Looking in the mirror for the first time after facial burns: A retrospective mixed methods study

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Abstract

Appearance-related concerns are common following burns. However, there is minimal research that has specifically investigated patients' reactions when they looked in the mirror for the first time following facial burns. The current study aimed to investigate patients' reactions and factors associated with distress. Burns patients (n=35) who had sustained facial injuries completed a questionnaire which examined their reactions when looking in the mirror for the first time. Data were collected between April and July 2013. Participants had sustained their burn injuries 12 months prior to participating, on average (ranging from one to 24 months). Forty seven percent (n=16) of patients were worried about looking for the first time, 55% (n=19) were concerned about what they would see, and 42% (n=14) held negative mental images about what their faces looked like before they looked. twenty seven percent (n=9) of patients initially avoided looking, 38% (n=13) tried to 'read' others' reactions to them to try to gauge what they looked like, and 73% (n=25) believed that it was important for them to look. Mean ratings suggested that patients found the experience moderately distressing. Patients most often found the experience less distressing compared to their expectations. Distress was related to feeling less prepared, more worried and increased negative mental images prior to looking. In conclusion, patients' reactions to looking in the mirror for the first time vary. Adequately preparing patients and investigating their expectations beforehand is crucial. The findings have a number of important implications for practice.

Keywords: Appearance; Facial; Distress; Reactions; Mirror

1. Introduction

Changes to appearance following burn injuries are most often sudden, unexpected and not under the control of the individual [1-2] and it is well-documented in the literature that appearance-related distress or body image disturbance is common [3-6]. Stigma associated with changes to appearance may be one of the most difficult challenges in adjusting to burn injuries [7]. Within the wider disfigurement literature, it has been concluded that premorbid and continuing psychological and social factors are better predictors of post-burn coping and adjustment rather than the objective characteristics of the burn injury itself. Indeed, factors such as pre-existing psychopathology, social support, coping styles, perceived importance of appearance prior to the injury and perceived severity of the disfigurement have been found to be predictive of distress, amongst others [8-9]. There is conflicting evidence about whether it is more difficult to adjust to visible or concealed scars [10]. However, it is acknowledged that the face has particular psychological significance and is central to social interactions [11]. Certainly, it has been widely reported that disfigurement or visible differences can significantly impact upon social interactions. For example, others may stare, ignore, feel awkward, recoil from or bully those who look different [12]. Likewise, the individual with the visible difference may feel self-conscious and preoccupied with their appearance which can lead to unhelpful or conspicuous behaviours which can make for difficult interactions [6]. Overall, reduced quality of life of individuals with facial burns has been documented [11] suggesting the importance of enhancing our knowledge of the area.

The above literature largely focuses on longer-term adjustment to changes in facial appearance following burn injuries and there is comparatively less research which has specifically aimed to investigate patients' reactions in the acute phase. We have identified five studies [13-17] which incorporated some findings that specifically related to looking in the mirror at facial burns for the first time. However, none of these studies aimed to examine this topic specifically. Rather, findings related to looking in the mirror for the first time were part of a more global exploration of adjustment or experiences following burn injuries. This is surprising given that patients' first

experiences of looking at their altered appearance may have implications for how they adjust when leaving hospital and reintegrating into society.

The earliest study by Morse and Mitcham [13] explored six patients' experiences of pain and disembodiment using phenomenological analysis during which one patient reflected on her initial refusal to look in the mirror:

"I don't know what my body looked like because, like I said, I never saw it – I never wanted to look at it…My mom was really worried about my face…I guess on one side I had a large hole, a deep one on my cheek, so I knew it was bad, but I didn't realize how bad or anything because I would not, I would not look in a mirror" [13, p. 670].

Bergamasco, Rossi, Amancio and deCarvalho [14] explored body image changes post-burn and interviewed 35 patients. 'Facing the mirror' was one critical incident that was identified by patients in relation to body image changes. One patient reported needing to look in the mirror several times because he did not recognise himself. Moi, Vindenes and Gjengedal [15] aimed to explore 14 patients' lived experiences after burns through a phenomenological approach. Findings suggested that some patients postponed looking in the mirror for the first time and that when they looked it was difficult:

"I was not very pretty before (the accident), but I was a normal person and suddenly you see a person in the mirror, without hair and with an ugly face, and you think 'That is not me!' Even though I knew it was me I saw in the mirror, I refused to admit it was me. It was painful, indescribable. Me, like that" [15, p. 281].

Hunter, Medved, Hiebert-Murphy, Brockmeier, Sareen, Thakrar and Logsetty [16] explored 10 women's experiences in the first year following a burn injury found a dominant narrative of

adjustment and coping well. However, counter-narratives suggested an ambivalent relationship with their injury. One woman in particular talked about her experiences of looking at her injuries in the mirror with a nurse whilst in hospital and recalled:

> "Oh my god, it looks like raw meat" [16, p. 7].

Kornhaber, Wilson, Abu-Qamar and McLean [17] explored 21 burn patients' experiences of rehabilitation. One finding was that patients experienced a strong self-awareness and that confronting their altered appearance following the injury was a challenge, especially when looking in the mirror for the first time. Patients recalled:

> "I walked in and yeah it was a bit of a shock. Oh that's what I'm going to look like for the rest of my life. Ah Oh shit" [17, p. 5].

These studies all suggest that looking in the mirror for the first time can be difficult, and that distressing feelings and cognitions can arise. Furthermore, Partridge [18] discusses his personal account of sustaining severe facial burn injuries and looking in the mirror for the first time and writes:

> "Facing up to the mirror for the first time is a vital step in changing faces - and getting used to looking in a mirror day by day is one of the biggest hurdles in the process of recovery. Can you ever accept that the reflection you see if really 'you'? It is an alien and unfamiliar sight..." [18, p. 9]

Partridge's [18] personal account details his perceived change of identity and how the internal image of himself gradually changed over time to adjust to his altered appearance post-burn.

He documented his early reactions which included disbelief, sadness, anger, repulsion and stoicism, in line with findings from other studies [13-17]. Partridge [18] also noted the importance of looking in the mirror once an individual feels ready and with support from burn care staff. Certainly, it has been acknowledged that the inability to recognise the self, or an enforced change to a person's usual appearance, can create considerable disruption to self-concept and psychological models describe stages akin to a grief reaction (e.g. denial, anger, depression, bargaining and acceptance) [6].

In addition, there are two studies [19-20] that can be drawn upon which have investigated burn care staff's experiences of patients looking at their burn injuries (not just facial) for the first time. Birdsall and Weinberg [19] surveyed burn care nurses who reported that burns patients were most frequently accompanied by a nurse when they viewed their injuries for the first time and that patients typically used verbal and nonverbal cues to express to caregivers their readiness to view their injuries. The nurses reported that the initial viewing of injuries was not typically a planned event and that patients often asked their opinion regarding the appearance of their injury. The importance of remaining honest, positive and hopeful to patients was also highlighted by the nurses. Shepherd and Begum [20] aimed to investigate burn care staff's (n = 33) confidence in helping patients look at their burn injuries (not just facial) for the first time and how often they offered patients help with looking at their injuries. Findings suggested that the majority believed it was important for patients to look at their injuries but a significant proportion lacked confidence in preparing patients for what they might see and having the necessary practical skills required. Moreover, practice was reported to vary considerably within the sample. These studies [19-20] highlight some pertinent issues, such as suggesting that some staff working in burn care may lack confidence in helping patients, which may impact on the patient experience of initially viewing their injuries.

Further research that is relevant to the topic is that which suggests that mirrors are lacking in healthcare settings generally and that hospital wards are often artificial environments given the absence of mirrors or minimal mirrors available [21]. With specific reference to burn care, one

study found that the presence of mirrors in UK burns units/centres varied, with some services having minimal available for patient use despite patients generally reporting a favourable attitude towards the presence of mirrors [22]. In the case of facial burns, access to mirrors is essential for patients to look at their injuries. Environmental constraints, such as a lack of mirrors for patient use, may also impact upon these patients' experiences.

The current study aimed to investigate patients' reactions to looking in the mirror for the first time after facial burns and examine factors which may affect their responses. Due to the minimal published research on the topic, it was considered important to investigate patients' reactions to looking in the mirror for the first time. Identification of any implications for the provision of burn care based on the findings was also of importance.

2. Method

2.1. Design

A mixed methods retrospective study design was employed, using both quantitative and qualitative methods of data collection. A questionnaire was developed and used to gather both quantitative and qualitative data. Data were collected between April and July 2013. The study was classed as a clinical audit by the affiliated hospital trust and received ethical approval from the affiliated University.

2.2. Setting, participants and recruitment

The most recent 200 patients who had been treated for facial burns at the Nottingham Burns Service in the UK were approached to participate in the study. These patients were identified using The International Burn Injury Database (iBID). Inclusion criteria were patients over the age of 18 years, who were fluent in the English language and with no known cognitive impairments. Patients who had experienced their burn injuries due to non-suicidal self-injury or suicide attempts were excluded from the sample, consistent with other studies [15,17]. iBID only extracted patients who

met the inclusion criteria. These patients were sent the questionnaire in the post along with an information sheet and a pre-paid stamped addressed envelope. Informed consent was gained and patients were asked to return the questionnaire within three weeks of receipt.

Thirty five patients returned the questionnaire, reflecting an 18% response rate. Of these, 20 (57%) were female and the mean age was 46 years (ranging from 19 to 94 years). The majority were White British (n=31). One patient was Black (i.e. African, Caribbean, or any other Black, African or Caribbean background) or Black British, one was Asian (i.e. Indian, Pakistani, Bangladeshi, Chinese or any other Asian background) or British Asian, one classed their ethnicity as 'Other' (and one did not wish to disclose their ethnicity). Data extracted from iBID suggests that the UK national burn population is typically 63% male and 37% female, and the average age is 42 years. iBID does not hold information about ethnicity. Therefore, the study sample was of similar age to the national mean but a higher proportion of females participated compared to those injured nationally.

The average total body surface area (TBSA) was 4.6% (ranging from 0.5-74%). Seventy three percent (n=24) of patients' injuries were superficial or partial thickness, and 12% (n=3) had full-thickness or deep dermal burns. Depth was not clearly recorded for two patients. The area of the face affected by the burn injury was 1.2% TBSA on average (ranging from 0.5-7%). Twenty nine percent (n=10) of injuries had been caused by flame/fire, 26% (n=9) by explosions, 26% (n=9) by scalds, 11% (n=4) by contact with hot objects and 9% (n=3) by chemicals. Sixty two percent (n=21) had received inpatient treatment for their burns whereas 38% (n=13) had received outpatient treatment only. At the time of participation, the average length of time since the burn was 12 months (ranging from one month to 24 months).

2.3. Data collection

In the absence of any suitable published or standardised measures, a questionnaire was designed by the authors and this can be found in the Appendix. The questionnaire captured demographic and injury-related information as well as multiple-choice questions, anchored and Likert-scaled items exploring various factors before looking in the mirror for the first time and whilst looking. The content was driven by cognitive-behavioural theory. Questions captured emotional (e.g. "I was concerned about what I would look like"), cognitive (e.g. "I had negative or unpleasant images in my mind about what my face might look like") and behavioural (e.g. "I initially avoided or put off looking") elements before looking in the mirror for the first time. It also investigated where patients were when they looked in the mirror for the first time, what mirror they used and who they were with. Patients were also asked how distressing they found the experience, how prepared they felt and how their experience compared to their expectations or mental images. The questionnaire also investigated satisfaction with help received by the burns service in relation to looking in the mirror for the first time. Open-ended questions were also included to capture patients' emotions and thoughts when they looked in the mirror for the first time, mental images and worst fears that patients experienced before they looked in the mirror and ways in which the burns service could have improved this aspect of care.

2.4. Data analysis

Data were inspected for skewness and kurtosis using visual inspection and Z-scores. The data were not normally distributed therefore non-parametric analyses were used in addition to descriptive analyses using the Statistical Programme for the Social Sciences (SPSS). Spearman Rho correlation analyses were performed to analyse relationships between variables and Mann-Whitney U tests and Kruskal-Wallis ANOVAs were used to analyse differences between independent variables. Content analysis was used to analyse the qualitative data which is considered to be appropriate for open-ended responses in surveys and when studies are exploratory [23]. Indeed, as the data were exploratory a bottom-up approach was used, that is the categories came from the data,

rather than employing a pre-existing framework. Categories and sub-categories were identified from the data by one of the authors (HT) and categories were then combined (e.g. when overlap was apparent) and re-coded. Frequency of occurrence was then calculated by two authors (HT and HB). Kappa scores were calculated to determine inter-rater reliability which showed good agreement (K = 0.7 – 0.8).

3. Results

The results have been divided into five sections: Cognitive, affective and behavioural features before looking in the mirror; Distress, preparedness and emotional reactions when looking in the mirror; Factors associated with distress; Comparison of experiences compared to expectations; and Satisfaction with help received.

3.1. Cognitive, affective and behavioural features before looking in the mirror

As Table 1 demonstrates, 47% (n=16) of patients were worried about looking in the mirror for the first time, 55% (n=19) were concerned about what they would see, and 42% (n=14) held negative mental images about what their faces looked like before they looked in the mirror for the first time. Twenty seven percent (n=9) of patients initially avoided looking in the mirror. Thirty eight percent (n=13) of patients tried to 'read' others' reactions to them to try to gauge what they looked like. Seventy three percent (n=25) believed that it was important for them to look at their facial burns.

Table 1 here

Twenty two patients (63% of the sample) responded to an open-ended question about their worst fears about looking in the mirror for the first time. Three categories were identified from the

responses: 'disfigurement,' 'social consequences,' and 'no worst fears/unsure.' Responses were most frequent in the category of 'disfigurement', with patients describing their fear about being disfigured (63%; n=15). Example quotes were, "*Worrying it had done permanent damage,"* "*I was worried my face would be disfigured and I wouldn't look like m*e," "*Being scarred for life,"* and "*I wondered what I would look like after my treatment."* The category 'social consequences' was represented least frequently in the by the responses (8%; n=2); participants described fears about the impact the burn injury would have on their relationships and interactions with others. For example, "*It...would ruin my relationship with my partner and little girl*" and "*What people would say to me*." Almost a third of patients (n=7) were represented in the 'no worst fears/unsure' category. For example, "*(I) did not have one*" and "*I cannot remember.*"

Eight patients (23% of the sample) responded to an open-ended question about what images they had in their mind prior to looking in the mirror for the first time. All responses described 'negative scarring-related images.' For example, "*I imagined all sorts of unpleasant scarring,*" *"Make-up I could use to hide any disfigurement or redness,"* '*My hair and eyelashes had been burnt and the thought of life without hair and eyelashes was unbearable"* and *"I had a vision in my mind about the degree of burning I sustained and a picture of my face."*

3.2. Distress, preparedness and emotional reactions when looking in the mirror

Patients most often reported looking in the mirror for the first time when family or friends were present (n=20; 57%). Thirty one percent (n=11) were alone and the same proportion were with a member of the burn care team. Two patients (6%) could not remember who was with them when they looked for the first time. Patients reported that it was most commonly their own idea to look at their faces for the first time (n=26; 74%). Nine percent of patients (n=3) reported that it was a member of the burn care team's idea for them to look in the mirror.

On a scale of zero to 10, with zero representing 'not at all distressing' and 10 representing

'extremely distressing,' the mean rating for patients was 4.97 for their first experience of looking in the mirror with a range of 0 - 10 suggesting a moderate level of distress. On the same scale, with zero representing 'not at all prepared' and 10 representing 'completely prepared,' patients rated their feelings of preparedness for looking in the mirror to be 7.2 with a range of 0-10. There was a statistically significant relationship between how distressing patients reported the experience to be and how prepared they reported feeling before they looked in the mirror ($r = -0.64$, $p<0.001$, two-tailed). As patients felt more prepared for looking in the mirror, the less distressed they reported feeling when they did so.

Twenty six patients (74% of the sample) answered an open-ended question about what emotions they felt when they looked in the mirror for the first time. Categories and sub-categories generated from the data are displayed in Table 2 demonstrating that patients' emotional reactions varied and patients often had a mixture of emotions.

Table 2 here

The majority (81%; n=21) of patients described negative emotions such as shock or anxiety. However, 31% (n=8) detailed positive emotions and 15% (n=4) patients described feeling neutral.

3.3. Factors associated with distress

Distress was not statistically different with regard to gender ($U=124$, $p>0.05$, two-tailed), age ($r=-0.06$, $p>0.05$, two-tailed), total % TBSA ($r=0.31$, $p>0.05$, two-tailed), % TBSA affecting the face ($r=0.27$, $p>0.05$, two-tailed), whether the injuries had led to an inpatient admission or not ($U=103$, $p>0.05$, two-tailed), or the cause of injury ($\chi^2=4.19$,$df=4$, $p>0.05$, two-tailed). However, increased distress was associated with more worry before looking in the mirror ($r=-0.46$, $p<0.01$, two-tailed) and more negative mental images before looking in the mirror ($r=-0.39$, $p<0.05$, two-

tailed). There was also a trend for increased distress to be associated with increased initial avoidance of looking in the mirror (r=-0.29, p=0.09, two-tailed), although this was not significant. Distress was not associated with patients' concerns about what they looked like before looking in the mirror (r=-0.28, p>0.05, two-tailed), believing that it was important to look in the mirror (r=-0.15, p>0.05, two-tailed), or reading others' reactions to gauge how they looked (r=-0.24, p>0.05, two-tailed).

3.4. Comparison of experiences compared to expectations

Patients gave a mixture of responses when asked how their experiences of looking in the mirror for the first time compared with their expectations before they had looked. It was most common (41%; n=14) for patients to report that their experience was less distressing than what they expected it to be. However, 35% (n=12) reported it to be about the same as their expectations and 24% (n=8) rated it as more distressing than their expectations. Patients were also asked how the reflections when looking in the mirror for the first time compared to the mental images they had in their minds prior to looking. There was a mixed response but it was most common, in half of the sample, for patients to report that the reflections were not as unpleasant as their mental images prior to looking. However, 21% (n=7) reported that the reflections were similar to what they had imagined and 29% (n=10) of patients reported that their reflections were worse than what they had imagined prior to looking.

3.5. Satisfaction with help received

In response to the statement 'I received enough support in looking at my face in the mirror' 50% (n=17) strongly agreed, 21% (n=7) agreed, 24% (n=8) were unsure and 6% (n=2) strongly disagreed. In response to the item 'I would have valued more support at looking at my face in the mirror' 18% (n=6) strongly agreed, 12% (n=4) agreed, 15% (n=5) were unsure, 15% (n=5) disagreed and 41% (n=14) strongly disagreed. Moreover, there was a statistically significant

association between patients believing that they would have liked more support in looking at their face in the mirror and reported distress when they first looked ($r=-0.45$, $p<0.01$, two-tailed).

4. Discussion

The primary objective of the current study was to conduct an investigation of patients' reactions to looking in the mirror for the first time following facial burns. An additional objective of the study was to identify factors associated with increased distress in relation to this. Quantitative and qualitative data were gathered and a number of important findings with some implications for practice emerged.

Findings suggested that 47% of patients were worried about looking in the mirror for the first time, 55% were concerned about what they would look like and 42% held negative mental images about what their faces looked like before they looked in the mirror, 27% of patients initially avoided looking and 38% of patients tried to 'read' others' reactions to them to try to gauge what they looked like. One previous study discussed initial avoidance of looking in one patient who was interviewed [13]. Cognitive behavioural theory [24-25] would also predict that anticipatory negative thoughts and/or images as well as avoidance behaviour would occur in anxiety-provoking situations and the results appear to fit with this theory. This suggests that burns professionals would benefit from exploring the thoughts and images that patients hold before looking in the mirror and talking with them about whether these thoughts and images are realistic or overly negative or positive. Seventy three percent of patients believed that it was important to look at themselves in the mirror. This may reflect the readiness to start the process of adjustment that is hypothesised to occur during the early stages following an injury [14] and is in many ways encouraging.

Another main finding was that average self-report ratings suggested that patients found the experience moderately distressing. This is in line with previous literature that has explored patients' accounts of looking in the mirror for the first time [13-18]. Indeed, all of these studies discussed this experience as a negative one. However, the current results suggested that distress did vary

significantly within the sample, intimating that not every patient finds the experience distressing. This may be due to the current study including a consecutive sample of patients seen within a UK burns service with a facial burn, regardless of severity. Results also highlighted that patients' experiences were most often less distressing than their expectations and mental images prior to looking, although there was variability. This highlights the need for burns professionals to explore patients' thoughts and images about what they look like and sensitively correct these if they are distorted by providing information, describing the injuries using lay language, and drawing pictures.

Increased distress when looking in the mirror for the first time was statistically significantly related to feeling less prepared, more worried and having increased negative mental images prior to looking in the mirror. As aforementioned, this is in line with cognitive behavioural theory [24-25]. These negative thoughts or mental images may be realistic or not. That is, the situation may be objectively negative or thoughts or mental images may be excessively negatively skewed or catastrophic. In the sample, patients' expectations were most often more negative. However, sometimes expectations were equal to or more positive than their experiences. It may be that some patients in the sample had realistic thoughts and images whereas others had negatively skewed thoughts and images, and some had overly positive or hopeful thoughts and images. Overall, the findings emphasise the important role that cognitions and images play in subsequent distress. It also implies that the principles of cognitive behaviour therapy to help prepare patients for what they will see when they look in the mirror and manage expectations accordingly will assist patients. This could include the identification of a patient's thoughts, images and worries, cognitive restructuring, providing coping skills, instilling a sense of self-efficacy and preparedness and reducing prolonged avoidance behaviour. Psychosocial professionals who deal with psychosocial issues (e.g., Clinical Psychologists) within burn care multidisciplinary teams would be well placed to provide this. However, all burns professionals can assist through some of the techniques detailed above.

Feeling prepared was also reported to be related to decreased distress. In Birdsall & Weinberg's study [19], nurses believed that the first time patients looked at their injuries was

typically unplanned. Furthermore, another study [17] described one patient's shock at their first experience of looking in the mirror as if unprepared. The current finding, that preparedness appears to be important, suggests that unplanned viewing would not be recommended and that preparation is key in managing distress. There is likely to be no set timeframe at which patients will be ready to look at their injuries as it will be individual to each patient. However, burns professionals can have conversations with patients to ask them whether they have thought about looking, when they may feel ready to look, and reassure them that when they are ready the professional will be able to assist. Techniques for increasing preparedness have already been discussed but practical issues such as burns professionals setting aside enough time to help patients to look in the mirror, in a quiet and private space, would also be important. It would also be appropriate to ask patients if they would like a relative present or whether they would prefer to be alone with the burns professional. A tentative theoretical framework for helping patients to look at their injuries was presented in a separate study and highlights the importance of adequately preparing patients [20].

Demographic (age, gender) and medical variables (total % TBSA, % TBSA affecting the face, inpatient vs. outpatient status, cause of injury) were not related to distress. This is consistent with research which suggests that psychological and social factors are better predictors of coping than demographics or the objective characteristics of the burn injury [8-9]. This implies that all patients with facial burns should be offered support when looking at their injuries if they are admitted to hospital. Furthermore, it also suggests that patients who do not need inpatient admission would also benefit from support and feelings about their facial injuries being investigated by burn care staff. A significant minority of patients reported that they would have liked more help from burn care staff when looking in the mirror for the first time and the strength of this belief was related to distress. That is, those who believed more strongly that they would have liked more support was associated with increased distress when looking in the mirror for the first time. This finding may be due to patients' (perceived or actual) lack of support creating increased distress. Alternatively, it may be that distress itself it causing these patients to believe that they should have

been offered more support than they received. Overall, it is indicative of the importance of burn care staff offering patients help with looking in the mirror for the first time.

In addition to the quantitative data, the open-ended questions allowed patients to provide their own accounts of looking in the mirror for the first time which was particularly salient in such an exploratory study. Their worst fears included disfigurement and social consequences, such as how it might affect relationships. In relation to mental images, all patients who responded described 'negative scarring-related images.' This may reflect patients' awareness of the perceived importance of the face in social interactions and other people's feeling and stigma when confronted with visible difference [7,11-12]. Finally, 81% of patients described 'negative emotions' (anxiety, shock, sadness), 31% detailed 'positive emotions' (relief, feeling grateful) and 15% described 'feeling neutral' when they looked at themselves for the first time. Emotions were typically mixed within the same patient. This suggested that patients' emotional reactions varied considerably. Overall, this highlights the individual nature of patients' reactions and the need for tailored emotional support following facial burns.

5. Limitations

The response rate was low for the study (18%) although perhaps in line with expectations of postal questionnaire studies [26]. Further research needs to be conducted with a larger sample size given the relatively small sample size in this study. The results may also reflect a self-selecting population of burns patients which may limit its generalisability. Specifically, a higher proportion of females participated compared to those injured nationally. Generalising to male patients may therefore needed to be made with caution and a future study exploring male patients' experiences would be important. Furthermore, the retrospective design relied on patients' remembering their experience accurately, in some cases many months after the event, and this may lend itself to memory bias [27]. Future research needs to be prospective. For example, asking patients to complete a questionnaire or engage in an interview prior to looking in the mirror for the first time

and as soon as possible afterwards. Following up patients at a later time point once they have left hospital, in terms of psychological functioning, well-being, body image and self-esteem as well as exploration of any ongoing difficulties looking in the mirror, would also be important in determining whether patients' first experiences of looking in the mirror impact upon subsequent psychological adjustment. Given that patients with non-suicidal self injuries and injuries caused by suicide attempts were excluded from the sample, the results may not generalise to this population. A future study should specifically explore these patients' experiences of looking in the mirror for the first time. Finally, the questionnaire developed for the purposes of the study has not been psychometrically examined. Despite these limitations, the study is one of the first to investigate burns patients' reactions to looking in the mirror for the first time and has important implications as previously discussed.

6. Conclusions

The current study suggests that patients' reactions to looking in the mirror for the first time following facial burns are highly variable although, on average, a moderate level of distress may be expected. Building resilience in patients is key, especially in those who are highly distressed about what they may look like and where the reality is a significant change to appearance. This can be aided by helping patients to feel prepared for looking as well as managing patients' anticipatory worry and negative thoughts and images may be important for managing distress. Patients' expectations prior to looking should be investigated to assist with preparedness and providing support within burn care teams is important for all patients. Techniques to assist in preparing patients for what they will see could include burns professionals asking patients to describe what their thoughts and images about what they look like and correcting any distorted thoughts or images by sensitively providing information, describing the injuries in lay language and drawing pictures. Ensuring enough time is set aside to help patients, and finding a quiet and private space, will also be important.

7. Conflict of interest

The authors have no conflict of interest to declare.

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Table 1: Patients' reactions before looking in the mirror

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
I felt worried about looking in the mirror for the first time	32% (n=11)	15% (n=5)	18% (n=6)	24% (n=8)	12% (n=4)
I was concerned about what I would look like	29% (n=10)	26% (n=9)	21% (n=7)	12% (n=4)	12% (n=4)
I felt it was important to look at my face in the mirror	41% (n=14)	32% (n=11)	12% (n=4)	6% (n=2)	12% (n=4)
I initially avoided looking at my face in the mirror	12% (n=4)	15% (n=5)	12% (n=4)	18% (n=6)	44% (n=15)
I had negative or unpleasant images in my mind about what my face would look like	18% (n=6)	24% (n=8)	26% (n=9)	15% (n=5)	18% (n=6)
I tried to 'read' other people's reactions to me to gauge what I looked like	26% (n=9)	12% (n=4)	21% (n=7)	3% (n=1)	38% (n=13)

Table 2: Emotions patients experienced when looking in the mirror

Category	Sub-category	Frequency	Example quote(s)
Negative		81% (n=21)	
	Anxiety	35% (n=9)	"Very anxious, scared, worried..." "Really worried about facial scarring" "Apprehensive and cautious" "Very frightening"
	Shock	27% (n=7)	"I was shocked at how bad I actually looked"
	Sadness	19% (n=5)	"I felt down..." "Sad" "I cried and just wanted my mum to be with me"
Positive		31% (n=8)	
	Relief	15% (n=4)	"Relief that it was not as bad as I thought it might be" "I was very lucky...had it been as bad as my hand, arms and legs it would be a different story" "Relief! I was expecting my face to look like my hands and legs"
	Grateful	15% (n=4)	"What a fabulous job the team had done" "Thankful it was no worse"
Neutral		15% (n=4)	"It was ok, (I) just had slight marks on my face" "I was unconcerned"
Total		N=26 (74% of sample)	

Appendix 1

Patient Survey - Burns Service

Thank you for completing this survey. We are specifically interested in learning about your experience of the burns service. Specifically, we would like to know about your experience of looking at your facial burns for the first time. Please answer the following questions as fully and honestly as possible. The survey mostly involves you circling a response option and should only take you 15 minutes to complete.

Part 1: About you

1. How old are you? _____ years

2. What is your gender? Please circle one of the following options.

a) Male b) Female

3. How would you describe your ethnic group? Please circle one of the following options.

a) White b) Mixed background c) Asian/British Asian
d) Black/Black British e) Other including Chinese f) Prefer not to say

Part 2: About your burn injury

1. How long ago did you sustain your burn injury? Please circle one of the following options.

a) 0-3 mths b) 3-6 mths c) 6-9 mths
d) 9-12 mths e) 12-18 mths f) 18 mths +

2. What was the cause of your burn injury? Please circle one of the options.

a) Flame/ fire b) Scald c) Explosion d) Chemical

e) Friction f) Contact with a hot object g) Other: _____

3. Did you require inpatient admission to the Burns Unit after you initially had your burn injury? Please circle one of the following options.

a) Yes, I was an inpatient on the Burns Unit b) No, I was an outpatient

Part 3: Your experience before looking in the mirror for the first time

Please indicate the extent to which you agree or disagree with the following statements by circling one number.

	Strongly agree		Unsure		Strongly disagree
1. Before I looked at my face in the mirror, I was worried about doing this for the first time	1	2	3	4	5
2. Before I saw my face in the mirror, I was concerned about what I would look like	1	2	3	4	5
3. I felt it was important for me to look at my face in the mirror	1	2	3	4	5
4. I initially avoided or put off looking at my face in the mirror	1	2	3	4	5
5. Before I looked in the mirror, I had negative or unpleasant images in my mind about what my face might look like	1	2	3	4	5

6. Before I looked in the mirror, I tried to 'read' other people's reactions to me as a way of gauging what my face looked like	1	2	3	4	5

Part 4: Your experience of looking in the mirror for the first time

1. When you first looked at your facial injuries in the mirror, where were you? Please circle one of the following options.

a) Burns Unit b) Other hospital ward (please specify): _____

c) At home d) Other (please specify): _____

2.. **Who was with you when you first saw your face in the mirror? Please circle one of the following options, or more if applicable.**

a) Doctor b) Nurse c) Psychologist

d) Therapist (e.g. Physio/OT/Dietician) e) Family/friends f) No-one – I was alone

g) Other (please specify): _____

3. Whose idea was it to look in a mirror at your facial injuries for the first time? Please circle one the following options.

a) Your own b) A member of the burns team
c) Family/friend d) It was accidental or unplanned

4. How distressing did you find looking in the mirror at your face for the first time? Please circle one of the numbers on the scale below:

Not at all distressing										**Extremely distressing**
0	1	2	3	4	5	6	7	8	9	10

5. How did your experience of looking in the mirror for the first time compare to how you had expected it to be? Please circle one of the following options.

a) Not as distressing as I expected it to be b) About the same as I expected it to be c) More distressing than I expected it to be

6. How did your experience of looking in the mirror for the first time compare to any negative or unpleasant images you had in your mind before you looked? Please circle one of the following options.

a) The reflection I saw in the mirror was better/not as unpleasant as the image(s) I had in my mind beforehand
b) The reflection I saw in the mirror was about the same as the image(s) I had in my mind beforehand
c) The reflection I saw in the mirror was worse/more unpleasant than the image(s) I had in my mind beforehand
d) Not applicable - I did not have any image(s) in my mind beforehand

7. To what extent did you feel ready and prepared for looking in the mirror at your face for the first time? Please circle one number on the scale below:

Not at all ready										**Completely ready**
0	1	2	3	4	5	6	7	8	9	10

Part 5: Your opinions about how the burns service at Nottingham could improve this aspect of care
Please indicate the extent to which you agree or disagree with the following statements by circling one number.

	Strongly agree		**Unsure**		**Strongly disagree**
1. I feel I received enough help looking at my face in the mirror	1	2	3	4	5
2. I would have valued more support around the area of looking in the mirror	1	2	3	4	5
3. I believe my experience in this aspect of my burn care could have been improved	1	2	3	4	5

Part 6: Further information
Below are some open-ended questions. If you feel able to answer these to provide us with further information about your experiences and opinions please complete these.

1. Please describe the feelings or emotions you had when you looked in the mirror at your face for the first time. _____

_____

_____2.
What was your worst fear about looking in the mirror for the first time? What thoughts or images went through your mind?
_____

_____

_____

3. Please describe what, if any, help you were offered whilst in hospital or by the burn care team to look in the mirror.

_____

_____

_____

_____

4. Could anything have been done differently by the burns service that may have improved your experience of looking in the mirror for the first time?

_____