

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

Bethany Jones¹, Dr Heather Buchanan² and Professor Dianna Harcourt³

¹ Loughborough University, School of Sport, Exercise and Health Sciences

² University of Nottingham, Faculty of Medicine & Health Sciences

³ University of the West of England, Health and Social Sciences

Corresponding Author:

Bethany Jones

B.Jones@lboro.ac.uk

Loughborough University,

Epinal Way,

Loughborough,

Leicestershire,

UK

LE11 3TU

Abstract

Advances in medical treatment mean more older people are living with burn injuries. However, little is known about experiences and support needs of this group. Interpretative Phenomenological Analysis of semi-structured interviews with ten burn survivors aged 51-71 identified four themes: Time and adjusting to an altered appearance; Living with a visible difference in the eyes of others; Me, myself and I; Importance of maintaining appearance. Adjusting to burns was a long process. Participants discussed feeling isolated, needing information about how ageing impacts on scars, and maintaining a socially acceptable appearance. Implications for care and further research are discussed.

Keywords

Appearance, ageing, burn injury, qualitative, older adults

Introduction

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

Burn survivors face an ongoing array of rehabilitative challenges and outcomes (Andrews et al., 2009), which are influenced by psychosocial factors and processes. For instance, He et al. (2014) found levels of depression to be significantly correlated with social support and optimism. This association is not surprising considering that the face is central in social interactions (Tagkalakis & Demiri, 2009) and living with a visible difference (such as scarring after a burn) 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), considered to be some of the most significant challenges

facing people affected by a burn injury (Patterson et al., 1993; Rumsey and Harcourt, 2004), and can provoke social anxiety, social avoidance, fear of negative evaluation and lowered body-esteem (Rumsey and Harcourt, 2004).

Although adjustment (i.e., the process of adapting to living with 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. Moreover, post-traumatic growth, 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).

To date, the conclusions drawn from the psychosocial burns literature are limited to children (e.g., McGarry et al., 2013), adolescents (e.g., Liber et al., 2008) and young adults (e.g., Lawrence & Fauerbach, 2003). Globally, life expectancy is increasing (United Nations, 2013) and advances in burns medical treatment (Klinge et al., 2009) mean that more people over the age of 50 are living with a burn injury. This includes older adults who sustained a burn earlier in life and the growing number

of adults affected by burns in later life. In contrast to medical research, the dearth of psychosocial research with this older population means that our understanding of the experiences and support needs of burn survivors over the age of 50 are not known. This group may have very specific needs (not seen in younger populations) considering they are at an age when signs of ageing (e.g., the menopause and greying of the hair) typically appear. Additionally, listening to the experiences of burn survivors over the age of 50 could not only benefit similarly aged peers, but also younger burn survivors that are yet to reach this age.

The lack of research with adults over the age of 50 may reflect a societal attitude given that Western society considers older looking bodies, especially female bodies, as unattractive and unworthy of recognition (Hurd-Clarke, 2010). Indeed, 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 and 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 (2014) 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). Psychosocial research within the field of visible difference has tended to adopt a quantitative methodology (e.g., Rumsey and 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 comparisons, however the extent to which quantitative measures can provide an in-depth understanding of psychosocial adjustment to visible difference has been questioned (Rumsey and Harcourt, 2004). Additionally, even though some burn survivors report positive outcomes (e.g., Thompson & Broom, 2009; Williams, Davey & Klock-Powell 2003), quantitative psychosocial outcome measures tend to focus on negative aspects (e.g., Fauerbach, Pruzinsky & Saxe, 2007). More qualitative research is required in order to provide a more in-depth understanding of both the positive and negative experiences of older

people living with a burn injury, in order that any support needs can be considered and addressed appropriately.

Therefore, to address the identified gaps within the existing literature Interpretative Phenomenological Analysis was employed in this study in order 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.

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 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 previously 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 and Harcourt, 2014).

Ethical approval was granted from the first author's Institution's 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 (a charity that aims to help people make the most of later life). 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 placed posters and flyers around their day centres in Nottingham and Leicester. The study was also promoted through local media. Adults over the age of 50 who had sustained a burn injury of any size at any age, but at least 12 months previously, were invited to contact the first author by phone or email for further information about the study and, if they wanted to take part, make arrangements for the interview to take place.

Ten participants aged 51-71 years (mean age=61) were recruited, which is an acceptable sample size for IPA (Smith, Flowers & Larkin, 2013). Participants were required to be at least 12 months post-burn because of the possibility of post-traumatic stress after a burn, which is likely to dissipate a year after the injury (Ehde et al., 2000). Participants were excluded if they self-reported any severe mental health issues. Table 1

provides participants' demographic information; all pseudonyms were chosen by the participants.

Table 1: Participants demographic information

Pseudonym	Gender	Age	Age when burnt	Total body surface area burnt?	Visible to Others (Subjective) ?
John	Male	60 years	27 months	25%	Yes
Alaster	Male	60 years	3 years	25%	Yes
Annid	Female	51 years	6 years	65-85%	Yes
Lucy	Female	53 years	3 years	48%	Yes
Louise	Female	68 years	62 years	10-15%	Yes
Fujda	Female	54 years	3 years	50%	Yes
Gary	Male	62 years	62 years	33%	Yes
Shaggy	Male	63 years	13 years	12%	Yes
Heidi	Female	74 years	5 months	20%	Yes
Venice	Female	71 years	68 years	15%	Yes

Interviews:

A semi-structured interview schedule was developed by consulting the burns, appearance and ageing literatures, and discussed and agreed by the co-authors. 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. She has previous experience of conducting qualitative research, semi-structured interviews 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 and, on average, took 2 weeks to complete.

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 that were clustered in order to develop emergent themes. The first author then visually organised these 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 increase the credibility 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. By doing this, it was ensured that the findings were congruent with reality.

Results

The analysis of participants' discussions of their experiences of living with a burn injury led to four main themes being 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 more accepting of their visible difference in comparison to those who sustained their injuries as adults, although they still appeared to experience some challenges. In 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 that her scars are for life. Her final comment "*Life goes on*" may suggest that she has learnt that her appearance is out of her control:

"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 a child explained how the journey of adjustment was still ongoing and was not constant. John's comment 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, one of these being Gary whose accident occurred just over a year before the interview. It was evident from his discussion that he was still coming to terms with this 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. However, Louise's injury was nearly fatal and it is evident from her comments that she considers her life has been enriched as a consequence of her accident and her resulting change in outlook on life and reduced inhibitions:

"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 seemed

to be accepting of their visible difference, they all discussed how society was less accepting. All the participants, apart from Louise, explained how they had felt stigmatised (e.g., being stared at) and judged because they did not convey what society perceives to be 'normal'. For example Venice, who sustained her burn aged 68, explains how she avoids social interaction (which may be perceived as an unhelpful coping mechanism) because she feels her scarring 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 being 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:

"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 burns 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 he consciously adjusts his posture in order to change others' attitudes towards him and 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 and romantic relationships to prevent passing his pain down to future generations:

"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 peer support could have helped:

"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, feelings of isolation could be exacerbated by not being able to access support services when they are required. Whilst Lucy is not currently seeking any support, in the extract below 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 support, she would have preferred face-to-face support that she could access locally.

(4) The importance of maintaining appearance

Maintaining a socially acceptable appearance:

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

“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)

Several participants also discussed engaging in appearance-enhancing strategies (e.g., hair-dye) to mask signs of ageing that were unrelated to their burn injury. The fact that Lucy describes how she is not "ready" perhaps implies that she feels visual ageing is negative:

"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 a child described how the ageing process was having a negative impact on their burn scarring. Some had therefore 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)

Participants described inadequate information and advice about how the ageing process may impact on burn injuries and scarring. For example, 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

There is a paucity of psychosocial research exploring the experiences and support needs of burn survivors over the age of 50. Therefore, it was the aim of the current paper to explore their experience and needs using a qualitative approach. IPA provided an in-depth understanding into what it is like for adults over the age of 50 to live with the results of 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 helped some of those participants who had been living longer with their burn injury, to integrate it into their identity. Over time, some participants also appeared to have accepted that their visible difference was life-long – a finding that concurs with Moi and Gjengedal (2008) who concluded that burn survivors needed to accept the unchangeable. Three participants who sustained a burn injury during childhood described themselves as still being on an ongoing journey of adjustment, which is

similar to the findings of Kornhaber et al. (2014 a, b) and Thompson and Broom (2009). This highlights the importance of offering psychosocial support to those living with a burn injury across the life span.

Participants who sustained their burn injury more recently appeared to be not only coming to terms with the traumatic event, but also their altered appearance. This struggle, in terms of their appearance, appeared to stem from the fact that they were focusing on what they had lost, a finding supported by Williams, Davey and Klock-Powell (2003). In contrast, Louise, whose burn injuries had nearly been fatal, seemed more resilient in relation to her burn accident and altered appearance. These varying accounts support the notion that psychosocial adjustment is multifactorial and individual in nature (Rumsey et al., 2002a, b) and every effort should be made by healthcare professionals and support organisations to provide tailored support.

All participants in the current study described their burn injury as being visible to others and all but one participant 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)). 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. A systemic review of interventions for adults with a visible difference (Bessell & Moss, 2007) concluded that CBT showed some promising effects, although none of the interventions in the review had strong evidence of effectiveness.

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 to deal with stigmatising behaviour. Participants also found it helpful to present themselves positively during social interaction in order to demystify any negative assumptions made on the basis of their appearance, for instance by smiling at those who stared at them. 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). The current study's findings and previous research suggest healthcare professionals and support organisations should ensure that social skills training that specifically incorporates the needs of older adults, is available and accessible. Future research is needed to explore the extent to which older adults access support services and whether their needs are met.

In contrast to being an object of public scrutiny, participants also reported feeling isolated due to the lack of contact with peers. Kornhaber et al. (2014a, b) 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 could usefully explore 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 with older adults (Hurd-Clarke & Griffin, 2008), appearance was still important to the participants (with the exception of Fudja) and they were keen to maintain a socially acceptable appearance, both in relation to their visible difference and ageing. Participants discussed how they engaged in 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 considered age-appropriate, in keeping with findings by Jankowski et al. (2014). At the same time, participants engaged in appearance-enhancing strategies that were not related to their burn, in order to mask the signs of ageing because they felt that ageing and looking older was perceived negatively in society (Hurd-Clarke, 2010). Therefore, some participants were experiencing contradictory societal pressures and organisations offering services to disguise, conceal or draw attention away from a visible difference (e.g., skin camouflage services) need to be sensitive to individuals' beliefs about what they consider to be a socially acceptable 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 line with XXX study of older adults with cleft lip, participants in the current study described a lack of access to information about how the ageing process could impact on burn injuries as the skin changes with age, which left participants feeling emotionally and practically unprepared. Consequently, healthcare professionals and support organisations could consider providing information relating to how natural age-related changes may impact on burn injuries.

Overall, these findings emphasise how stigmatisation is a significant problem for older adults living with the consequences of burn injuries. Public and school-based campaigns to challenge stereotypes and perceptions about visible difference have been developed in recent years, but these need to specifically address negative attitudes towards older adults (Hurd-Clarke, 2010).

These 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 the experiences of older adults with burns who do not associate themselves with these charities may be very different. Furthermore, appearance and ageing can be sensitive topics for some people and therefore it is possible that only those who are managing well and feel comfortable talking about

their experiences may have volunteered to take part. Alternatively, those who are struggling with appearance-related issues may have volunteered to participate as a way of seeking support.

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). Within the current study, the interviewer felt the telephone interviews were of the same quality as the face-to-face interviews, but 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 and also hindered the researcher's opportunity to seek clarification or expansion of the participants' responses, so the depth of data obtained from email, telephone and face-to-face interviews may have differed. This meant that deeper levels of interpretation were possible with the face-to-face and telephone interviews.

Despite these limitations, this study is (to the best of our knowledge) the first to specifically explore the lived 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; one participant was born in India. Future

research in this area should explore appropriate ways of engaging participants from ethnically diverse populations.

Conclusion

This study was conducted in response to the dearth of research into the experiences of older adults who are living with the consequences of a burn. Whether they sustained their injury as children or as adults, they faced an array of psychosocial challenges and although time appears to facilitate the adjustment process, it was still 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.

Acknowledgements

We would like to thank all the participants who took part in this research and also Changing Faces, The Katie Piper Foundation, Dan's Fund for Burns and Age UK for promoting the study.

Declaration of Conflicting Interests

None declared

References

- Andrews MR Browne LA Drummond DB and Wood MF (2009) The impact of personality and coping on the development of depressive symptoms in adult burns survivors. *Burns*, 36: 29-37.
- Baker L and Gringart E (2009) Body image and self-esteem in older adulthood. *Ageing and Society*, 29(6): 977-995.
- Baillie ES, Sellwood W and Wisely AJ (2014) Post-traumatic growth in adults following a burn. *Burns*, 40: 1089-1096.
- Bessell A and Moss PT (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 and 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 and 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 TF and Grant JR (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 and Jane 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%202%20pages.pdf>
- Cook C (2012) Email interviewing: generating data with a vulnerable population. *Journal of Advanced Nursing*, 68(6): 1330-1339.
- Ehde D, Patterson DR, Wiechman SA and Wilson LG (2000) Post-traumatic Stress Symptoms and Distress 1 Year After Burn Injury. *Journal of Burn Care & Rehabilitation*, 21(2): 105-11.

Fauerbach JA, Pruzinsky T and Saxe GN (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.

Hamelt C and Harcourt D (2014) Older adults' experience of living with a cleft lip and palate: A Qualitative study exploring ageing and appearance. *The cleft palate-craniofacial journal*, 52(2), 32-40.

He F, Zhou Q, Zhao Z, Zhang, Y and Guan H (2014) Effect of perceived social support and dispositional optimism on the depression of burn patients. *Journal of health psychology*, 1-7.

Hurd-Clarke L and 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-aging culture*. Toronto, Ontario, Canada: Rowman and Littlefield.

Jankowski G, Diedrichs, PC, 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. Retrieved from: <http://hpq.sagepub.com/content/early/2014/04/27/13>

Klinge K, Chamberlain JD, Redden M and 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 ZM and 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 ZM and McLean L (2014b) Adult burn survivors' personal experiences of rehabilitation: An integrative review. *Burns*, 40(1): 17-29.

Lawrence W J and Fauerbach A J (2003). Personality, Coping, Chronic Stress, Social Support and PTSD Symptoms Among Adult Burn Survivors. *Journal of Burn Care and Research*, 24(1): 63-72.

Liber M J, Faber W A, Treffers A D and Van Loey E E N (2008). Coping style, personality and adolescent adjustment 10 years post-burn. *Burns*, 34(6): 775-782.

McGarry S, Elliott C, McDonald A, Valentine J, Wood F and Girdler S (2013). Paediatric burns: From the voice of the child. *Burns*, 40(4): 606-615.

Moi A, and 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 and 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, and Larkin M (2005). Exploring lived experience. *The Psychologist*, 18(1): 20-23.

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 and 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.

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

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

Tedeschi RG, Park CL, and Calhoun LG (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.

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

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

Williams RN, Davey, M and 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.