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Post-traumatic stress symptomatology and appearance distress following burn injury: An interpretative phenomenological analysis

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Abstract

Objectives: Although many traumatic incidents result in changes to appearance, little research has examined the experience of individuals distressed by such changes in connection with psychological processes involved in post-traumatic stress disorder (PTSD). This study aimed to examine how PTSD and appearance concern associated with burn injury are experienced when both difficulties co-occur. *Method*: The qualitative method of interpretative phenomenological analysis (IPA) was utilized to provide a framework for building nuanced accounts of individual experience. In-depth analysis was conducted with interview data obtained from eight women, who were purposively selected on the basis of being distressed in relation to burn scarring, and having symptoms of PTSD. Results: Participants described how changes in appearance were experienced as maintaining a sense of threat through social stigma, and acting as a trigger for re-experiencing the traumatic incident that had caused the burn injury. As such, appearance concern and PTSD symptomatology appeared intertwined within the participants' accounts of their post burn injury recovery. Conclusions: This is the first study to consider some of the processes through which PTSD and appearance concern might be mutually maintained. The results suggest that psychosocial interventions need to be tailored to simultaneously address processes related to concerns about change in appearance and also with traumatic reexperiencing.

Keywords: Burn injuries; Disfigurement; Posttraumatic stress; Interpretative phenomenological analysis; Qualitative.

Burn injuries are a major source of physical and psychological trauma (World Health Organization, 2008). The majority of people who experience a burn injury adjust to the consequences (Altier, Malenfant, Forget, & Choinière, 2002; Patterson, Everett, Bombardier, Questad, Kent, Lee, & Marvin, 1993), although a substantial proportion may continue to experience ongoing psychological difficulties, including posttraumatic stress disorder (PTSD), mood disturbance, and appearance distress (Palmu, Souminen, Vuola, & Isometsä, 2011).

Some studies report that as many as a fifth of people who have suffered a significant burn injury may experience PTSD symptomatology up to a year after injury (Madianos, Papaghelis, Ioannovich, & Dafni, 2001). Current models of PTSD place emphasis on cognitive factors, particularly negative appraisals of the traumatic event and/or its consequences, in the maintenance of distress (Brewin & Holmes, 2003; Ehlers & Clark, 2000). Indeed, the identification and modification of unhelpful cognitive appraisals and processes are often essential elements in the treatment of PTSD (Ehlers & Clark, 2000). Consequently, understanding the nuances of cognitive appraisals following burn injury is essential (Van Loey, Van Son, Van der Heijden, & Ellis, 2008). However, there are relatively few qualitative studies that have examined the phenomenology of such post-trauma cognitions in people who have experienced burn scarring.

Burn injuries often cause permanent scarring or other bodily changes that result in visible difference or disfigurement. Mood disturbance specifically related to concern about appearance change is not unusual but has also not been subject to much investigation (Fauerbach et al., 2002; Lawrence, Fauerbach, & Heinberg, 2004). People with visible scarring are also known to be at risk of experiencing prejudice, discrimination and intrusive reactions from others such as stares, questions or comments (Kornhaber, Wilson, Abu-Qamar, & McLean, 2014).

Evidence from the wider field of disfigurement suggests that it is perceived stigmatization (rather than actual stigmatization) and its relationship to avoidant coping styles that is most likely to account for the majority of individual variation in presentations of distress (Thompson & Kent, 2001; Moss & Rosser, 2012). Recent theories of disfigurement have also attempted to explain appearance concerns with reference to cognitive processes. It has been posited that cognitive schema associated with the value placed on appearance (appearance salience), and the perception of attractiveness (appearance valence) play a pivotal role in adjusting to disfigurement in a similar fashion to as played in PTSD (Cash, 202; Cash, 2011; Moss & Carr, 2004; Moss et al., 2014; Thompson, 2012). However, despite clinicians reporting an anecdotal relationship between distress associated with disfigurement and PTSD symptomatology, there are only a small number of studies that have begun to investigate this (Bryant, 1996; Fukunishi, 1999; Roberts, Difede, & Yurt, 2001; Shepherd, 2015).

Fukunishi (1999) examined the relationship between the visibility of scars and PTSD symptoms in 56 participants and found that regardless of the size of the scar, females with facial scarring experienced the highest levels of symptoms of trauma-related avoidance and emotional numbing. This suggests that gender may be important in PTSD symptomatology associated with scarring. However, the study did not investigate distress related to scarring (only the presence of scarring itself). Indeed, Roberts, Difede, and Yurt (2001) interviewed 86 participants two weeks following burn injury and found that scarring to the face and hands was significantly associated with depression but not acute stress disorder, which might suggest that visibility per se is not the key factor. Further, Bryant (1996) measured visibility of scarring, appearance concern, and PTSD symptomatology, and found that visibility of scarring was not associated with PTSD symptomatology. Rather, concern about the scarring accounted for 40% of the variance in PTSD symptoms. This may be suggestive of a potential

relationship between PTSD and appearance concern due to trauma-related changes in appearance.

Shepherd (2015) explored this relationship directly with a sample of 33 patients referred to a specialist clinical psychology burns service. A significant positive relationship was found between appearance concern and PTSD symptoms. Further increased appearance concern was found to be related to increased intrusive and hyperarousal PTSD symptoms but not to trauma-related avoidance. Shepherd (2015) concluded that qualitative studies were needed to develop an understanding of the complex nature of the interaction between PTSD and appearance concern following trauma-acquired disfigurement.

Several qualitative studies (Dunpath, Chetty, & Van Der Reyden, 2015; McGarry et al., 2014; Moi, Vindenes, & Gjengedal, 2008; Rossi, Costa, Dantas, Ciofi-Silva, & Lopes, 2009) have reported that scarring might act as a permanent reminder of the burn injury, triggering recollections and psychological distress. However, the exploration of this phenomenon has not been a primary focus in any existing study, and the experiential processes that might tie appearance concern and trauma symptomatology together have yet to be elaborated upon in any detail.

The aim of the current study was therefore to address this gap in the literature by examining how PTSD symptomatology and appearance concern associated with a burn injury are experienced when they co-occur. We sought to get close to the personal embodied experience of living with both post-burn scarring and PTSD symptomatology, which is best addressed by a hermeneutic and phenomenological approach. Consequently we chose to use interpretative phenomenological analysis (IPA: Smith, 1996; Smith, Flowers, & Larkin, 2009; Larkin & Thompson, 2012). IPA has become an established approach to qualitative research within clinical and health psychology (Biggerstaff & Thompson, 2008; Brocki & Wearden, 2006) because it was developed with the specific aim of getting close to individual

meaning making experience whilst acknowledging and allowing room for interpretation and enabling those involved in the study to draw upon psychological theory.

Method

Ethical and research governance approvals for the study were obtained via the UK NHS Ethics Committee process and the NHS collaborating Trust. Scientific approval was also gained following scrutiny by an independent University panel. Ethical guidance in relation to conducting in depth interviews in connection with sensitive topics was followed (Thompson & Russo, 2012).

Participants

Purposive sampling was used to recruit participants from a UK regional burns service, and a UK based burns charity. Eight participants were included in the study. Small numbers are desirable in IPA in order to perform meaningful analysis that does not compromise the idiographic intent of the methodology (Smith et al., 2009). The inclusion criteria were people who had sustained a burn injury, identified themselves as either currently experiencing, or previously having experienced symptoms of PTSD associated with the incident that led to the burn injury; and who also identified themselves as having a visible difference caused by the burn injury that caused them distress. Participants were excluded if they were below the age of 16, were not fluent in English, sustained their injuries through self-harm, or had significant cognitive impairment. There is evidence that the objective severity and location of the burn injury is not related to the degree of psychological distress (Fauerbach et al., 2002; Kleve & Robinson 1999; Lawrence et al., 2004; Wallis et al., 2006), therefore these factors did not form part of the inclusion criteria.

Data collection

Participants were interviewed at a venue of their choice. Questionnaire results, medical information, and demographic data were collected to enable the context and characteristics of the sample to be delineated. This involved completion of a brief demographic questionnaire, the Derriford Appearance Scale (DAS24: Carr, Moss, & Harris, 2005) to measure appearance concern, and the Impact of Events Scale-Revised (IES-R: Weiss & Marmar, 1996) to measure symptoms of PTSD. The DAS24 is a 24-item scale measuring general self-consciousness of appearance and sexual and bodily self-consciousness (Moss et al., 2015). It has been shown to have good test-retest reliability (r=0.68 following a six-month interval) and internal consistency (α = .92: Carr et al., 2005). The IES-R has also been reported to have good internal consistency (α = .96). Using 33 as a cut-off, sensitivity and specificity have been identified at 0.91 and 0.82 respectively (Creamer, Bell, & Failla, 2003).

The first author then conducted semi-structured interviews, lasting approximately one hour. The interview schedule (see supplementary materials) was devised and piloted through discussions with clinical experts and the collaborating charity. The interviews were designed to be sufficiently open so as to facilitate the emergence of novel information. The interviews were recorded using an encrypted digital device and subsequently transcribed verbatim. *Data analysis*

Data was analyzed in accordance with principles of IPA with each transcript initially treated as a discrete individual case (Larkin & Thompson, 2012; Smith et al., 2009). The analysis proceeded on a case-by-case basis before any attempt was made to make interpretations across cases. The first author led the analysis, which commenced with reading and listening to each individual's account on multiple occasions. During this phase, initial observations were noted down before being set aside for review later on. Each interview transcript was then loaded into the data analysis software package, NVivo (QSR International, 2012), which facilitated line-by-line descriptive coding and the storage of links

within the data as these emerged. The use of NVivo also enabled a thorough audit of the process to be conducted by the third author.

Initial codes were grouped into descriptive themes, according to similarity of content or connections between them. Connections between themes were explored by considering similarities, differences, contradictions and potential interactions. Conceptual pictorial maps were used to facilitate this process as the analysis moved from the descriptive to the interpretative. This process is well documented in the literature and usually involves a cyclical or iterative process (Biggerstaff & Thompson, 2008).

Once all transcripts were analyzed, the data was drawn together for collective consideration. The subthemes from each transcript were recorded in a format that allowed them to be moved into new groupings within NVivo, and an iterative process of recategorization was carried out in a similar fashion as to the earlier within case analysis that similarly culminated in the production of an evidenced group table of themes.

Quality control and reflexivity

The third author and an independent researcher with experience of IPA reviewed the coded transcripts and each stage of the analytic process for two participants and also audited the material generated within the analytic process (Spencer & Ritchie, 2012). In order to consider the influence of personal and professional knowledge and viewpoints on the emerging findings, the research group met periodically to discuss and disclose the influences that they brought to the study. In addition, the first author kept a detailed reflexive diary and in order to consider reflexivity this was used to focus discussions between the authors. The aim of facilitating reflexivity was not to simply reduce 'bias' in the process but to be transparent and reflective in acknowledging potential influences upon the data (Biggerstaff & Thompson, 2008).

Results

Detailed characteristics of the sample are available within the supplementary materials. All eight participants were female and ranged in age from 17 – 61 years. The sample varied in the body areas affected by the burn injury and in injury severity (which ranged from 0.5% - 33% total body coverage). The time since burn injury varied between six months and fourteen years. Six of the eight participants scored above the clinical threshold for PTSD as measured by the IES-R (mean score 43.3), and all eight participants scored in a range indicating that they had significant levels of appearance concern as measured on the DAS24 (mean score 54.9).

Three super-ordinate themes were evident in the data: 'The Struggle for Integration'; 'Processes of Adaptation'; and 'Being Re-scarred: Ongoing Trauma and Threat'. These three themes contained a number of subordinate themes that are described in detail below.

The Struggle for Integration

This superordinate theme describes a core struggle contained within all of the participants' accounts. This refers in the large part to difficulties adjusting to the scarring, but also to other psychological changes, and physical limitations, that occurred as a result of the injury.

Resignation

Integrating the injury into the self-concept represented an ongoing challenge. Some participants described it as a temporal process, with the implications of the injury gradually developing, often accompanied by initial disavowal, followed by a process of grieving for what has been lost. However, this was not a linear process and was experienced differently by different participants. Furthermore, the passage of time alone was not sufficient for this process of integration to occur.

Different participants had integrated their injuries to a greater or lesser extent. Some appeared to have integrated them completely, feeling their experiences had brought about positive changes:

'People still ask me now- "how's your hand?" and I say, "look!" "Oh isn't that wonderful!" And I say, "see, if you look after it, it will heal" (Participant 7).

Others described being resigned to the appearance changes, a process of just getting on with it but without real integration or acceptance of the bodily changes:

'...when I look at my scars now it's not like looking at them and thinking 'oh, they're beautiful' because I'd be lying, because I don't think they are, but it's just a case of acceptance and that's all it is really' (Participant 4).

Some participants appeared to have remained in a stage of disavowal even many years after their injury:

'I feel like as if you know, this is not me, it's not me' (Participant 6).

Lack of Continuity in the Self

There was a lack of continuity of self within the narratives of those participants who referred to their old self as a completely different from their current self. The 'pre-burn selves' tended to be idealized whilst the 'post-burn selves' were devalued. For example, Participant 6 describes her pre-burn self as:

'...such a nice person like, people would want to be near me and around me all the time' in contrast to the meaning she had attributed to her post-burn self 'horrible, I feel like a monster.'

For participant six, the desire to resume her former life was constructed as a positive driving force. However, the rigidity by which this goal was held could be seen to hinder integration:

'I want to bring my old self back again, but how can I? ... maybe after my surgeries, when I'm a bit more self-confident, maybe when I look a bit more like my old self again'.

Integrating the changed appearance appeared to be more problematic for participants for whom physical appearance was more central to their overall self-concept, which in this sample appeared to be younger participants, and those who equated attractiveness with femininity:

"... it's about self-image and um being a woman really... I think it's um, feeling whole and feeling pretty and, being, feminine and, and all the other things that go with it I suppose' (Participant 2).

Even where participants felt generally positive about their appearance, contradictions within the accounts often revealed the fragility of this:

"...when I look in the mirror, I, don't feel, like, I don't feel pretty at all," and "...I feel, yeah, I am good looking, I am just as good as everyone else" (Participant 8).

Processes of Integration

While participants' own perceptions of how well their injuries had healed was important, the ongoing scarring had an impact on the social stigma they reported being exposed to, which in turn impacted upon the psychological healing process, as discussed further under the superordinate theme of 'being re-scarred'. Another factor that may affect the ability to integrate is the nature of the incident that caused the injury. Within this sample, one participant sustained her injuries from a deliberate attack, and consequently appraises her scars as the mark of her attacker, making it very difficult to accept them as a part of her:

'...It's like, it's what he's created, he's put on me basically, and I want to get rid of it and make it somehow go away... that's where he exists, he doesn't exist in me anywhere else except from my scars' (Participant 6).

By comparison, participants who felt they were responsible for their injuries appeared more able to accept them:

'You know, you can't complain, just get on with it because you caused this really'

(Participant 5).

Emotional suppression was a common theme throughout the narratives, and appeared to be a consequence of, and contribute to, difficulties with psychological healing and integration. If participants were struggling to accept the injury and its consequences on their

life, including the changed body, then thoughts and emotions associated with it felt intolerable, and were therefore suppressed. The suppression of these thoughts and feelings appeared to prevent the incident from being emotionally processed, thus integrated into a sense of self.

'I feel like I deal with things better when I don't talk about it. Because if I don't talk about it I don't think about it, and if I don't think about it, then it's not happened' (Participant 1).

Emotional suppression took a number of different forms, including trying not to think about the incident, not talking about the incident, and pushing down any associated emotions. Many participants also avoided looking at their own bodies or scars as a way of suppressing the emotions associated with doing so.

"...and I'm supposed to have a big mirror there you know, but we haven't got one because of me, I just avoid looking at myself" (Participant 6).

Avoiding looking at the body appeared to prevent the scars from being accepted and integrated, and also means that when they were seen, the changes come as a shock, making the emotional reaction even stronger and more traumatic. This participant describes accidentally catching sight of herself in a mirror after years of avoiding her own reflection:

"...so I came out of the shower and I just looked up and I thought, "that's me, that's what I look like" and I just broke down.... Just crying, hysterically... I think because,

(pause) I don't even, I can't really say, it was, um, that I wasn't, how I should be in my mind, you know what I mean, how you-perceive yourself to be' (Participant 2).

Adaptation

The superordinate theme of adaptation refers to ways in which participants have changed as a result of their injuries. It encapsulates both internal processes, which occur to reduce the dissonance that the injury causes with previously held beliefs and assumptions, and changed behaviors in response to psychological and physical changes caused by the incident. These are considered under the headings of 'Daily Battles Towards Recovery', which describe how participants gradually confront their difficulties, and 'Retreating', which represent more avoidance based adaptive strategies. The majority of participants engaged in both adaptive styles to a greater or lesser extent, dependent in part on the appraisals they made about their injuries, including the meaning of their changed bodies. This concept reciprocally interacts with integration, with some level of integration being required for adaptations to occur, and adaptations to thinking or behavior making changes more possible to integrate.

Daily Battles Towards Recovery

The majority of participants described developing new behaviors to help them manage some of the physical, psychological and social difficulties they had encountered. These were experienced as a series of ongoing daily battles. This adaptive style involved developing practical strategies for getting around physical limitations, and working towards their own rehabilitation goals. These goals often involved gradually facing situations that evoked anxiety, due to their associations with the injury, or anticipated social stigma:

'... I think I can stay out, I would try it, I would do it, I would, but maybe try in a small place first, and then maybe go bigger and bigger' (Participant 8).

Confronting such difficulties seemed to require the injury to have been integrated and accepted to some extent, and may facilitate further self-acceptance through providing opportunities for positive social and recreational experiences. Several participants described attending peer support groups as a positive adaptive strategy that normalized their experiences and provided a different perspective that allowed them to be more accepting of, and therefore confront their own difficulties:

'...there are people out there in the world that are, that have been through a lot worse. A lot, lot worse, and have not even survived. You know... it's not as bad as it could have been' (Participant 6).

The reappraisals participants made about themselves and the world in order to make sense of their injuries appeared to drive further adaptive processes. Some reported an altered perception of what is important in life following their injury, leading to a greater emphasis on family, and a greater sense of empathy and desire to help others. Additionally, some participants redefined physical appearance as less important than others and less central to the self-concept than it was previously:

'It's just skin at the end of the day' (Participant 8).

These reappraisals about the meaning of the scars may serve to reduce selfconsciousness and fear of negative evaluation, thus facilitating re-engagement with previously valued activities. Some participants reported taking on new activities and roles in line with these reappraisals, such as spending more time with their family, or taking on an advocacy role for other burn patients, thereby building on their newly developing post-burn identities:

'... so, now I'm far more chilled out, in the fact that not everything is about money, quite a lot is about family, and family time, and more things that are important' (Participant 2).

Finally, positive reappraisals about the self and the meaning of the scars may have further enabled participants to put on a strong front in response to negative reactions from others:

'This is me, if you don't like it I'm not really interested. It's just I've hardened myself up now' (Participant 4).

Retreating

There was a general sense of wanting to withdraw from the world following the injury, driven in large part by participants' negative appraisals about their own appearance, and the feelings of shame this evoked for them. For some participants this was a temporary state of recuperation, but for many, it was a more long-term retreat. As is characteristic with PTSD symptomatology, participants avoided a range of specific reminders of the incident, including candles, fireworks, and television programs showing fire or explosions. However, this did not appear to limit their lives as much as avoidance of situations in which others might notice their scars. Retreating behaviors included going out less and stopping previously

valued activities, primarily to avoid situations in which other people might notice the scars, leading to a more limited life:

'I just can't walk outside by myself' (Participant 3).

Being Re-Scarred: Ongoing Trauma and Threat

Participants were psychologically scarred by the social stigma they believed they encountered, and the painful memories and feelings triggered by looking at their scarred body. This superordinate theme describes how feeling continuously re-scarred by these experiences makes it difficult for participants to heal psychologically.

Stigma as a Constant Social Threat

The majority of participants reported re-appraising the world as a less safe place following their injury, and themselves as being more vulnerable than they previously believed:

'... I am really nervous – my whole concept of danger is, um, a bigger issue for me.

So, like, the whole like 'it'll never happen to me' situation, because I've been in a fire, it has brought it home, a lot closer to home, so I know that bad things can happen to me' (Participant 4).

Increased hypervigilance, or being alert for danger, was therefore widely reported, even among participants that felt they had recovered well from their injuries psychologically. Being constantly alert for danger had an impact on the way participants led their lives; they described being more safety conscious, having to risk assess new places, and avoiding situations in which they felt trapped or out of control.

' ... it's almost like a daily process now, you know, like where I park my car, you know, or if I'm going to be driving will I be driving at night, or you know, this sort of thing, or where I'm walking. It sort of has had a domino effect on to that general sort of awareness of safety' (Participant 5).

This perceived sense of being under threat was strongly linked with changes to appearance. Being visibly different impacted on participants' social interactions and how they felt in public places. The perceived response from society to their changed appearance was generally negative, with participants reporting instances of being stared at, teased or asked intrusive questions.

"...when I used to walk around, people did used to make comments like, "oh, look what happened to her face" (Participant 8).

These reported experiences of social stigma and rejection were incredibly painful, and contributed to self-rejection and negative beliefs about themselves and their appearance.

They also led to an ongoing anticipation of negative evaluation from others, leading to intense anxiety and self-consciousness in social situations.

'...when somebody looked at me, I thought- even if they weren't thinking anything horrible, or even when the burns weren't getting that bad, I felt like, ah they're staring at me, they're thinking I'm really ugly and horrible and a monster and disgusting, so even when they probably weren't thinking it, it made me feel panicky' (Participant 2).

The scarring, and others' anticipated reactions to these, led to participants feeling constantly conspicuous and unable to blend in. This was exhausting, and left them feeling exposed and vulnerable. Actual or anticipated hostility from others, combined with increased feelings of vulnerability, contributed to feelings of being unsafe and under threat.

'I'm on my own sticking out if you know what I mean, like because people, all the people would look, and stare and, things like that, I think I feel more vulnerable if I'm on my own. I feel more kind of, able to be picked out, of a crowd' (Participant 4).

The Body as a Reminder of Trauma

The changed body acted as a constant reminder of the traumatic event, and noticing it, or being noticed because of it, brought up painful memories and emotions for participants. Living with a changed appearance therefore meant that memories of the trauma were always present and salient in participants' minds. Several participants described how looking at their scars, or thinking others were looking at them, triggered intrusive recollections of the incident itself.

'... every time I look at myself I do remember the incident, as much as I try not to' (Participant 6).

Memories recounted during the interview often emphasized the sudden and horrific nature of the incident, and sometimes that participants felt it was caused by their own complacency. The scars therefore acted as a constant reminder that traumatic events could occur at any time, representing another means through which a constant sense of threat was maintained.

'I think it (looking at the scars) was like a reminder of how fragile things are... so what you consider to be safe or whatever is... is very fragile and it shouldn't really be taken for granted' (Participant 5).

The scars also acted as a trigger for the painful emotions associated with the injury and its consequences. Primarily, seeing their scars, or other people's reactions to them acted as a reminder of loss and grief, but they also triggered worries about the future, anxiety, anger and self-blame.

'It was just people staring at you, you know, like 'why, why, why are they staring at me?' You know, 'I'm really ugly, no one's ever going to like me, I'll never have a boyfriend' (Participant 4).

"... every time I do look at my scars, I do feel I do feel that sadness" (Participant 8)

These thoughts and feelings felt overwhelming and traumatic to many participants, who were consequently motivated to avoid experiencing them. This appeared to be another process that maintained previously described 'retreating' behaviors; participants avoid situations in which others might notice their scars as a way of avoiding the painful memories and feelings this evokes. Changes to the body therefore appeared to contribute to a sense of ongoing trauma and threat in multiple ways, thereby increasing hypervigilance and the use of retreating strategies and safety behaviors.

Discussion

This study sought to gain an in-depth understanding of how participants experienced PTSD symptomatology and appearance concern following burn injuries, in order to consider

how the two might potentially interact. Experiences of PTSD symptomatology and appearance concern were interlinked within participants' accounts, and three super-ordinate themes were identified, providing a detailed account of the nature of the relationship between these phenomena: 'The Struggle for Integration', 'Adaptation to Injury, and 'Being Rescarred: Ongoing Trauma and Threat'. These themes will now be discussed in consideration to how they relate to the broader research literature on trauma, appearance change, and adapting to injury.

Within the current study, the changes to the body resulting from the burn injury were particularly difficult to integrate for some participants. This fits with Moss and Rosser's (2012) argument that appearance plays a key role in how we experience ourselves, and how others experience us, therefore changes to our appearance can be threatening to our sense of self. Body image is a multi-faceted construct consisting of perceptual and cognitive elements and it has been suggested by a number of authors that cognitive schemas associated with body image might be broken down into evaluative schemas, focused on the ranking of appearance, and investment schemas focused on beliefs about the importance appearance holds to the self (Cash, 2002, 2011; Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2013). Considered within this context one might predict that integration would be particularly problematic for individuals who negatively evaluate the changes in their appearance, and for whom body image investment is also high.

Emotional and thought suppression also appeared to be processes that contributed to difficulties with integrating the injury into self-accounts for participants in this study. Ehlers and Clark (2000) propose that thought suppression serves to maintain PTSD symptomatology and that it is only when the trauma memory is retrieved and elaborated upon and thus integrated into the autobiographical memory, that unintentional retrieval triggered by related stimuli is inhibited. Consequences of traumatic events that are perceived as threatening or

unacceptable to the self-concept may therefore lead to greater use of thought suppression, leading to more trauma-related intrusions, thus maintaining trauma symptomatology.

Re-appraisals of the self and the world following injury are described across several themes in the current study. This fits with Bury's (1982) concept of biographical disruptions, in which previously held beliefs about the self are called into question and re-evaluated following a critical incident. Ehlers and Clark (2000) argue that the re-appraisals of the self and the world made following this disruption have an impact, with those making global negative appraisals about the injury and its consequences more likely to feel a sense of current threat, therefore being at greater risk of persistent PTSD. This may be an external threat, such as belief that the world is dangerous, or a threat to one's sense of self, such as believing oneself to be incapable or unacceptable. The current study found that many threat-based appraisals participants made about their injuries related to their scars, including negative appraisals about their own worth, beliefs that they were unacceptable to others, and beliefs about the implications of the scars for their future, such as their partners leaving them or not being able to find a partner in the future.

Adaptive responses to the injury appeared to be partially dependent on the meaning made of the injury and its sequelae. The processes described under 'daily battles towards recovery' fit with a number of recent qualitative studies reporting positive coping following changed appearance (Egan, Harcourt, & Rumsey, 2011; Thompson & Broom, 2009). For example, Thompson and Broom (2009) also describe their sample of people living with a range of disfiguring conditions as perceiving positive adjustment to be associated with pragmatism and engagement with social challenges.

In the current study, body shame and perceptions of social stigma appeared to contribute to a more 'retreating' adaptive style. This is consistent with Scambler and Hopkins' (1986) concept of 'felt stigma' and Kent and Thompson's (2002) model of body

shame, in which anticipation of rejection leads to concealment and avoidance behaviors. This retreat from the world limits access to information that contradicts negative appraisals about trauma-related stimuli and emotions (Ehlers & Clark, 2000; Foa, Steketee, & Rothbaum, 1989), thus may maintain trauma symptomatology. The current study further suggests that this social threat may contribute to attributions about one's own vulnerability and the world being unsafe, thereby maintaining the hypervigilance and associated safety behaviors characteristic of PTSD symptomatology.

Whilst this study uniquely reports on the lived experience of people who have experienced both PTSD symptoms and appearance concern, it has a number of limitations. All of the participants were female and there is some evidence that women may have higher appearance investment as a result of internalizing sociocultural pressures and indeed some of the participants in this study reported equating attractiveness with femininity and clearly saw the changes in appearance as a wider threat to their identity (Cash, Morrow, Hrabosky, & Perry, 2004). Consequently our findings may well lack transferability to males who have experienced burn injuries. We are also unable to be certain that the sample would have met diagnostic criteria for PTSD. Nevertheless, the participants' scores on the measures of PTSD symptoms and appearance concern indicated that the group was significantly distressed. In addition, in line with the epistemology of the methodological approach used the inclusion criteria were based on self-identification of meeting the inclusion criteria as opposed to external clinical assessment, in so far as we were primarily interested in subjective experience rather than objective clinical assessment. That said we must acknowledge that the characteristics of the sample limits the transferability of the findings to differing populations and therefore further investigation is required using both quantitative and qualitative methods.

The current study identifies several potential mechanisms through which scarring and PTSD symptomatology may interact, which merit further exploration. These include; the impact of perceived social stigma on threat-perception and hypervigilance, the changed body as a cue for trauma-related intrusions and re-experiencing, acceptability of the sequelae of the injury within the self-concept and the extent to which thought suppression is utilized, and the impact of appearance change on cognitive re-appraisals of the self and avoidance behaviors following injury. In order to examine these mechanisms further, studies are required which might for example investigate the extent to which appearance schemas contribute to stigmatization and trauma symptoms.

The findings of this study do indicate that it would be beneficial to consider tailoring interventions that specifically target appearance related distress associated with trauma in people living with scarring resulting from burn injuries. Given that there was some heterogeneity in the sample in terms of the extent and visibility of the injury it suggests that clinicians may need to be mindful of considering the relationship between PTSD and scarring regardless of objective severity, and that the emphasis should be placed on assessing perceived severity/visibility.

References

- Altier, N., Malenfant, A., Forget, R., & Choinière, M. (2002). Long-term adjustment in burn victims: A matched-control study. *Psychological Medicine*, *32*, 677-685.doi: http://dx.doi.org/10.1017/S0033291702005354
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA) as a method of choice for research in health care settings. *Qualitative Research in Psychology*, *5*, 1-11. doi: 10.1080/14780880802314304

- Brewin, C. R., & Holmes, E. A. (2003). Psychological theories of posttraumatic stress disorder. *Clinical Psychology Review, 23,* 339-376. Doi: 10.1016/S02727358(03)00033-3
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, *21*, 87-108. Doi: 10.1080/14768320500230185
- Bryant, R.A. (1996). Predictors of post-traumatic stress disorder following burns injury.

 *Burns, 22, 89-92. Doi: 10.1016/0305-4179(95)00099-2
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4, 167-182. doi: 10.1111/1467-9566.ep11339939
- Carr, T., Moss, T., & Harris, D. (2005). DAS24: A short form of the Derriford

 Appearance Scale DAS59 to measure individual responses to living with problems of appearance. *British Journal of Health Psychology, 10,* 285–298. doi: 10.1348/135910705X27613
- Cash, T. F. (2002). Cognitive behavioral perspectives on body image. In T. F. Cash & T. Pruzinsky (Eds.), Body image: A handbook of theory, research, and clinical practice (pp. 38–46). New York: Guilford Press
- Cash, T., Morrow, J., Hrabosky, J., & Perry, A. (2004). How has body image changed? A cross-sectional investigation of college women and men from 1983 to 2001. *Journal of Consulting and Clinical Psychology*, 72, 1081-1089. doi: 10.1037/0022-006X.72.6.1081
- Cash, T. (2011). Cognitive-behavioural perspectives on body image. In: Cash, T.F., & Smolak, L. (Eds.) *Body Image* (p. 39-47). London: The Guilford Press

- Clarke, A., Thompson, A.R., Jenkinson, E., Rumsey, N., Newell, R (2013). *CBT for*appearance anxiety: Psychosocial interventions for anxiety due to visible difference.

 London: Wiley
- Creamer, M. Bell, R. & Falilla, S. (2002). Psychometric properties of the Impact of Event Scale-Revised. *Behaviour Research and Therapy.* 41, 1489-1496. doi: 10.1016/j.brat.2003.07.010
- Dunpath, T., Chetty, V., & Van Der Reyden, D. (2015). The experience of acute burns of the hand patients perspectives. *Disability and Rehabilitation*, *37(10)*, 892-8. doi: 10.3109/09638288.2014.948129
- Egan, K., Harcourt, D., Rumsey, N., & Appearance Research Collaboration (2011). A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *Journal of Health Psychology*, doi: 10.1177/1359105310390246.
- Ehlers, A., & Clark, D. M. (2000). A cognitive model of posttraumatic stress disorder. *Behaviour Research and Therapy*, 38, 319-345. doi: 10.1016/S0005-7967(99)00123-0
- Fauerbach, J.A., Heinberg, L.J., Lawrence, J.W., Bryant, A.G., Richter, L., & Spence, R.J. (2002). Coping with body image changes following a disfiguring burn injury. *Health Psychology*, 21,115-121.doi: 10.1037/0278-6133.21.2.115
- Foa, E. B., Steketee, G., & Rothbaum, B. O. (1989). Behavioural and cognitive conceptualizations of post-traumatic stress disorder. *Behaviour Therapy*, 20, 155-176. doi: 10.1016/S0005-7894(89)80067-X
- Fukunishi, I. (1999). Relationship of cosmetic disfigurement to the severity of posttraumatic stress disorder in burn injury or digital amputation. *Psychotherapy and Psychosomatics*, 68, 82-86. doi: http://dx.doi.org/10.1159/000012317

- Kent, G., & Thompson, A. R. (2002). The development and maintenance of shame in disfigurement. *Body shame: Conceptualisation, research and treatment*, 103-116. doi: 10.1348/135910702169457
- Kleve, L., & Robinson, E. (1999). A survey of psychological need amongst adult burninjured patients. *Burns*, *25*, 575-579. doi: 10.1016/S0305-4179(99)00070-4
- Kornhaber, R., Wilson, A., Abu-Qamar, M. E. Z., & McLean, L. (2014). Coming to terms with it all: Adult burn survivors 'lived experience' of acknowledgement and acceptance during rehabilitation. *Burns*, 40, 589–597. Retrieved from:

 http://www.sciencedirect.com/science/article/pii/S0305417913002805
- Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In Harper, D., & Thompson, A. R. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. London: Wiley pp101-116
- Lawrence, J.W., Fauerbach, J.A., & Heinberg, L. M. (2004). Visible vs. hidden scars and their relation to body esteem. *Journal of Burn Care & Rehabilitation*, *25*, 25-32. doi: 10.1097/01.BCR.0000105090.99736.48
- Madianos, M. G., Papaghelis, M., Ioannovich, J., & Dafni, R. (2001). Psychiatric disorders in burn patients: a follow-up study. *Psychotherapy and Psychosomatics*, 70, 30-37. doi: http://dx.doi.org/10.1159/000056222
- McGarry, S., Elliott, C., McDonald, A., Valentine, J., Wood, F., & Girdler, S. (2014).

 Paediatric burns: From the voice of the child. *Burns*, 40, 606-615. doi: http://dx.doi.org/10.1016/j.burns.2013.08.031

- Moi, A. L., Vindenes, H. A., & Gjengedal, E. (2008). The experience of life after burn injury:

 A new bodily awareness. *Journal of Advanced Nursing*, 64, 278–86. doi:10.1111/j.1365-2648.2008.04807.x
- Moss, T., & Carr, T. (2004). Understanding adjustment to disfigurement: The role of the self-concept. *Psychology & Health*, *19*, 737-748. Retrieved from: http://www.tandfonline.com/doi/abs/10.1080/08870440410001722967#.U30E-DNOVMs
- Moss, T, Harris, D., & Carr, T. (2004). *Manual for the Derriford Appearance Scale 24* (DAS24). Bradford on Avon: Musketeer Press.
- Moss, T.P., & Rosser, B. (2012). Adult psychosocial adjustment to visible differences:

 Physical and psychological predictors of variation. In: Rumsey, N. & Harcourt, D.

 (Eds.) *The Oxford Handbook of The Psychology of Appearance* (p. 373-397). Oxford:

 Oxford University Press
- Moss TP, Lawson V, White P, & The Appearance Research Collaboration (2015)

 Identification of the underlying factor structure of the Derriford Appearance Scale 24.

 PeerJ, 3:e1070; DOI 10.7717/peerj.1070
- Nvivo (QSR International, 2012) Nvivo 10 (Computer software). Available from: http://www.gsrinternational.com
- Palmu, R., Suominen, K., Vuola, J., & Isometsa, E. (2011). Mental disorders after burn injury: A prospective study. *Burns*, *37*, 601- 609. doi: 10.1016/j.burns.2010.06.007
- Patterson, D.R., Everett, J.J., Bombardier, C.H., Questad, K.A., Kent, A., Lee, V.K., & Marvin, J.A. (1993). Psychological effects of severe burn injuries. *Psychological Bulletin*, 113, 362-378. doi: 10.1037/0033-2909.113.2.362

- Roberts, J., Difede, J., & Yurt, R.W. (2001). Does visible disfigurement correlate with depression or PTSD after burn injury? *Burn Care & Rehabilitation*, *22*, S154. doi: http://dx.doi.org/10.1097/00004630-200103002-00215
- Rossi, L. A., Costa, M. C. S., Dantas, R. S., Ciofi-Silva, C. L., & Lopes, L. M. (2009).

 Cultural meaning of quality of life: Perspectives of Brazilian burn patients. *Disability*and Rehabilitation, 31, 712–9. doi:10.1080/09638280802306257
- Scrambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. Sociology of Health & Illness, 8, 26-43. doi: http://dx.doi.org/10.1111/1467-9566.ep11346455
- Shepherd, L. (2015). A pilot study exploring the relationship between trauma symptoms and appearance concerns following burn injuries. *Burns*, *41*, 345-351. doi: http://dx.doi.org/10.1016/j.burns.2014.07.001
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, *11*, 261-271. doi: 10.1080/08870449608400256
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis:*Theory, Method and Research. London: SAGE
- Spencer, L., & Richie, J. (2012). In pursuit of quality. In D. Harper & A. R. Thompson (Eds.)

 Qualitative research methods in mental health and psychotherapy: A guide for students
 and practitioners. London: Wiley pp227-242
- Thompson, A. R., & Broom, L. (2009). Positively managing intrusive reactions to disfigurement: an interpretative phenomenological analysis of naturalistic coping. *Diversity in Health and Care*, 6, 171-180.

- Thompson, A., & Kent, G. (2001). Adjusting to disfigurement: Processes involved in dealing with being visibly different. *Clinical Psychology Review*, *21*, 663-682. doi: 10.1016/S0272-7358(00)00056-8
- Thompson, A. R., & Russo, K. (2012). Ethical dilemmas for clinical psychologists in conducting qualitative research. *Qualitative Research in Psychology*, *9*, 32-46 DOI: 10.1080/14780887.2012.630636
- Thompson, A. R. (2012). Research directions in appearance research: models for the future.

 In Rumsey, N., & Harcourt, D. (Eds.), *Oxford handbook of appearance*. Oxford:

 Oxford University Press pp 91-109
- Van Loey, N.E.E., Van Son, M.J.M, Van der Heijden. P.G.M., & Ellis, I.M. (2008). PTSD in persons with burns: An explorative study examining relationships with attributed responsibility, negative and positive emotional states. *Burns*, *34*, 1082-1089. doi: 10.1016/j.burns.2008.01.012
- Wallis, H., Renneberg, B., Ripper, S., Germann, G., Wind, G. Jester, A. (2006). Emotional distress and psychosocial resources in patients recovering from severe burn injury.
 Journal of Burn Care & Research, 27, 734-741. doi: 10.1097/01.BCR.0000238094.33426.0D
- Weiss, D.S., & Marmar, C.R. (1996). The Impact of Event Scale- Revised. In: Wilson & T.M. Keane (Eds.) *Assessing Psychological Trauma and PTSD* (399- 411). New York: Guilford.
- World Health Organisation (2008). A WHO plan for burn prevention and care. *World Health Organisation*. Retrieved from:

 http://whqlibdoc.who.int/publications/2008/9789241596299_eng.pdf?ua=

1. What were you like as a person before your burn injury, and what are you like now? Do you feel you've changed at all?

Prompts:

- Have there been any changes in your day-to-day life, daily routine, work?
- Have you noticed any changes in your relationships with others? Ask about: partner/romantic relationships, family, friends, work, services.
- Has it changed how you see yourself/ others?
- 2. Have you experienced any changes in your emotions/ mood since the burn injury?

Prompts:

- What was it like for the first few weeks/ months following your injury- what were your thoughts/ feelings? Have these changed over time?
- Do you ever avoid doing or seeing things that remind you of the accident, or try to block it from your mind?
- Do thoughts or memories about the incident ever pop into your mind when you don't
 want them to/ do you ever remember the incident so clearly it feels as though you are
 going through it again?
- What makes this happen more/ what makes worse? And what do you do next?
- 3. How do you feel about the change to your appearance/ scarring caused by the burn injury?

Prompts:

- How did you feel about it straight after the accident? How do you feel about them now?
- How do you feel when you look at your scars or see them in the mirror?
- How to others respond to your scars?
- Does this affect how you see yourself?
- 4. Does anything make the (list appropriate symptoms/ feelings) better?

Prompts:

- Can you tell me a bit more about this?
- Why do you think that helps?
- What advice would you give to someone who was feeling the same way?
- 5. Is there anything else I should know to understand your experiences better?

Supplementary materials: Semi-structured interview schedule