because she feels her visible difference attracts unwanted attention. Her comments imply that she feels other people do not see past her burn injuries, and that she is socially defined by her visible difference:

*"If people are looking at me I don't want them to be looking at me because I have burns ... I don't like it and hence I avoid it"* (Venice, age 71)

In the extract below, Alaster (who sustained a burn aged 3) explains his annoyance at becoming affected by people's reactions. There is an element of surprise in his comments; it is as if he feels he should have developed resilience to such stigmatising behaviours:

*"When people see my hands, recoiling as they do sometimes, it annoys me that I'm still affected by such things at the age of 60"* (Alaster, age 60)

Lucy, who also sustained her burn aged 3, describes how she feels she is frequently taken at 'face value'. The assumptions people make on the basis of her visible difference have clearly left her feeling as if she is worthless and has no social value:

*"Talking to me as if I am of low intelligence or just completely ignoring me as if I don't exist"* (Lucy, age 53)

However, over time, the majority who had sustained their burn as children appeared to have developed effective coping mechanisms for dealing with others' negative reactions. For instance, they explained how they would ignore culprits, devalue their opinions and/or normalise stigmatising reactions. Four participants who sustained their injury as children and Louise, who sustained her burn as an adult, also described the importance of self-presentation during social interaction. Shaggy describes how a change in stance changed others' attitudes towards him and perhaps by presenting himself more positively (e.g. by smiling), he is actually demystifying any negative assumptions (e.g. people with scars are villains) made on the basis of his appearance:

*"trying to stand up straight and walk around the bedroom feeling a lot more confident...and erm I attached a smile to that as well...it worked a treat"* (Shaggy, age 63)

### **(3) Me, Myself and I**

In contrast to the previous theme's focus on interactions with other people, this theme explores the notion of isolation and the need for peer support. In this way, Alaster explained how he has isolated himself from others. He talks of himself as if he is a contagious disease and does not want others to become infected:

*"Best to keep to oneself, it's less complicated and fewer people get hurt. I've always wanted a family, to be a husband and father but feel to pass all that pain further down the generations would not be good at all."*  
(Alaster, age 60)

Some participants felt their accident and/or burn injuries were a taboo topic that they could not discuss with others. Lucy explains how this left her unable to express herself during her childhood because she had nobody to connect with on an emotional level:

*"I would have liked someone to have given me the permission and opportunity to share my inner most thoughts and feelings. But I grew up feeling that my accident was a TABOO subject"* (Lucy, age 53)

Connecting with others on an emotional level seemed to be important to several participants. John reflects on how valuable peer support could have been when he had needed psychosocial support to alleviate loneliness:

*"It would have been great to meet someone like myself, with burns, who could empathise with my fears and concerns."* (John, age 60)

In some cases, feeling isolated is perhaps exacerbated by not being able to access support services when they are required. Whilst Lucy is not currently seeking any support, in the below extract she discusses an episode when she had previously sought support during adulthood:

*"Accessing counselling in London whilst the individual is hundreds of miles away and having to make contact by phone, email or Facebook might work for some people but ... is not always the best option for some people."* (Lucy, age 53)

It is evident that when Lucy needed psychological support, she would have preferred face-to-face support that she could have accessed locally.

#### **(4) The importance of maintaining appearance**

*Maintaining a socially acceptable appearance:*

All the participants discussed how appearance was currently important to them, with the exception of Fudja, who said her appearance ceased to be of importance in her 50s. Several participants discussed engaging in appearance-enhancing strategies to disguise, detract attention from or conceal their burn injuries. For instance, both Annid and John described how they disregarded medical advice and exposed their burn injuries to sunlight to change the pigmentation of their scars. Their comments imply that they were aiming to reduce the noticeability of their burn injuries so they would be seen as more socially acceptable:

*"The only thing I might do is ensure my chin gets some sunshine as the pigmentation is very white. When it tans it isn't as noticeable"* (John, age 60)

Louise lost an eyebrow in her accident and in the extract below she describes how she has considered having an eyebrow tattooed to restore symmetry. However, her discussion implies that she is concerned about maintaining an appearance that would be seen as socially acceptable for a woman of her age, since natural eyebrows thin with age:

*"There has been talk of having eyebrows tattooed ...if you're young I think it could be stunning but then if you have it done then what happens when you get old and you've got these stunning eyebrows and the rest of you is crinkling up ((laughs))"* (Louise, age 68)

At the same time, several participants also discussed engaging in appearance-enhancing strategies that were unrelated to their burn injury (e.g. hair-dye) to mask the signs of ageing. The fact that Lucy describes how she is not "ready" perhaps insinuates that she feels visual ageing is perceived as negative in society and therefore she is attempting to maintain her social value:

*"I dye my hair because I am not ready to go completely grey yet."* (Lucy, age 53)

*A changing skin:*

Three participants who sustained their injury as children described how the ageing process was having a negative impact on their burn scarring. In some cases this meant that they had started to invest in their appearance for functional as opposed to aesthetic reasons, since the skin loses elasticity with age:

*"As I get older obviously erm things deteriorate and the skins starts to contract... I have had some work done under my chin to help my mouth work properly that's it though"* (Shaggy, age 63)

There appeared to be inadequate information and advice about how the ageing process may impact on burn injuries. For example, the following quote from Lucy illustrates how the lack of information may have impacted on her self-confidence as she describes feeling embarrassed when her scars were more noticeable during the menopause:

*"I am also going through the menopause and the skin graft on my chin can look very red indeed for as long as I am having a hot flush. This can be rather embarrassing if in public...as I'm not sure what causes this to happen"* (Lucy, age 53)

## **Discussion**

IPA provided an in-depth understanding into what it is like for adults over the age of 50 to live with a burn injury, which subsequently provided insight into this population's support needs.

In accordance with Williams, Davey and Klock-Powell (2003) and Hamlet and Harcourt (2014), this study demonstrates that the passage of time had a positive impact by enabling those participants who had been living longer with their burn injury to integrate it into their identity and appreciate what they had gained from their adversity, as opposed to lost. Over time, some participants also appeared to have accepted that their visible difference was life-long which concurs with Moi & Gjengedal (2008) who concluded that burn survivors needed to accept the unchangeable. These findings highlight the need for researchers and clinicians to consider both the positive and negative aspects of living with a burn injury.

In support of Kornhaber et al. (2014a; 2014b) and Thompson and Broom (2009), three participants in the current study who sustained a burn injury as children described themselves as being on an ongoing journey of adjustment which highlights the importance of offering psychosocial support to those living with a burn injury across the life span.

In the current study, participants who sustained their burn injury more recently appeared to be less well-adjusted to their altered appearance and accident. Gary had his accident just over a year ago and not surprisingly it was evident that he hadn't come to terms with this traumatic event. Additionally, both Gary and Venice appeared to be struggling to come to terms with their altered appearance because they were holding onto their former self and appeared to be focused on what they had lost, a finding supported by Williams, Davey and Klock-Powell (2003). In contrast, Louise,

who had a near death experience, seemed more resilient in relation to her burn accident and altered appearance. This finding supports the notion that psychosocial adjustment is multifactorial and individual in nature (Rumsey et al. 2002a, 2002b) and every effort should be made by healthcare professionals and support organisations to provide tailored support.

All participants in the current study had a burn injury that they described as being visible to others and had experienced stigmatising behaviours and reactions (identified in previous research as being a common and difficult challenge for people living with a visible difference (Patterson et al. 1993; Rumsey and Harcourt, 2004)). This finding is understandable considering that lack of social support is significantly correlated with depression (He et al., 2014). Cognitive Behavioural Theory (CBT) models of body-esteem and disfigurement (Cash & Grant, 1996) also support this finding as they suggest that some individuals with a disfigurement hold the belief that they are worthless, which is reinforced by stigmatising behaviour. In light of this, CBT interventions focused on challenging these core beliefs may be particularly beneficial to reduce this negative cycle. In support of this, Bessell and Moss (2007) conducting a systemic review of interventions for adults with a visible difference and found none of the interventions were effective, although CBT showed some promising effects.

Overall, these findings also emphasise how stigmatisation is a significant problem and campaigns have started to make a difference, more campaigns are needed that specifically incorporate older adults, especially since ageing in society is also devalued (Hurd-Clarke, 2010).

However, in the current study, the majority of participants who had been living longer with their visible difference appeared to have developed effective coping mechanisms (e.g. ignoring culprits) to deal with stigmatising behaviour. Participants also found it effective to present themselves positively during social interaction to demystify any negative assumptions made on the basis of their appearance, for instance by smiling at staring culprit. In support of this, researchers have argued that those with a visible difference and higher levels of social skills experience more positive social interactions (Rumsey, Bull & Gahagen 1986; Blakeney et al. 2005). In light of the current study's findings and previous research, healthcare professionals and support organisations need to ensure social skills training, that specifically incorporates the needs of older adults, is available and accessible. Future research could explore whether older adults access support services and whether they met their needs.

In contrast to being an object of public scrutiny, participants also felt isolated in a variety of ways. For instance, some participants felt isolated due to the lack of contact with peers. Kornhaber et al. (2014a; 2014b) have previously described how connecting with others who have had a similar lived experience is important for both emotional and practical reasons. This is not surprising considering that social support has been associated with post-traumatic growth (Baillie, Sellwood & Wisely, 2014). However, participants in this study felt that peer support was not always available. Future research would benefit from exploring how to promote peer support

amongst older adults living with a visible difference, in a manner that would be acceptable and feasible.

In support of previous research (Hurd-Clarke & Griffin, 2008), appearance was important to participants (with the exception of Fudja) and all participants appeared keen to maintain a socially acceptable appearance, both in relation to their visible difference and ageing. Within the broader appearance and ageing literature, Hurd-Clarke and Griffin (2008) claimed that older adults engage in appearance-enhancing strategies to increase their social visibility and self-esteem. However, in this study participants appeared to be engaging in such behaviours to achieve an appearance that would allow them to 'fit in' with the rest of society. Participants discussed how they would engage in appearance-enhancing strategies to disguise, conceal or draw attention away from their burn injuries, although Louise was also particularly mindful that she needed to maintain an appearance that would be seen as age-appropriate by society, in keeping with findings by Jankowski et al., (2014). At the same time, participants engaged in appearance-enhancing strategies, not relating to their burn, to mask the signs of ageing because they felt visually appearing old was perceived negatively in society (Hurd-Clarke, 2010). Therefore, some participants appeared to be experiencing several contradictory societal pressures and any organisation offering services to disguise, conceal or draw attention away from a visible difference (e.g. camouflage clinics) need to be sensitive regarding individual beliefs about what burn survivors consider to be socially acceptable in respect of their appearance.

In accordance with Baker and Gringart (2009) and Jankowski et al. (2014), several participants explained how they invested in their appearance for functional, as opposed to aesthetic, reasons. In accordance with a study conducted by Hamlet and Harcourt (2014), participants in the current study described there being a lack of information about how the ageing process could impact on burn injuries as the skin deteriorates with age, which left participants feeling emotionally and practically unprepared. Consequently, healthcare professionals and support organisations could consider providing information relating to how age-related changes may impact on burn injuries.

Findings should be considered in light of the study's limitations. Even though qualitative research does not aim to be representative, the majority of participants were recruited via support organisations and therefore the experiences of those who do not associate themselves with these charities may be very different. It must also be considered that appearance and ageing may be sensitive topics for some people and therefore only those who feel comfortable talking about their experiences may have volunteered to take part.

Email and telephone interviews have previously been criticised because important social cues cannot be responded to, which may have a detrimental effect on the development of rapport between the participant and interviewer (Cook, 2012; Novick, 2008). However, within the current study, the researcher felt the telephone interviews were of the same quality

as the face-to-face interviews, but it was felt that there was not the same opportunity to build rapport during the initial stages of the email interview, because the exchange of conversation was not instant. This may have hampered the elicitation of high quality data during this stage.

Despite these limitations, this study is (to the best of our knowledge) the first to specifically explore the experiences of adults over the age of 50 who are living with a burn injury and highlights important areas for future research. Most of the participants in this study described their ethnic origin as White/UK; only one participant was born in India. Future research in this area should explore appropriate ways of engaging participants from ethnically diverse populations.

## **Conclusion**

These findings suggest that adults over the age of 50 are under-researched in burns research. Whether they sustained their burn injury as children or as adults, they have faced an array of psychosocial challenges and although time appears to have a positive impact on the adjustment process, this still continues to be a difficult issue for some. It is hoped that this study will prompt researchers to continue to conduct research with this important, yet under-researched population so high quality and tailored psychosocial support and appropriate interventions can be provided.

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### **Declaration of Conflicting Interests**

None declared

### **References**

Andrews, M. R., Browne, L. A., Drummond, D. B. & Wood, M. F. (2009). The impact of personality and coping on the development of depressive symptoms in adult burns survivors. *Burns*, 36, 29-37.

Baker, L. & Gringart, E. (2009). Body image and self-esteem in older adulthood. *Ageing and Society*, 29(6), 977-995.

Baillie, E. S., Sellwood, W. & Wisely, A. J. (2014). Post-traumatic growth in adults following a burn. *Burns*, 40, 1089 – 1096.

Bessell, A. & Moss, P. T. (2007). Evaluating the effectiveness of psychosocial interventions with a visible difference: A systematic review of the empirical literature. *Body Image*, 4, 227-238.

Blakeney, P., Thomas, C., Holzer, C., Rose, M., Berniger, F., Meyer, W. (2005). Efficacy of a Short-Term, Intensive Social Skills Training Program for Burned Adolescents. *Journal of Burn Care & Rehabilitation*, 26(6), 546-555.

Brusselaers, N., Monstrey, S., Vogelaers, D., Hoste, E. & Blot, S. (2010). Severe burn injury in Europe: a systematic review of the incidence, aetiology, morbidity, and mortality. *Critical Care*, 14(5), 1-12.

Cash, T. F., & Grant, J. R. (1996). *Cognitive-behavioural treatment of body-image disturbances*. In V. B. Van Hasselt & M. Hersen (Eds.), *Sourcebook of psychological treatment manuals for adult disorders* (pp. 567-614). New York: Plenum Press.

Carr, T., Harris, D. & Jame, C. (2000). The Derriford Appearance Scale (DAS-59): A new scale to measure individual responses to living with problems of appearance. *British Journal of Health Psychology*, 5(2), 201-215.

Changing Faces (2007). The Incidence and Prevalence of Disfigurement. Retrieved from <https://www.changingfaces.org.uk/downloads/FE%20Campaign,%20Epidemiology%20%20pages.pdf>

Cook C. (2012). Email interviewing: generating data with a vulnerable population. *Journal of Advanced Nursing*, 68(6), 1330–1339.

Fauerbach, J, A., Pruzinsky, T. & Saxe, G. N. (2007). Psychological Health and Function after Burn Injury: Setting Research Priorities. *Journal of Burn Care & Research*, 28(4), 587-592.

Gilboa, D. (2001). Long-term psychosocial adjustment after burn injury. *Burns*, 27(4), 335–341.

Hamlet, C. & Harcourt, D. (2014). Older adults' experiences of living with cleft lip and palate: A qualitative study exploring ageing and appearance. *The Cleft Palate-Craniofacial Journal*. Advance online publication. DOI: <http://dx.doi.org/10.1597/13-308>

Harris, D. L. & Carr, A. T. (2001). Prevalence of concern about physical appearance in the general population. *British Journal of Plastic Surgery*, 54, 223-226.

Hurd-Clarke, L. & Griffin, M. (2008). Visible and invisible ageing: beauty work as a response to ageism. *Ageing and Society*, 28(5) 653–674.

Hurd-Clarke, L. (2010). *Facing age: Women growing older in an anti-ageing culture*. Toronto, Ontario, Canada: Rowman and Littlefield.

Jankowski, G., Diedrichs, P. C., Williamson, H., Harcourt, D. and Christopher, G. (2014) Looking age-appropriate while growing old gracefully: A qualitative study of ageing and body image among older adults. *Journal of Health Psychology*, Advance online publication. Retried from: <http://hpg.sagepub.com/content/early/2014/04/27/13>

Klinge, K., Chamberlain, J. D., Redden, M. & King, L. (2009). Psychological adjustments made by post-burn injury patients: an integrative literature review. *Journal of Advanced Nursing*, 65(11) 2274- 2292.

Kornhaber, R., Wilson, A., Abu-Qamar, Z. M., McLean, L. (2014a). Coming to terms with it all: Adult burn survivors' 'lived experience' of acknowledgement and acceptance during rehabilitation. *Burns*, 40(4), 589-97.

- Kornhaber, R., Wilson, A., Abu-Qamar, Z. M., McLean, L. (2014b). Adult burn survivors' personal experiences of rehabilitation: An integrative review. *Burns*, 40(1), 17-29.
- Mendelson, B. K., Mendelson, M. J., & White, D. R. (2001). Body-Esteem Scale for Adolescents and Adults. *Journal of Personality Assessment*, 76, 90-106.
- Mendelson, M. J., Mendelson, B. K., & Andrews, J. (2000). Self-esteem, body-esteem, and body-mass in late adolescence: Is a competence x importance model needed? *Journal of Applied Developmental Psychology*, 21, 249-266.
- Moi, A. & Gjengedal, E. (2008). Life after burn injury: striving for regained freedom. *Qualitative Health Research*, 18, 1621-30.
- Novick, G. (2008). Is there bias against telephone interviews in qualitative research? *Research in Nursing and Health*, 31, 391-398.
- Patterson, D., Everett, J. Bombadier, C., Questad, K., Lee, V. & Marvin, J. (1993). Psychological effects of severe burn injuries. *Psychological Bulletin*, 113, 362-378.
- United Nations, Department of Economic and Social Affairs, Population Division. (2013). Retrieved from <http://www.un.org/en/development/desa/population/publications/dataset/urban/profilesOfAgeing2013.shtml>
- Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-23.
- Rossi, A. L., Vilab, C. S. da V., Zagoa, F. M. M. & Ferreirac, E. (2005). The stigma of burns: Perceptions of burned patients' relatives when facing discharge from hospital. *Burns*, 31, 37-44.
- Rumsey, N. (2002a). *Body image & congenital conditions with visible differences*. In T. F. Cash & T. Pruzinsky (Eds.), *Body image: A handbook of theory, research, and clinical practice* (pp. 226-233). New York: Guilford.
- Rumsey, N. (2002b). *Optimizing body image in disfiguring congenital conditions*. In T. F. Cash & T. Pruzinsky (Eds.), *Body image: A handbook of theory, research, and clinical practice* (pp. 431-439). New York: Guilford.
- Rumsey, N. & Harcourt, D. (2004). Body image and disfigurement: issues and interventions. *Body Image*, 1, 83-97.
- Rumsey, N., Bull, R. and Gahagen, D. (1986). A preliminary study of the potential of social skills for improving the quality of social interaction for the facially disfigured. *Social Behaviour*, 1, 143-146.

Shepherd, L., Tattersall, H. & Buchanan, H. (2014). Looking in the mirror for the first time after facial burns: A retrospective mixed methods study. *Burns*. Advanced online publication. DOI: 10.1016/j.burns.2014.03.011

Smith J, Flower P, Larkin M. (2013). *Interpretative Phenomenological Analysis; Theory, Method and Research*, London: Sage.

Tagkalakis, P. & Demiri, E. (2009). A Fear Avoidance Model in Facial Body Image Disturbance. *Annals of Burns and Fire Disasters*, 22(4), 203-207.

Tedeschi, R.G., Park, C.L., & Calhoun L.G. (1998). Posttraumatic growth; Conceptual issues. In R.G. Tedeschi, C.L. Park, & L.G. Calhoun (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis*. Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.

Thombs, D. B., Haines, M. J., Bresnick, G. M., Magyar-Russell, G., Fauerbach, A. J. & Spence, J. R. (2007). Depression in burn reconstruction patients: symptom prevalence and association with body image dissatisfaction and physical function. *General Hospital Psychiatry* 29, 14–20.

Thombs, D. B., Notes, L. D., Lawrence, W. J., Magyar-Russell, G., Bresnick, G. M., Fauerbach, A. J. (2008). From survival to socialization: A longitudinal study of body image in survivors of severe burn injury. *Journal of Psychosomatic Research*, 64, 205–212.

Thompson, A. & Kent, G. (2001). Adjusting to Disfigurement: Process involved in Dealing with Being Visibly Different. *Clinical Psychology Review*, 21(5), 663-682.

Thompson, R. A. & Broom, L. (2009). Positively managing intrusive reactions to disfigurement: an interpretative phenomenological analysis of naturalistic coping. *Diversity in Health and Care*, 6, 171–80.

The Centre for Appearance Research (n.d). Guidelines for Appearance Research. Retrieved from: <http://hls.uwe.ac.uk/research/Data/Sites/1/docs/GuidelinesforAppearanceResearch.pdf>

Williams, R. N., Davey, M. & Klock-Powell, K. (2003). Rising from the Ashes: Stories of Recovery, Adaptation and Resiliency in Burn Survivors. *Social Work in Health Care*, 36(4), 53-77.