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**The Impacts of the Visible Differences in Appearance Caused by Burn Injuries, and
Medical Tattooing as an Appearance-based Intervention.**

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Portfolio Abstract

Burns injuries can affect both adults and children. They can cause severe and enduring physical and psychological consequences, for both the individual and their family. Changes to appearance are a fundamental part of a burn injury. Medical tattooing (MT) is an intervention designed to address appearance/body dissatisfaction.

Systematic Review: a systematic search was completed of five electronic databases (CINAHL, Cochrane Library, MEDLINE, EMBASE and PsycINFO), reference lists and 'cited by' referencing sources to identify and evaluate all published qualitative research literature on the psychological experiences of parents of children who have experienced burn injuries. Seven studies met the selection criteria and four themes were identified: 'the trauma of witnessing a family member's burn injury', 'the 'mixed blessing' of hospitalisation', 'attempting to return to 'normal' life -adapting to new roles', and 'guilt and blame: core issues'. The results suggest parents experience three phases of recovery following a child's burn, all impacted on by feelings of guilt and blame.

Journal Article: Interpretative Phenomenological Analysis (IPA) was applied to eight in-depth interviews with burn survivors with medical tattoos. Three themes were extracted: *Management of Hope*, *The Process* and *Impacts of MT: 'Normal-ish is Fantastic'* which were set within a context of *'Conflict about Legitimacy'*. The findings suggest MT may facilitate a regained sense of normality and an improved sense of being acceptable in society. However, a potential paradox was identified between a pressure to conform to certain expectations of appearance and a sense that a desire to meet these expectations is also not viewed as important or acceptable.

By understanding these experiences, healthcare professionals can increase awareness of the lived experienced of individuals with burn injuries and of those around them. It also demonstrates that MT is a potentially valuable intervention. Further research needs are highlighted.

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Systematic Review

**The Lived Experiences of Parents following a Child's Burn Injury: A Systematic
Review and Meta-synthesis**

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Abstract

Background: A proportion of child burn survivors will endure both a traumatic injury and subsequent life-changing events impacting, not only on themselves, but also on their parents. Qualitative research methods have been utilised to gain in-depth understanding of the experiences of such parents.

Objective: The review aims to identify and evaluate all published qualitative research literature on the psychological experiences of parents of children who have experienced burn injuries.

Method: A systematic search of five electronic databases (CINAHL, Cochrane Library, MEDLINE, EMBASE and PsycINFO) was completed utilising predefined search terms. *A priori* inclusion criteria identified studies which used qualitative methodology to evaluate psychological experiences of parents of burn survivors. Reference lists and 'cited by' referencing sources were also searched. The quality of each identified study was evaluated and a meta-study methodology applied.

Results: Seven studies met the review criteria. The quality of each study was evaluated and four themes presented: 'the trauma of witnessing a family member's burn injury', 'the 'mixed blessing' of hospitalisation', 'attempting to return to 'normal' life -adapting to new roles', and 'guilt and blame: core issues'.

Discussion: The identification of only seven studies highlights the paucity of available research. The results suggest parents experience three post-injury phases following a child's burn, all impacted on by feelings of guilt and blame, and the need for support for parents particularly related to trauma and hypervigilance of threat.

Key words: Burns, psychological, adjustment, qualitative, parents, siblings.

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Introduction

The potential for severe and enduring physical and psychological damage following a burn injury is self-evident. In the UK, around 250,000 people a year suffer a burn injury, 13,000 of whom are hospitalised, with 1,000 treated for severe burns [1]. Improvements in care have decreased mortality rates and improved the prognosis for recovery [2]. Consequently, a proportion of burn survivors will need to come to terms with traumatic and life-changing events alongside intensive treatments, rehabilitation, and changes in body image (e.g. scarring), mobility, independence, adverse social interactions, psychological and somatic symptoms and challenges to occupational and social reintegration [1, 3-7].

Family Members

The experience of burn survivors has been well-evidenced; however, less consideration has been given to the experience of parents of children who experience a burn injury. While support is available for the family within paediatric burn units, the emphasis appears to be on the child's adjustment [8]. Yet, ultimately, parents frequently become the long-term providers of care and support [9] and family dynamics have been shown to either improve or impair recovery [10], with a supportive family predicting better adjustment of a child with burns [10-12].

Evidence suggests that the acute phase of treatment is an extremely stressful experience for parents and may be as distressing for them as it is for the individual [13-15]. Between 18.8% [16] to 50% [13] of parents of a child with a burn injury report clinically significant symptoms of post-traumatic stress disorder (PTSD), and 18.8% [16] to 69.9% [17] report anxiety and depression during the acute phase of treatment. Parents continue to experience clinically significant symptoms of PTSD between three months and ten years later [14, 17-19], alongside psychosocial distress including experiencing guilt, anxiety and anger, encountering blame from others [20] and suffering loss of self-confidence [21]. Additionally, as the child integrates back within their social context, there is increased likelihood of adverse social responses from others [22, 23]. Consequently, parents must not only manage their own traumatic experience but also their reactions to the negative experiences of their child, potentially

impacting upon the parents' ability to provide the supportive environment which is linked to improved adjustment [10]. Therefore, understanding the experiences of parents is crucial in providing appropriate support to them and the child and to facilitate adjustment.

A systematic review of the psychological consequences of paediatric burns from the perspectives of the child and family considered 328 articles published between 1993 and 2011 and identified 22 relevant quantitative studies [24]. The findings indicated that parents reported high rates of PTSD, depressive symptoms and guilt feelings, and the long-term family outcomes suggested that psychological problems persist in a substantial subgroup of parents. However, focusing on the measurement of psychosocial constructs may not fully reflect the lived experience of parents of a burn survivor. In contrast, qualitative methodology can directly explore such experiences and, thus, deepen understanding of these processes and further develop clinical knowledge [25].

The present review aims to systematically identify, critically appraise and synthesise the existing qualitative research on personal perceptions and experiences as described by parents of children with a burn injury. Its purpose is to understand the lived experience of parents, generate clinical knowledge, inform and offer recommendations to clinicians on ways to support positive adjustment within families and also identify research needs. A systematic review process was utilised to identify and assess all the current literature in this area in a replicable and standardised manner. In doing so, this review aims to answer the following research questions:

What is the current status of qualitative research in this area?

What does the qualitative research literature say about the experiences of parents of children with burns?

Method

Literature Search

An exhaustive systematic search of five electronic databases was completed in December 2016 using the search terms presented in Table 1. These comprised CINAHL (1984 to present), Cochrane Library, MEDLINE

(1950 to present), Embase (1980 to present) and PsycINFO (1806 to present). Search terms were entered individually, and in combination, and final results were limited to peer-reviewed journals (to ensure a level of quality) that are published in English. Given the assumed paucity of research, the search terms were kept broad to ensure that no articles relating to parents, family members or carers were excluded. Reference lists and 'cited by' referencing were also searched.

Table 1 - Search terms and combination, in title or abstract, used to identify studies

Burn* OR Post-burn, Post burn	AND	“Psychosocial adjustment” OR “Post-traumatic growth”, “Quality of life” (QoL), Post-traumatic stress disorder (PTSD), Distress, Depression, Anxiety, Psychopathology, Adjustment, Psychosocial, Psychological, Recovery, Outcome*	AND	Qualitative OR, IPA, “Grounded Theory”, “Thematic Analysis”, “Narrative”
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Inclusion Criteria

The inclusion criteria for full text review were:

- 15.1 Participants were parents of an individual who had a burn injury. Mixed samples were excluded if the data could not be separated for analyses;
- 15.2 Results considered the personal experiences of parents and not solely their perception of the individual with the burn injury;
- 15.3 Qualitative design;
- 15.4 Published in a peer-reviewed journal in English. Unpublished papers were, therefore, excluded.

Data Extraction and Synthesis

A total of seven studies were identified using the procedure summarised in Figure 1. All titles identified from the searches were pre-screened by the primary author for key words and relevant research field/aims. If titles included key words and were within the relevant field, the abstract was obtained and the inclusion criteria applied. If the abstract did not provide sufficient detail to fully assess the inclusion criteria, the full text of the paper was retrieved and evaluated. The data were extracted using standardised data extraction sheets

to obtain general characteristics and the key findings were summarized. To facilitate synthesis of the results, a meta-study methodology was utilised, including meta-data-analysis (identification of the similarities and differences within findings), metamethod (an appraisal of the rigour and soundness of the original studies, using predefined criteria) and metatheory (identification of major schools of thought inherent in theoretical frameworks and emerging theory) [26].

Finally, the quality of each study was evaluated using adapted criteria for the assessment of qualitative research [27] (Appendix A). The criteria were rated with “2” if the study adequately fulfilled the description, “1” if it partially fulfilled the description and “0” if it did not.

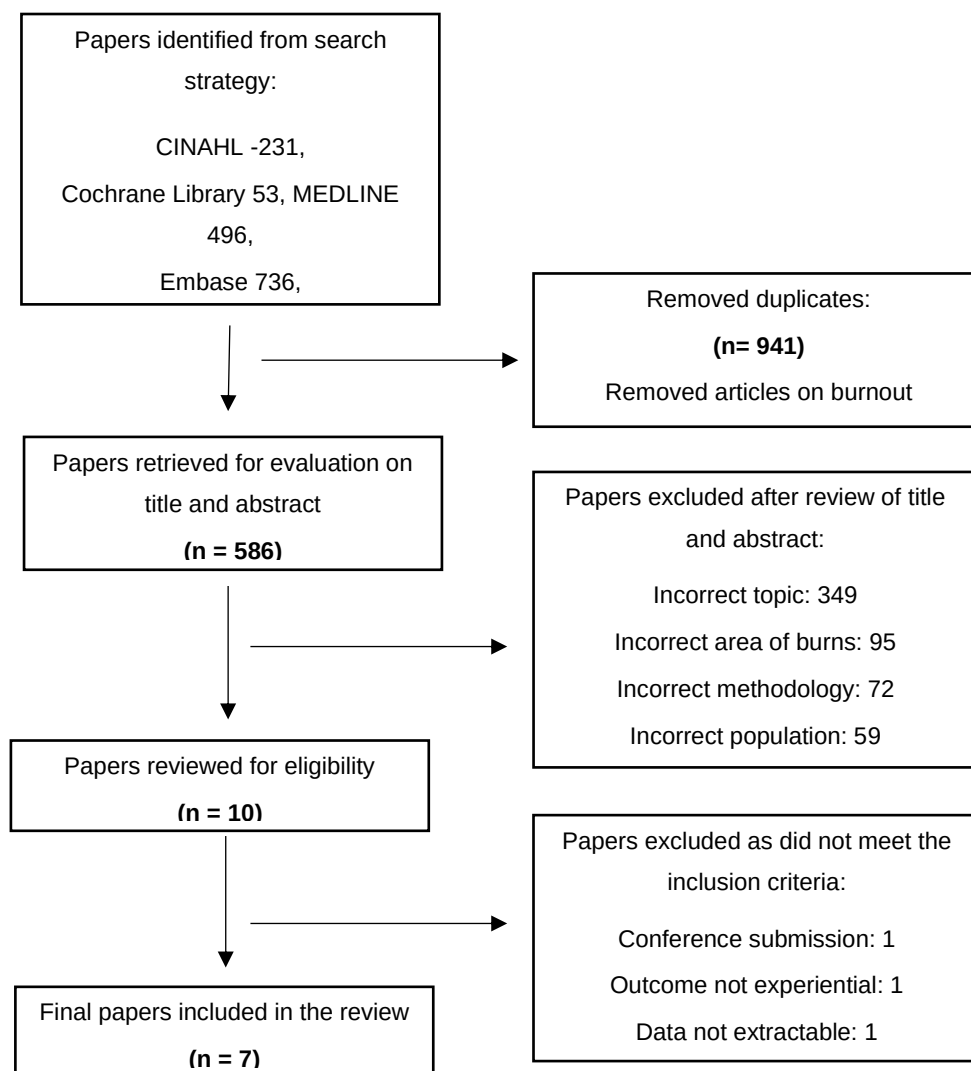


Fig. 1 – Flow diagram: systematic literature review.

Results

Study Characteristics

Table 2 summarises the general characteristics of the 11 studies included in this review.

Table 2: General characteristics of presented studies

Study	Author/s, year and country	Purpose	Recruitment (method)	Sample and study population	Individuals with burn injury	Method of collection	Method of analysis
1	Barnett et al., (2016) (Malawi)	To provide an account of the first recorded support group for burn survivors and caregivers in Sub-Saharan Africa, outside of South Africa.	Burns' unit	48(35f) Age: 19–63 Ethnicity: N/S	18(6F) Age: 12-45 TSBA (%): 3 - 36 (M- N/S)	Group support sessions	Thematic analysis
2	Horridge et al., (2010) (UK)	To develop a theory describing the relationships between psychological and other processes that facilitate and impede a child's reintegration into school from the parents' experience.	Paediatric burns' unit	Parents: 12(8F) Age: N/S Ethnicity: N/S	9 (3F) Age: 8-5 TSBA (%) - 1.5-13 (M=5.4)	Interview	Grounded theory
3	Kilburn & Dheansa, (2014) (UK)	To gain empirical data on the social and economic impacts of child burns on children and parents, in the context of the outpatient setting.	Burns' unit	Parents: 52 (N/S) Age: N/S Ethnicity: N/S	N/S (N/S) Age: M=4 TSBA (%) - 0.3- 9 (median 1%)	Questionnaire	Content analysis
4	Mason (1993) (UK)	To investigate the mother's response in the early stages following the child's thermal injury.	Burns' unit in children's hospital - Convenience sampling	57F Age: N/S Ethnicity: N/S	57 (20F) Age: 5m to 4y 2m TSBA (%) -1- 41 (M=N/S)	Interviews	N/S

Table 2: General characteristics of presented studies cont.

5	McGarry et al. (2014) (Australia)	To investigate and describe the lived experience of both mothers and fathers of children with burn injuries.	One paediatric hospital-purposeful sampling	21 (14F) Age: N/S Ethnicity: N/S	17 (7F) Age 6m to 15y TSBA (%): 0.5-15 (M=4.12)	Interviews	Phenomenology
6	Oster et al. (2014) (Sweden)	To explore parents' experiences after their child's burn injury, focusing on how the burn had influenced family life and child adjustment.	Two burns' centres	Parents 8 (5F, 3 couples) Age: N/S Ethnicity: N/S	6 (3F) Age: N/S TSBA: N/S	Interviews	Content analysis
7	Ravindran et al. (2013) (India)	To explore parents' experience.	Paediatric burns' unit - purposeful sampling	22 (13F) Age: Female: 25 to 33y/Male:28 to 41y Ethnicity: N/S	12 (4F) Age: 2-5y TSBA (%): 20-60 (M=N/S)	Interviews	Grounded theory

Note: F = female; M = mean, m = months; N/S = Not specified, TSBA = total body surface area; y = years

Key Findings of Presented Studies

Table 3 outlines the key findings of the presented studies:

<i>Table 3: Key findings of presented studies</i>	
<i>Study No.</i>	<i>Summary of results</i>
1	Four themes of families' and carers' experiences: 'guilt and self-blame'; 'how this guilt created an 'emotional distance' between them and the patient'; 'fear that being admitted to the hospital meant that their child would likely die'; and 'concerns about their child's future and the stigma associated with burn scars'.
2	Five themes related to parents' experiences of their burn-injured child's return to school: (1)'parental emotional reactions'; (2)'regaining confidence in the self, child and system'; (3)'role adaptation - skill acquisition and lifestyle flexibility and support', (4) 'child's psychological and physical functioning'; and (5) 'school receptivity'.
3	Three categories of socioeconomic experiences of parents of children with burn injuries: 'issues with journeys to the hospital and hospital appointments'; 'impacts on parents'; and 'impacts on siblings'.
4	Four stages of parental adjustment to children experiencing a burn injury: (1) Initial Stage – which included one sub-theme: developing realization of the consequences; (2) Phase 1 - 'Continuing Emotional Trauma - stigmatizing residual factors which contained the sub-themes: 'protection failure', 'scarring of the child', and 'three interacting areas for mother': (i) the mother's perception of herself, (ii) her responses to the child, and (iii) her responses to the reactions of other people; (3) Phase II - 'Attempting to Rationalize'; and (4) Phase 3 - 'Rationalization of the Thermal Injury'.
5	One theme for parents of children with burn injuries: "Feeling quite alone in striving to regain family wellbeing" which had four sub-categories: 'difficulties due to and worries about remaining physical problems'; 'alterations in everyday life'; 'affected family relations'; and 'need for parental and family support'.
6	Three stages of parental adjustment to children experiencing a burn injury: (1) Phase 1: 'Experiencing the Accident' had two sub-themes: 'witnessing the burn' and 'accessing medical help'; (2) Phase 2 – The 'In-patient Phase' had six categories: 'stressors' (realising the severity and witnessing traumatic medical procedures); 'positive coping strategies' (relief to know your child is in the best hands and seeking information); 'the importance of social support'; 'feelings of blame'; 'staying strong for your child'; and 'non-productive coping strategies'; and (3) Phase 3 - 'Return to the Community' had five categories: 'providing care in the home'; 'changes in the child'; 'changes in the parent'; 'dealing with the public stigma to the burn scars'; and 'the long journey of recovery'.
7	Two themes (1) 'Blame: the core issue' including of four subthemes: 'blame from family members'; 'blame from healthcare professionals'; 'blame from others'; and 'blame from the burn-injured child'.; and (2) 'enduring the blame: the core process' including four subthemes: 'internalizing blame'; 'submitting to blame'; 'rising above blame'; and 'avoiding blame'.

Quality of Presented Studies

Table 4 summaries the quality of the presented studies [27]. This was utilised to facilitate the metamethod analysis. Following the evaluation of quality, papers of lower quality are less represented within the synthesis to ensure increased validity of results.

Table 4: Quality of the presented studies

Criteria	Study						
	1	2	3	4	5	6	7
Clarification	1	2	2	2	2	2	2
Justification	0	2	0	1	2	0	2
Epistemological stance	0	2	0	0	0	0	2
Sample description	2	1	1	2	2	1	2
Procedural rigour	1	2	1	1	2	2	2
Representativeness	0	1	1	0	0	1	1
Interpretative rigour	1	2	1	1	2	1	2
Reflexivity and evaluative rigour	0	0	0	0	1	1	2
Transferability	1	2	2	1	2	1	2
Limitation discussion	1	1	1	0	0	2	1
Overall score (max 20)	8	15	9	8	13	11	18

Note: 2- clearly demonstrated, 1- somewhat demonstrated, 0- not demonstrated.

The metatheory analysis stage highlighted limited discussion on theory. Two studies utilised grounded theory and proposed theories relating to specific aspects of parental experience: blame within the Indian culture [28] and children's experience of reintegration into school from parents' perspective [21]. Another study presented a theory on parents' rationalisation of the injury; however, it offered no details on methodology [29]. Overall, the studies suggest a complex, multifaceted experience, depicting at least three phases.

Themes

Following the synthesis of the seven studies using the three stages of meta-study analysis, a three-stage pathway was proposed: 'the trauma of

witnessing a child's burn injury', 'the mixed blessing of hospitalisation', 'attempting to return to 'normal' life whilst adapting to new roles' and with the overarching theme of 'guilt and blame: core issues'. Table 5 highlights those studies that reflect the discussed themes, which also reflects the metadata analysis.

Table 5: Themes and the studies which reflect them

<i>Proposed themes</i>	<i>Number of study</i>						
	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
1. The trauma of experiencing child's accident and the resulting injury		x		x	x	x	
2. The 'mixed blessing' of hospitalisation	x	x	x	x	x	x	x
• Realising the severity	x			x	x		
• Idealising medical care	x	x			x	x	
• Witnessing treatment					x		
• Impact on day-to-day life			x		x	x	x
• Support and involvement					x		x
3. Return to 'normal' life whilst adapting to new roles	x	x	x	x	x	x	x
• Returning home to new roles	x	x	x	x	x	x	x
• Trying to prevent further harm	x	x	x	x	x	x	x
• Coping with the scars	x	x		x	x	x	x
• The importance of support			x				x
4. Guilt and blame: core issues (overarching theme)	x	x	x	x	x	x	x

The Trauma of Witnessing a Child's Burn Injury

Four papers reported a theme related to the reaction to the accident or burn injury. Three studies [21, 22, 29] described the unexpected nature of the accident, which frequently occurred within the context of day-to-day life, leaving parents neither expecting nor prepared for the injury. These studies discussed the parental reactions to the injury. Two of the papers suggested the reactions

were “panicked” or “calm” [21, 29] whereas the third discussed parents reporting being on “auto-pilot” when seeking medical attention for the injury [22]. Regardless of the injury, all studies discussed that parents reported feeling shocked, horrified and traumatised by the accident, with many parents describing it as “something [they would never] forget” [22]. Some parents were significantly distressed by thinking about the burn incident between two and seven years following the injury, with strong emotions surfacing when talking about the injury [30]. This suggests that, not only witnessing the accident, but also witnessing the injury following the accident is traumatic for some parents, even after many years have passed.

Two studies [21, 29] reported that many parents, once aware of the injury, had a primary emotional reaction of “guilt” due to their “failure to protect the child” [29]. Following this, parents went on to describe either a continuation of “guilt” or a range of secondary emotional reactions: panic, calm and thoughtfulness [21], suppression of their emotions for the child [22], blame of others, objects or circumstances [29].

The Mixed Blessing of Hospitalisation

All seven papers discussed parents’ experiences of their child’s hospitalisation following the accident. This theme comprised five sub-themes: realising severity, idealising medical care, witnessing treatment, impact on day-to-day life, and support and involvement.

Realising the Severity

Three of the seven papers identified that it was the hospitalisation of their children that made parents aware of how serious the injury was [22, 29, 31].

It was reported that, for some parents, admissions caused the realisation that “this wasn’t just something that was going to be fixed in the next few hours”[22], and that, when informed their children would require skin grafts, parents were shocked by the severity of the injury and the possible physical consequences of the injury [22, 29]. Furthermore, for some parents, hospitalisation even lead to them to become fearful their child may die:

“When my child was burned and the clinical officer [at the clinic] directed us to KCH, I was fearful that he would die. Only people who are very ill go there.” (Mother [31])

Idealising Medical Care

Four papers discussed parents’ reliance on and praise of the medical care provided [21, 22, 30, 31].

Parents described hospital care as “perfect care” [21]. Parents felt an enormous sense of relief when their child was admitted and that they could hand over the responsibility of care to professionals. Parents reported confidence in the hospital system and relief at their child receiving care : “relief to know your child is in the best hands” [22]. They also reported that paramedics who arrived to deal with the injury also provided relief as “it was more than [they could] deal with on [their] own”, and parents felt “reassured” that their child was receiving medical attention and that the hospital felt “safe” [30]. However, within these discussions, there appeared to be a discourse that indicates longer term negative impacts on parents. For example, parents might experience a sense of helplessness during admission, increasing anxiety and self-doubt and a reduction in confidence in making independent decisions [21]. Additionally, while parents reported the hospital felt safe, this sense of safety was unachievable outside this setting [30], thereby potentially increasing anxiety.

Witnessing Treatment

Only one study discussed the witnessing of medical procedures [22], but the potential impact of this experience appears significant and often traumatic. Parents discussed internal conflict experienced when appreciating that their child needed the treatment and the emotional reaction it triggered, and how this caused them to “[break] down”, or not be able to “stop crying” [22]. Medical dressing changes were a significant source of distress with many parents reporting psychological, somatic symptoms, such as feeling “physically sick” and describing the process as “horrific” and something they would “never forget” and also of the triggering of guilt and memories of the accident itself:

“So every time he had the dressings done, I had to remember the accident, and I kept thinking, what have I done to my baby? (Mother [22]).

The trauma of witnessing their child in pain during dressing changes was frequently relived for up to six months: one mother reported she and others would see the nurses *“popping blisters, cutting skin and pulling it off, over and over again in [their] mind[s]”* (Mother) [22].

Impacts on Day-to-day Life

Four studies reported on the impacts of the injury on everyday life [22, 28, 30, 32].

Parents reported difficulties in managing both the emotional and practical aspects of their child’s period of hospitalisation, particularly if dealing with this alone [22, 28, 30]. Hospital visits were time-consuming, difficult to organise (particularly if there were siblings) and costly, with one parent stating:

“We spent £30 each time on diesel travelling to hospitals, car park fees and toll charges, and my partner has had to take time off work.”[32]

The emotional impact was also significant: parents described not having time for themselves and “neglecting” their partner and other children, particularly when there was limited support available to them. [22]:

“You think the other children aren’t really getting their fair share of attention. It’s okay for a week, but doing it for a longer period, you wonder does it affect them? (Father [22])”

Parents also reported feeling “too stressed out to lean on each other” leading to increased partner conflict and a need to “stay strong for your child” and not let their children see them upset. These emotions appeared to be exacerbated by parents feeling “lonely” and isolated in managing their emotions as only one parent could stay with the injured child, usually the mother. For one father, this separation lead to him turning to substance misuse to manage his emotions [22].

Support and Involvement

Two studies specifically discussed the impacts of support and involvement in care [22, 28]. Parents spoke of the importance of information and “knowing what was happening next” during their time in hospital [22]. Parents reported that they felt “frustration” and “anxiety” when they believed they did not have all required information, particularly not knowing what would be happening next and about their child’s progress. Parents who felt they knew what was happening next stated the situation was “easier to deal with”. However, some parents identified that too much information may have caused “panic” given the nature of the injury. Parents from India portrayed a different experience of healthcare professionals where parents described them apportioning “blame”. Parents felt devastated by the lack of support but felt they needed to accept ‘blame’ to access the necessary support [28]:

“Health professionals did not understand. Mistakes and accidents can happen in anyone’s life irrespective of whom and what they are. Such mistakes should not be used against them [as a weapon of mockery]. Instead of accepting it as an accident and saying comforting words, “Why did you do like this? After having a child you should also know to look after” ...”. (Father F8; [28])

Support also came from family, friends and strangers: parents spoke about social support facilitating coping and that they “could not have done it on their own”. Absence of support was associated with feelings of isolation and loneliness, with some parents describing feeling “scared, because I didn’t have anybody to talk to throughout the day”, and expressing difficulty in managing both the emotional and practical aspects of their child being in hospital alone [22]. Again, in India, the impact of lack of social support, or more specifically blame from others, was distressing for parents:

“I was crying, like a mad woman I was crying, “I did not do anything, I thought there was cold water only in that [bucket]” like that, but everyone was scolding as they liked, “you have done like this. . .

after doing what she did see how she is crying” like that and all they [parents-in-law and sister-in-law] talked”. (Mother F8; [28])

However, if parents were able to form “a team” to face the blame together, they were more able to cope with the experience: “My husband only helped me, in all ways. . . mentally. . . everything. My husband only was my support” [28].

Return to ‘Normal’ Life whilst Adapting to New Roles

This theme included four sub-themes: ‘returning home to new roles’; ‘trying to prevent further harm’; ‘coping with the scars’; and ‘the importance of support’

Returning Home to New Roles

All the studies touched on the long-term adjustments required to adapt to a new way of life [21, 22, 28-32].

Parents had conflicting feelings towards discharge from hospital. Some parents reported a “yearning to go home and return to a sense of normality”, whereas others felt “worried” or “pressure” that responsibility for their child’s care was returned to them so early, and considered that coming home was the “start of the struggle” [22, 30].

Parents reported making “large adjustments to their family lives”, particularly assuming new roles to support their child’s “physical and psychological recovery”. In particular, parents had to apply after-care treatments, which were frequently painful and thus rejected by the child. Parents were aware of the importance of such procedures and felt pressure to administer them correctly but were apprehensive about managing their child’s pain. They also felt shame when they were unable to handle their child’s refusal to wear the required pressure garments. Subsequently, parents became anxious about the impact that the treatment and/or non-compliance might have on the child’s pain, distress and future [21, 29, 30]. Again, these procedures created further feelings of guilt and inadequacy as parents over the injury and for not being able to protect or care for their child:

“I was still feeling really terrible and then if someone asked me what happened, telling them again, it obviously makes you feel worse,

and as much as you know people are trying to be honest, saying, 'It's not your fault', you think to yourself, 'Do they really think that?', especially when my own mother-in-law said it was my fault"
(Mother:[22]).

One study suggested these feelings of inadequacy were influenced by the transition from the idealised medical care with continuous guidance to the responsibility for their child's care being placed back in the parents' hands, potentially creating anxiety, isolation and self-doubt [21]. Additionally, parents spoke of this pressure within the relentless demands of further appointments, managing their emotions, maintaining work and caring for other children [21]. Nevertheless, despite this, the parents in all studies assumed these new roles, underwent personal sacrifices and made adjustments for their children, frequently placing limited focus on their own needs.

Trying to Prevent Further Harm

All papers discussed the long-term psychological impacts on parents following the return home. Parents reported continued feelings of guilt, anxiety, doubts over parenting ability, hyperarousal, hypervigilance, ruminating over the injury and the recovery, difficulties with sleeping, and vivid nightmares (e.g. their child "losing a limb" or changing the injury dressing) which generally lasted up to three months after the accident [22]. These features suggest ongoing trauma:

"I'm an emotional, paranoid, anxious wreck. I cannot concentrate and have become irritable as I blame myself constantly. I am always tearful" [32]

However, the most frequently reported difficulty was parents' need to protect their child from any further physical or psychological harm. Parents reported becoming highly threat-orientated and ruminating on "what if" scenarios. Consequently, most parents overcompensated by becoming over-protective, making adjustments to levels of home safety and avoiding or removing the item that caused the accident. This was sometimes at the expense of the child's freedom, or their own:

"Due to the baby's accident, I am scared to leave him alone for even a few seconds so it makes general tasks harder." [32]

Furthermore, several parents experienced a strong desire to warn others of the dangers of thermal injury [29].

Coping with the Scars

Most studies discussed parental anxiety and worry about the reactions of others to their child's scarring, the need to shelter their children from others' responses and the impact this stigma might have in the future:

"..., I just hope these scars really do fade as she gets bigger. That's the only thing. My worst thought is her being a young woman and having this freak out, or feeling revulsion at her own body and the way she looks" (father; [30]).

One paper considered the scarring in more detail [29]: mothers reported that the scars triggered memories of the accident and feelings of guilt. Consequently, mothers would make efforts to cover scarring and pressure garments and focus on the treatment to reduce/improve scar appearance. The mothers described experiencing mostly negative interactions with others which increased guilt and feelings of isolation; however, some supportive reactions were experienced.

A difference across genders was also highlighted [22]: parents of female children expressed more concerns about scarring whereas parents of boys expressed fewer concerns and sometimes could frame it positively:

I think they feel like they've survived, you know, that sense of victory and in actual fact, he wears his scar like a badge of honour (Mother; [22]).

The Importance of Support

Few studies explored the role of support when families have returned to their homes. However, two studies highlighted the necessity of support [28, 32]. Parents who reported feeling more "supported by their friends, families and communities" felt better able to cope with adapting to their new roles. One significant example related to reintegration with 'normal' life when school staff appeared more receptive and understanding so parents could positively contemplate their child's return to school. However, parents reported feeling less supported by healthcare professionals at this stage, subsequently feeling

isolated and anxious about the care they were providing and the care pathway for their child. They reported wanting psychological support but this was not offered. Moreover, Ravindran et al [28] highlights negative impacts on parents' confidence and self-image when blame emanates from those considered to be sources of support (such as friends, family, professionals) and also the central role of social support from partners in "moving forward" following the injury.

Guilt and Blame: Core Issues

While guilt and blame have been discussed through the themes, they appear to be powerful emotions which are central to parents' experiences and run through each stage of the burn injury including the accident, hospitalisation and returning home; there appears to be an attempt to rationalise the accident which was deemed a 'failure' on their part to protect the child. Three studies specifically considered the role of blame [22, 28, 29]; parents spoke of attributed blame to either themselves or others. Blaming themselves for the accident led to feelings of guilt [22, 29] (which parents reported they could not, or did not, resolve) whereas blaming others resulted in feelings of resentment and anger. Potentially, apportioning blame to others may be a method by which parents avoid guilt, albeit temporarily [29]. Consequently, many parents described ruminating on thoughts of guilt, their feelings of incompetence as a parent and the potential judgements from others. Most studies expressed that the feelings of guilt/blame were most evident in the parents themselves although, on occasions, some did talk about feeling blame from others although it was never directly stated to them. However, within Indian culture, blame was experienced from others and even from the injured child [28]. Parents who experienced this situation would internalise the blame, increasing their feelings of guilt and doubt in their parenting ability. Only when parents were able to "rise above" the blame and guilt, could they begin to "move forward". Blame and guilt are likely to be non-linear cyclical process with parents anticipating and encountering them at all stages of the burn injury trajectory [28] and, therefore, important factors in the psychological adjustment of parents.

Discussion

This qualitative systematic literature review aimed to establish:

- 1) What is the current status of qualitative research in this area?

- 2) What does the qualitative research literature say about the experiences of parents of individuals with burns?

The review produced seven studies that provide some level of understanding of the experiences of parents of children with burns; however, given the paucity of articles, the results must be reviewed in an exploratory nature. The studies were evaluated in terms of their general characteristics, key findings, themes and overall quality. The following interpretations are offered in relation to the qualitative research currently available.

Current Status of Research

The identification of only seven studies highlights the paucity of available, relevant research at the present time. The purpose of the studies varied significantly and there was limited discussion of theory or theoretical stance within them. However, it appears that the studies were strongly influenced by the assumption the child is the focal point of the experience rather than the parent (i.e. details of the child are accurately reported in the sample but the details of the parents are often sparse). This situation was also reflected in the experience depicted by parents, with a general impression that parents tend to focus on the needs of their children, frequently considering their needs as secondary or simply not considering them at all. This might limit the perspectives of existing research, narrowing the information collected from parents. However, it also highlights a potentially important process that might maintain distress that requires further investigation through research. Additionally, only two studies addressed the research from a non-westernised perspective and indicate that there may be important cultural differences between parents' experiences [22, 28] which need consideration.

Quality of the Presented Studies

The systematic review process indicated several problems concerning the quality of the presented studies. All but one study failed to demonstrate one or more of the ten quality criteria evaluated, highlighting a number of limitations. The most common problems encountered were lack of reflexivity and epistemological stance, and the limited justification for the qualitative research design utilised. Researchers should aim to show theoretical rigour in justifying the soundness of fit of the research questions, aims and the choice of

methodology [33]. Additionally, researchers must identify their own views, biases and assumptions in order to make the research credible and trustworthy [34] as, without this, the “accuracy” of the studies’ findings ~~are~~were questionable [27]. Additionally, participation selection and characteristics are limited within all studies due to the population convenience sampling utilised which indicates a self-selection bias. This limitation is exacerbated by the lack of detailed demographic information of the parents, instead with focus on the injured child and minimal discussion of the impact of any such demographic detail on the results (such as sparse detail about fathers compared to mothers). This limits assessment of the adequacy of representativeness and transferability of the data, which would be crucial in understanding parents’ experiences.

What does the qualitative research literature say about the experiences of parents of children burnt during childhood?

The results suggest ~~s~~ three phases of the parents’ experiences; (1) ‘the trauma of witnessing a child’s burn injury’, (2) ‘the mixed blessing of hospitalisation’, and (3) ‘attempting to return to ‘normal’ life whilst adapting to new roles’. These phases are all influenced by feelings of guilt and blame which justify the use of a fourth theme: core issues in guilt and blame. Yet, as all the studies identified were limited by the time frame of the research, it is possible that there is a further phase following the return to home from the hospital with an initial phase of adjustment.

As anticipated, the results suggest that witnessing a family member sustain a burn injury is significantly distressing. This concurs with current evidence that reports high prevalence of PTSD amongst parents of children with serious injuries and illnesses [35]. However, the results suggest that, additionally, parents experience extreme guilt and sense of responsibility over the injury and question their role in causing or preventing it.

The ‘mixed blessing of hospitalisation’ is a phase in which parents identify complex conflicting experiences. Parents have positive feelings, such as relief when accessing medical care for their child, whilst simultaneously becoming aware of the severity of their child’s injury and considering the possibility of death. As treatment continues, there are advantages and

disadvantages of receiving continuous support, with negative impacts particularly pertinent during the third phase: returning home. Parents also highlighted the importance of provision of information throughout the treatment, but that this was not always available. These findings concur with established literature which suggests that parents generally wish to participate in their child's care although their roles in hospital are not clearly defined [36] and also that supporting a child with a serious injury is significantly stressful for parents [35]. The results also highlight the practical difficulties for parents supporting hospitalised children (e.g. around costs and travel) and the necessity to rearrange their lives around the child's requirements at the expense of their own, and others', needs.

'Attempting to return to 'normal' life' is a phase in which parents need to take on new and difficult roles to support their children, particularly when completing complicated and painful after-care routines and adjusting to their child's altered appearance due to scarring. Parents appear to become hyper-vigilant to, and hyper-aroused by, potential threats to the detriment of themselves and their children, for example, by avoiding all causative objects and situations such as hot water (e.g. hot drinks) for months after the injury regardless of risk. It is possible that these items may trigger memories of the accident and the feelings of guilt and, as such, elicit highly anxious states for parents. It may also be a symptom of their ongoing trauma during this phase. Again, this supports the quantitative literature which suggest parents continue to experience trauma for long periods following a child's burn injury [14, 16-18]. Additionally, while not using the term 'depression' within these studies, they talked about ruminating on negative thoughts and experiencing complex anxieties, for their child, themselves and others as suggested by previous research [19, 22]. Consequently, parents must manage both responses during each stage (e.g. response to the accident) while managing their own, potentially complex, emotional reactions to the injury in the context of influencing day-to-day practicalities, such as travel costs, maintaining current employment and caring for other family members.

The results suggest experiencing guilt and blame are core issues for parents, which significantly impact upon their mental well-being and interactions

with their children. These emotions affect the quality of interactions with their child and the care they provide. For example, while only discussed briefly within the studies, it seems likely that parents' emotional reaction of guilt impacts on how they respond to the accident (across 'calm' versus 'panicked' descriptions of responses) which, in turn, may potentially compound feelings of guilt. It is possible that some parents use acting on "auto-pilot" and suppression of emotions as methods to manage this dual burden or utilise blame of others to minimise their own feelings of guilt. However, the reviewed data was limited in depth and, therefore, the conclusions that can be drawn from this review are also restricted. Nevertheless, given the power of these emotions, and the likely shame associated with them, it may be beneficial to explore these specific processes in depth utilising further qualitative research.

It is likely, therefore, that the stressors described by parents will impact upon their ability to provide an optimally supportive environment [10-12, 17]. The results suggest parents might not only struggle to provide their children with the support they would desire but also cause damage to their own wellbeing, by prioritising their child above themselves to achieve this goal. Some of the difficulties are partially alleviated by social support from family and friends, with increased levels of support creating flexibility and increasing parental confidence in their ability to cope. This is supported by previous investigations that suggest social support may moderate the levels of stress experienced by parents of ill children [37, 38]. However, many parents did not discuss social support which may indicate it was not important to them. It has been shown there appears to be no link between social support and distress in mothers of children with long-term illnesses [39, 40].

Clinical Implications

The current review suggests that parents may need different support at different phases of the child's injury. While little can be offered during the initial phase, parents highlighted the need for support during the hospitalisation and home-care phases. Most significantly, parents reported both trauma symptoms and high levels of anxiety which they identified were unhelpful for them and their children. Additionally, although not discussed in many of the studies, there was evidence that parents did not always feel supported, or fully informed,

particularly in relation to treatment expectations and provision of care at home. Specifically, parents had not always felt that psychological support was available to them. While it is not clear what psychological input was offered to participants, many hospital policies ensure such support is offered to parents. Therefore, it is possible that there are factors which prevent parents from engaging with the support when offered, for instance, when parents feel like they are acting on “auto-pilot”. It would also be useful for healthcare professionals to consider the timing of psychological and social support in both the hospital and home-phases, the nature of information parents might benefit from and how information is provided (e.g. online guidance which can be easily reviewed). Consideration might also be given to support within specified areas such as improving communications, assessment of feelings of overprotectiveness and anxiety, coming to terms with scarring and integration back into a ‘normal’ life.

Limitations

The current review does not claim to be exhaustive; for example, the sampling strategy will not have identified articles published within relevant books. However, the sampling procedure was designed to increase sensitivity and utilise increased levels of hand-searching to ensure all relevant articles were included. As such, it represents a thorough assessment of the current research articles available but further information may be available via other sources. While this was an exploratory review, the process of synthesising the themes could have benefited from a more strategic method of reflexivity. However, the researcher’s views were acknowledged and discussed within supervision prior to analysis and considered throughout the process.

The themes presented within this paper may be transferable to other caregivers. However, due to the constraints of this review, other family members (e.g. partner, grandparents, siblings or children of a burned individual) are not represented but may be involved in support and care for individuals following a burn injury. It is possible that similar or confirmatory experiences may be conveyed.

Recommendations

Greater high-quality qualitative research is required to examine parents' experiences with children who suffer a burn injury, particularly focusing on improved methodology (such as a clearer justification for method of analysis), theoretical consideration and increased consideration of reflexivity and evaluative rigour. This would thereby improve the evidence base on which both clinical practice and theoretical understanding is grounded and deepen the appreciation of the processes involved for parents of a child with burns. Specific areas for investigation would be in relation to cultural impacts on parents' experiences, the role of guilt and blame on adjustment and the impact of scarring and change in appearance. Also relevant would be consideration of the long-term experience of parents (for instance, post-12 months), the potential emotional conflict between parents' desires and expectations to support and focus on their child's needs, and the need to focus on their own psychological wellbeing.

Given the potentially traumatic experience of parents, understanding whether other family members have similar or differing experiences will also help develop the support and services offered to those around the burned individuals. This may be particularly pertinent for those who experience a burn during adulthood and siblings who are often highly impacted by a burn injury within the family.

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Appendices

Appendix A: Criteria for Assessing Qualitative Research (Kitto, Chesters & Grbich [27])

Clarification

- What are the aims of the research?
- What is the research question?

Justification

- Why is a qualitative approach the best option to answer this question?
- Why was the particular qualitative research design chosen?

Procedural Rigour

- Have the techniques of data collection been clearly documented?
- Are the forms of data analysis completely transparent?

Representativeness

- What sampling techniques have been used to answer the research question?
- Do the sampling techniques support conceptual generalisability?

Interpretation

- Has a more conceptual discussion of the results and linkage to existing theory or new theory been developed to explain the relevance of findings to a targeted audience or discipline?
- Have any negative cases been included and discussed?

Reflexivity and Evaluative Rigour

- Has a clear statement of the effect on the data of the researcher's views and the methods chosen been included?
- Has an explicit evaluation of the relationship between the researcher and those under research, addressing any ethical issues, been discussed?
- Has ethical approval been obtained from an appropriate institution?

Transferability

- Has a critical evaluation of the application of findings to other similar contexts been made?
- Has the relevance of these findings to current knowledge, policy, and practice or to current research been discussed?

Journal Paper

Article for Submission to the Journal “Burns”

**The Experiences of Medical Tattooing for Adult Patients following Burn Injuries:
An Interpretative Phenomenological Analysis**

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Abstract

Burns injuries can cause severe and enduring physical and psychological consequences. Body image dissatisfaction has been shown to be a moderating factor in psychological outcomes following such injury. Medical tattooing (MT) is an intervention designed to address appearance/body dissatisfaction by restoring appearance.

Eight in-depth interviews were conducted with burn survivors who have undergone MT. Using Interpretative Phenomenological Analysis (IPA) for the investigation of the verbatim transcripts of interviews, three themes were extracted: *Management of Hope*, *The Process* and *Impacts of MT: 'Normal-ish is Fantastic'* which were set within a context of '*Conflict about Legitimacy*'.

The findings suggest MT may allow burn survivors to regain a sense of normality and an improved sense of being acceptable in society. The findings additionally highlight a potential paradox of a pressure to conform to certain expectations of appearance, alongside a sense that a desire to meet these expectations is also not viewed as important or acceptable. By understanding these experiences, healthcare professionals can increase awareness of MT as a potentially valuable intervention and provide those considering it with maximal and tailored support and information. Further research is required to extend and validate the findings, to consider other populations (such as men and those who declined MT), and to explore the role of societal perceptions on the need for improved appearance.

Key Words: Burns, medical tattooing, body image, disfigurement.

Introduction

Burn injuries can be sudden and devastating events, causing severe and enduring physical and psychological damage to the individual [1]. In the UK, approximately 250,000 people per year suffer a burn injury, 13,000 of whom are hospitalised, with 1,000 being treated for severe burns [2]. Improved approaches to burn care have decreased mortality rates and improved the prognosis for recovery [3]. However, this comes with the physical, psychological, and social challenges that recovery and rehabilitation entail [4–6]. Many adult burn survivors adjust well to their injuries, do not seek mental health services after discharge and report satisfying quality of life on long-term outcome measures [7,8]. However, approximately 30% of adult burn survivors demonstrate moderate-to-severe psychological and/or social difficulties [8] (See Extended paper-1.0.1.).

In severe burns, regardless of subsequent skin grafting, the structures ordinarily relied upon for healing (termed adnexal structures which include glands and hair follicles) are partially or wholly destroyed. Therefore, undamaged healthy skin cells must be used for repair, which frequently results in abnormal scarring. Where skin grafts are used, visible variation in appearance can also occur between the colour, shade and texture of different skin grafts and between the skin graft and healthy skin. Reactions to these variations are the interaction between social norms and individuals' attitudes and values (e.g. personal expectations and value of appearance) [9]. If an individual negatively evaluates the scarring, they can experience behavioural, emotional and cognitive impacts, including psychological distress and dissatisfaction [9–11] (Extended paper-1.0.2.). The degree of this psychological distress is not necessarily correlated with the physical severity of the changed appearance [11]. 'Visible differences' have been shown to hinder an individual's capacity to lead a 'normal' life [12,13]. Specifically, burn scars have been associated with poorer social adjustment and increased psychological distress, and can be triggers for intrusive recollections [14,15] (Extended paper-1.0.4.).

Increasingly, physical appearance is becoming understood to be central in defining personal identity within many social groups. Failure to maintain or improve one's appearance can be viewed as a manifestation of 'moral laxity' - refusal to adhere to societal standard [16] (Extended paper-1.0.4/5.). Therefore, those who have experienced a burn injury must also adjust to impacts on their identity and how they might be perceived by others, including the relationship between body and identity, perceived disconnection with body, appearance and functioning, and conflicts between acceptance and resentment of appearance [17–21].

Body image dissatisfaction is considered a moderating factor in psychological outcomes following a burn injury and a predictor of psychological functioning twelve months post-burn injury [22,23]. A review of the personal experiences of adult burn survivors [24] revealed difficulties with acceptance of, and adaption to, new body image, the perceived negative reactions of others, and the need to renegotiate social situations with a 'new' appearance [24]. It is proposed that the experience of negative self-appraisals of appearance is one of the most challenging aspects of adjustment [11], with shame about appearance intensifying over time [25]. Furthermore, scarring may act as a reminder of the trauma experienced [24] with links between post-traumatic reactions, negative appraisal of appearance, social withdrawal and reduced engagement in valued activities [26]. However, some individuals report a positive experience of an altered appearance [27].

Appearance also influences the way individuals are perceived by others [28]. When explored, individuals with visible differences express the inherently social nature of appearance and appearance-based judgements [32]. Scarring can lead to unwanted and stigmatizing attention (Extended paper-1.0.8.), can elicit social rejection and avoidant responses within both intimate and non-intimate relationships, negatively affect dyadic relationships, and reduce affection and responsiveness from others [29–31]. Thus, individuals experience anxiety about being in public places and concerns about how others, including strangers, may react [24], alongside feelings of awkwardness, embarrassment and isolation [2,33].

Interest has grown in treatment options aimed at reducing the impacts of scarring and improving or ‘normalising’ appearance. It is argued that such treatments could facilitate self-acceptance and re-engagement with valued activities [37]. One such treatment is medical tattooing (MT), a procedure which can enhance the appearance of eyebrows, lips, eyelashes [37], and other physical features via the implantation of pigments into the skin or mucous membranes to create a discolouration referred to as a tattoo (Extended paper-1.0.8.). Within the UK, MT is offered within private practice and in a limited number of burns and plastic surgery NHS services. However, limited research has been undertaken on individuals’ experiences and ‘meaning-making’ of being offered and undergoing MT and its subsequent impacts.

Within other clinical populations, such as those undergoing breast reconstruction, it seems that patients report having this procedure due to a desire to be ‘normal’ or ‘fit in’ [34–36]. Yet, the meaning of ‘normal’ remains complex and unclear (Extended paper-1.0.9). Similarities may exist between populations as burn survivors also identify the need to actively engage in efforts to create ‘coherence’ following this life disruption by accepting what could not be changed and regain ‘freedom’ from the injury by addressing what could [20].

To date, one study (n=25) which aimed to evaluate the Katie Piper Foundations’ (KPF) MT service (in terms of accessibility, referral process, and potential improvements) highlighted some psychological and psychosocial impacts of MT for individuals with burn injuries [38] (Extended paper-1.0.8). The study found a high degree of overall satisfaction with the service which mirrors levels of satisfaction demonstrated for those who have undergone nipple-areolar reconstruction [39], and lip pigmentation for vitiligo [40], and some dissatisfaction with pain and long-term results. Further qualitative interviews (n=5) indicated improvements in confidence and mood, and ability to socialise and carry out essential and enjoyable activities. However, these experiences were not explored in depth as the study was not primarily focused on examining the complexities of individuals’ experiences and perceptions of the MT as part of their recovery.

Rationale

Following a burn injury, individuals face ongoing psychological adjustment in which they attempt to come to terms with, not only with the incident and physical recovery, but changes to appearance, body image and their social interactions [14]. Adapting to and being accepting of one's altered appearance appears crucial to recovery [11]. MT is suggested to improve wellbeing by restoring appearance and reducing body dissatisfaction. Yet, the detailed nature of adjustment in this context is not well understood.

Given the complexities, and paucity of research, a qualitative methodology was employed to supplement the existing literature. This should offer critical insights into the psychosocial effects of MT including how individuals understand and make sense of these experiences. (Extended paper-2.0.5.), thus providing valuable, detailed perspectives and interpretations of subjective personal lived experiences and of the impacts of MT. Additionally, there is evidence that those who have burn injuries benefit from the opportunity to 'tell their stories' and express their views [42–44]. This suggests that a qualitative approach may both be beneficial and improve engagement.

It was anticipated that findings would help deepen scientific and clinical knowledge, particularly in understanding how burn survivors experience MT, and to appraise the effects of treatments that focus on 'improving' appearance. The descriptive and explorative information gained may inform services on issues such as how MT is best explained and offered to patients and guide clinicians about optimal support during rehabilitation to promote maximal psychosocial adjustment. It would also guide further research into this form of intervention and whether it is, indeed, warranted.

Aims

This study aimed to explore burn survivors' psychosocial experiences of MT to answer the following questions: (1) What expectations did patients have of their MT and did these relate to the experience of undergoing MT?; (2) What psychological processes do patients go through in relation to their MT?

Method

Design

Interpretative phenomenological analysis (IPA) is particularly suited to analyzing incidents of psychological distress, managing the inherent sensitivity of burn injuries and the subsequent recovery whilst simultaneously revealing the complexity of the experience [45] (Extended paper-2.0.1-3.). The research aimed to develop deeper levels of explanation, understand individual and/or social processes and identify structures at the core of events [46]. Therefore, in-line with an IPA approach, a critical realist framework was adopted (Extended paper-2.0.4.).

A purposive sample of adults who had received a MT was accessed via The Katie Piper Foundation (KPF), a charity which provides medical tattoos to burn survivors (Extended paper-2.0.6.) and by subsequent snowball sampling. To obtain a homogenous sample, exclusion criteria were applied, based on self-report during recruitment: if the injury resulted from self-harm (Extended paper-2.1.2.); if cognitive impairment was present that may impact upon engagement in interviews (Extended paper-2.1.3.); and non-fluency in spoken English (Extended paper-2.1.4.). Although the sample homogeneity was ensured to some degree (i.e. individuals who had received a medical tattoo as a treatment for a burn injury), some factors could not be controlled (such as the type of injury and type and location of MT) due to the inherent variability of this population. Additionally, the recruitment process did not exclude men but only women expressed interest in recruitment.

Ethical Approval

Ethical approval was granted by the University of Nottingham's Ethics Committee (Appendix B) after consideration of relevant issues including sensitivity of the subject matter, confidentiality, informed consent and time limits on withdrawing data (Extended paper-2.1.5.).

Recruitment

Between August 2018 and May 2019, KPF staff telephoned 13 individuals who had previously agreed to be contacted and provided them with a research invitation (Appendix C) and Participant Information Sheet (PIS) (Appendix D) via email. Eleven individuals responded. The first eight

participants who responded were contacted by telephone. Any questions relating to the study were answered and a convenient interview time arranged. A pilot interview was completed and included within the analysis due to adequate data quality (Extended paper-2.1.7.). No individuals dropped out of the research. In keeping with IPA's focus on depth of questioning, only eight participants were selected. Consequently, three individuals were contacted and thanked for their interest but not interviewed.

Data Collection

Each participant completed one telephone interview which was audio-recorded (Extended essay-2.2.1.). Recordings ranged from 49 to 104 minutes in duration (mean=77 minutes). Prior to commencing the interview, the PIS was summarized, including stating the purpose of the study as a means by which to gain understanding of their own experience of MT, and oral consent was gained (Appendix E). All aspects of the interviews were completed verbally.

Demographic information was gained including date of birth, ethnicity, gender, marital status, religion, employment, details of the burn injury, length of hospitalisation, total body surface area of the burn and receipt of psychological support (Appendix F) (Extended paper-2.2.5.).

The Derriford Appearance Scales (DAS 24) is a psychological measure of appearance concern. It is validated for use in clinical and research settings, with excellent validity and reliability ($\alpha=0.92$, $r=0.82$) [48] (Appendix G) (Extended paper-2.2.6.). The DAS 24 does not have a clinical cut-off [48]. This data was collected to characterise participants (Table 2), contextualize the results and consider individuals' responses in the context of the scores collected. Interpretations of the data and emergent themes were developed and potential correlations with the DAS24 scores across the sample were considered. This was to provide context for clinicians when considering the application of the results in clinical settings.

A Semi-structured Interview (Appendix H) was completed: The questions included were to ensure an exploratory approach and were developed based on the aims of the study. Questions included "Why did you want the medical tattoo?" and "What were your expectations of medical tattooing?". Following an

inductive data collection approach [49], the interview was guided by the participant's experience and clarifying questions were utilised to prevent the researcher from making assumptions about meaning such as "Could you give me an example?" (Extended paper-2.2.7.).

Following the interview, each participant was debriefed about the purpose of the study, signposted to appropriate support (Extended paper-2.2.8.) (Appendix I) and thanked for their participation.

Data Analysis (Extended paper-2.18)

Interview recordings were transcribed verbatim by an established and reputable transcription service (Extended paper-2.3.) with the exclusion of personal data to protect participants' identities. The researcher evaluated each interview for relevance, depth and detail provided.

The IPA was guided by six stages detailed by Smith et al., [45]: (1) transcripts were read and re-read to ensure familiarity with the data; (2) transcripts were annotated with exploratory notes to generate ideas and questions about the way the account was constructed and potential meanings for the participant; (3) interpretation and thematic grouping of the exploratory comments were made to create emerging themes; (4) themes were organised by comparing and contrasting them to create a coherent structure; (5) Stages 1 to 4 were repeated for each case; and (6) themes were explored across cases (Extended paper-2.3.1.) (Appendix J).

Quality Issues

IPA aims to create a rich insight into the 'lived experience' of participants in their own words/terms, whilst acknowledging and embracing the role of researcher in interpreting and making sense of each participant's world [45]. Consequently, attention is directed to issues of rigor, context and transparency [50]. The main author acknowledges she has approached this research from her perspective as a trainee clinical psychologist. However, she appreciates she does not have a burn injury or personal experience of medical tattooing (Extended paper-2.4.1.).

A critical and reflective approach to analysis was taken [51]. The author engaged in a process of bracketing (Extended paper-2.4.2.) and acknowledged

the inevitable influence of expectation and experience throughout the analysis via a reflective diary (Appendix K). This allowed potential biases to be considered. Additionally, the main author re-examined the data and coding to check interpretations that arose and ensure themes remained related to the primary source (Extended paper-2.4.3.). Themes were chosen considering prevalence, the richness of the data and their relation to, and impact upon, other themes [45].

Results

Participants

Eight adult female burn survivors who had undergone MT were recruited (mean age: 47 years; range: 30–69 years). Participants had mixed backgrounds in terms of ethnicity, religion, marital status, employment and psychological support regarding their injury (Table 6). ~~For six of the eight participants the KPF funded the medical tattooing procedure. This may have influenced the experience and data provided by these participants. However, all participants were aware that their participation was confidential and all data would be anonymised.~~ For six of the eight participants the KPF funded the medical tattooing procedure. This may have influenced the experience and data provided by these participants. However, all participants were aware that their participation was confidential and all data would be anonymised.

Table 6: Participants' Demographic Information

		n			n
Ethnicity	White British	6	Religion	No Religion	6
	African	1		C of E	1
	Asian Indian	1		Christian	1
Employment Status	Full-time	4	Psychological Support	Yes	2
	Part-time	1		No	6
	Unemployed	2			
	Retired	1			
Marital Status	Single	5			
	Married	1			
	Cohabiting	1			
	Widowed	1			

Details of burn injuries are presented in Table 7.

Table 7: Pertinent Details of Participants' Burn Injuries

	<i>Range</i>
Age at the Time of the Injury	1.5–57 years
Length of Time before MT	2–56 years
Total Body Surface Area Affected	2 –85%, Unknown (n=3)
Location of the MT Tattoo	Face (n=7) Body (n=2) Nipple (n=1)
Length of Hospital Stay	3 months–2 years, Unknown (n=1)
Derriford Appearance Scale Score (24)	M=42.13, Study Range 27–64*

*Potential range 11-96 – the mean score from the general population is 34.96 (SD14.12), and the mean of the clinical population was 52.2 (SD18.3)

An idiographic approach was taken with consideration of the DAS24 scores to assess any apparent relationship between the scores and the views expressed. While the DAS24 questions highlighted that all participants reported some appearance concerns, the scores did not appear to correlate with the themes to which they contributed.

Themes

Data analysis demonstrated that participants experienced MT within a broader context of conflict around its perceived legitimacy as an appropriate treatment option. Within this context, one major theme was identified (Impact of MT), alongside two minor themes (Management of Hope and the MT Process). The results reflected the participants' emphasis that the waiting time for MT was short-lived (<two months) and the procedure rapid (30 minutes - 5 hours), whereas the impacts were long-term and participants' core focus. Within discussion, themes are supported by direct, anonymised quotes.

Conflict about Legitimacy

The conflict of legitimacy was rarely directly voiced but was alluded to by most participants. Their experiences encompassed dissonance between apparent expectations to achieve rigorous beauty standards while remaining modest and 'body positive'. The desire to regain a resemblance of their pre-burn features, or a more normal appearance, conflicted with expectations for acceptance of, and positivity about, their scars. This was expressed as a continued sense of conflict within themes described. Another example of this

conflict came from Penny who highlighted that 'medical procedures' were essential. Yet, as with other participants, she indicated that MT could be viewed as a non-essential, or a cosmetic intervention and, thereby, felt less legitimate or warranted:

"I mean it wasn't... a medical procedure that's necessary,...I think it's two totally separate things.... any appearance thing was very secondary."

The perceived expectations of others appeared to exacerbate this conflict as participants talked about being viewed as too 'damaged' for 'beauty' treatments or influenced by views that appearance should not be important. Lilly's account of omitting her partner from discussions alluded to a perceived lack of validation and her perceived sense of 'selfishness' in prioritising appearance:

"No, not even my partner.... I daren't even tell him. ..., I didn't want him to say, I love you the way you are and don't do it... It was a bit selfish"

The difficulties observed in expressing experiences, and the language chosen, also reflected this perceived pressure to legitimise experience and choice. It appeared that there was a sense of shame related to their appearance and the desire to change it. While the need to justify decisions appeared minimal when experiences were shared within the burn community, it was fundamental, yet arduous, when communicating to those outside this group (Extended paper-3.1.1-4.), including the interviewer. Participants struggled to believe non-burn survivors could understand and, therefore, provide validation, as described by Helen:

"It's hard, ..., it's difficult. You don't know ... how to explain to someone who's not felt those things, because you have to explain how you felt ... and then try and understand that before you can explain, ..., what difference it's made..."

This context of uncertainty in their own and others' perception of validity in attempts to improve appearance provided a framework that may have constrained participants'

experience of, access to, and communication about the MT process, and the following impacts:

Management of Hope

When informed MT was a possibility, all participants decided instantly to access the procedure. This appeared to be due to the immediate intense hope and anticipation that intervention offered a radical solution to scarring. Additionally, participants had varying levels of hope for improved confidence and inter-relational experiences, including a decrease in negative reactions of others (Extended paper-3.2.1-4.). Helen's direct and open statement typified the strength of hope experienced initially, but also acknowledged it may have been unrealistic:

"I think we all ... , in our heads, ... think, ... it's going to be like, wow, it's all done, perfect, ... It's just our like fantasy..."

Emmy's account typified all accounts that improving appearance was central to participants' hopes (Extended paper-3.2.5.):

"If you have eyebrows... it frames the face a bit more... My face would start to look a little bit more symmetrical, ... it would have a shape. I wouldn't just kind of be this ... a blank canvas ... Well just looking like a face... More like me ",

All participants voiced the appreciation that the outcome could never meet their initial 'fantasy', which led to moderation of expectations, as demonstrated by Emmy's powerful desire to regain 'a face' and a sense of identity alongside intrinsic attempts to limit hope to only looking "a little bit" better, or "more" like herself (Extended paper-3.2.6.). Most frequently, participants used explicit self-talk (i.e. telling themselves to only expect small improvements) to do this (Extended paper-3.2.7.), as typified by Lucy:

"Just saying, ..., it would be nice to have some shape back.. even a bit better is better...."

However, inconsistent narratives were suggestive of oscillation between intense hope and efforts to limit disappointment (Extended paper-3.2.8.) which often increased in intensity as MT approached (Extended paper-3.2.9.). Lilly described the dissonance:

"It's a mixture ... I really hope this works but I don't want to have hope, but it's worth a try but what if it gets worse?"

This theme demonstrates that participants felt a desire and hope for improved appearance (Extended paper-3.2.1-10.), with an equal drive to manage hope and disappointment. The apparent difficulty in accessing or voicing intense hope, even after successful MT, suggests participants were influenced to varying degrees by the conflict about legitimacy of their hope.

The Process

At the first MT session, participants experienced anxiety stemming from lack of information about the procedure or clinic (Extended paper-3.3.1.), as demonstrated by Milly:

"... just fear of the unknown, of what I was going to actually, ... do".

Anxiety also arose from the inevitable exposure of their scars. While some focused on the incongruence of attending a 'beauty' clinic (Extended paper-3.3.2.), Penelope stated explicitly her fear that clinicians would be disgusted by her scars (Extended paper-3.3.3.).

"I remember ... thinking, if I get there and they're like, oh I don't want to touch her.".

Concerns regarding undergoing a facial MT and the possible results also created anxiety, as described by Emmy (Extended paper-3.3.4.):

"then I heard the tattoo machine start, and... it's about my face.... how do you cover it if it goes wrong ...".

Penny had previously experienced permanent make-up/cosmetic tattoos and was the only participant to report no concerns (Extended paper-3.3.5.). It is possible her prior knowledge alleviated anxiety, which is supported by the lessening of anxiety the others felt during subsequent 'touch-up' appointments.

Generally, participants' anxieties were managed largely by the interpersonal relationships with clinicians who appeared non-judgmental, informative and knowledgeable about scars and equally invested in generating

the best results. This appeared to create a sense of acceptance, assurance and legitimacy (Extended paper-3.3.6.) as described by Lucy:

"It was an absolute doddle ... She'll never ever do something that she doesn't think is going to look right... But never once do you ever feel different [from client's without burn injuries], ... it's really important"

Participants felt MT was straightforward (Extended paper-3.3.7.). Even Lily, whose skin pigmentation MT was of the longest duration and involved physical trauma over a larger surface area, emphasised the legitimacy of MT as an efficient, life-changing treatment within the context of more invasive medical procedures:

"they're not anaesthetizing people.... It's just a quick process and away you go... ... [and the benefits are] massive, and they're changing people's lives "

Although all participants acknowledged MT was painful, this was not central to their experience (Extended paper-3.3.8.). Milly's account showed how pain experienced at injury influenced the perception of pain at MT:

" I can't be in anymore pain than ... when I had the accident "

This theme highlights MT as a comparatively straightforward procedure with manageable levels of pain and, while participants experienced anxieties, these were quickly alleviated by professionals through expertise and non-judgmental support.

Impacts of MT: 'Normal-ish is Fantastic'

Participants gained the first impression of treatment results immediately following MT when skin remained swollen and sore (Extended paper-3.4.1.). Those who were uninformed about such consequences voiced fluctuations in feelings about the MT and welcomed support in envisioning appearance post-healing from both clinicians and family (Extended paper-3.4.2.). Those, like Emmy, who had been prepared, reported instant results (Extended paper-3.4.3.):

"When I knew they were permanent, I was just so happy because literally, as soon as I saw my face, I looked like a face now ... I almost owned my name and said, this is what [I] looks like."

Lilly's account encapsulated how, once healed, MT was experienced as life-changing regardless of location and severity of the burn injury (Extended paper-3.4.4.):

"Oh my god, it's game changer-better... unless somebody got up close and stared, they wouldn't actually know. Whereas, before, it was pretty horrific."."

Some did voice limitations of MT, including its inability to fully restore original appearance and MT was frequently received in conjunction with other appearance-related treatments (e.g. laser treatment). Milly's resigned description illustrated the enduring difficulties of burn injuries and the inevitable truth that no procedure can fully restore appearance.

"... if you've got a burn, you're always going to be bothered by it when you look in the mirror. ... I mean reminded ... , it's positive, [MT] gave me the eyebrow, but the scars are always going to be there... it's not like she can do a miracle tattoo that's going to take away, ... the scarring...."

Nevertheless, the interviews were infused with overwhelmingly positive language (Extended paper-3.4.5.). This is suggestive of the importance of the results for participants; even modest improvements in appearance were pivotal in improved well-being (Extended paper-3.4.6.). Yet, many found it hard to either access, explain or share why MT was life-changing (Extended paper-3.4.7.). Penelope's account explored this inconsistency, alluding to conflict around the legitimacy of facial and bodily appearance seeming so innately important:

"I'm not sure if the words are hard to find ... you think you've been through so much, do I sound stupid saying, out of everything, I miss my eyebrows? ... I've lost sensation in the whole bottom half of my legs but I'm more concerned about having eyebrows.".

Nonetheless, these life-changing impacts could be identified and were frequently framed, during interviews, as improved confidence (Extended paper-3.4.8.). Sara, for example, explained, although her appearance was not ‘fixed’, there was still notable improvement in confidence:

"Even though it hasn't changed much but it's changed massive on my confidence."

Improved confidence appeared to relate to regaining a sense of being ‘normal-ish’ through reclamation of aspects of their ‘true’ appearance, identity or relationships. Subsequently, participants reported increasing acceptance of their ‘new MT appearance’ and feeling free from the sense of immense control and social barriers (Extended paper-3.4.9.) the burn had exerted over their lives. This related particularly to the perceived constant pressure to camouflage scars to manage their own negative perceptions and/or the reactions of others. These extracts show different variations of this experience (3.4.10.):

"And I felt normal, ... , I felt like instantly, like more confident and happy" (Helen)

"You don't realise how ridiculous you look on the beach with jeans on and a long sleeve top in thirty-degree heat, ... It's just, I can go away on holiday and just be like everybody else, which is all I ever wanted to be." (Lily)

"I guess, the eyebrows and lips, it sounds crazy, but I guess that's given me the confidence to be that crazy person again because I don't care. ... Now, I'll .. put a post up ... of me with no makeup, no filter, no nothing," (Penelope)

Underlying the participants’ MT experiences was damage to identity post-injury and a realisation their new appearance was unacceptable within society, creating a pressure to prioritise camouflage above comfort or relationships. Their experiences suggest that MT enabled them to begin to reclaim their identity, legitimacy within society and freedom from the perceived exerted control from the injury and scarring. Even Penny, who had reported no expectations, anxieties or changes to her life post-procedure, voiced how MT allowed her to reclaim her humanity (Extended paper-3.4.11.):

"I don't wear a lot of makeup, only when I go out. ... but it was just, before I had [the MT] done I felt that I needed to do something with them... [the MT] just means I can see a face and, you know, I'm not just a scar, basically. I'm a face, I am somebody."

This theme highlights the potentially intrinsic importance of viewing appearance as 'normal-ish' for those within the burns' community. Although MT could not resolve every difficulty, the impact was overwhelmingly positive and allowed participants to reclaim a sense of identity and worthiness within society. It also created an overall feeling of being 'more normal' through improved relationships and fewer controls exerted by the need to disguise scars.

The most compelling finding was the complex and contradictory nature of the narratives that emerged within this study. Overall, the results demonstrate that participants unanimously found MT to be "life-changing". While the extent of the transformative nature varied between the participants and took various forms including improved confidence and self-esteem and regaining identity, the strength of the positivity towards MT as a remedy to the burn injury was central to their experience. However, a contradictory narrative emerged which depicted a sense that MT was a 'non-essential' treatment and had not made substantial changes to the participants' lives. This indicates that choosing to undergo a MT within the context of a burn injury and the impact of the results ~~is~~were an interaction of complex multifaceted processes impacted upon by psychosocial, cultural and societal factors. Notably, there appears to be a 'push and pull' between personal and societal beliefs related to 'inner-beauty' and 'outer-beauty'.

Discussion

This study aimed to provide a detailed and ideographic account of the psychosocial experiences of MT for those living with a burn injury, including their expectations of the procedure and how this related to experience, and the psychological processes involved.

Overtly, the positive impact of improvement in appearance was the quintessential experience for participants regardless of the location and severity of the burn injury (Extended paper-4.0.1.). This supports previous research that suggests severity of the burn is not a predictor of distress [11]. It also reflects

the high levels of patient satisfaction previously reported with a service evaluation of MT for burn injuries (n=25), also recruited from the KPF [38]. Similarly, high levels of satisfaction with MT are reported within evaluation studies in nipple-areolar reconstruction and for lip vitiligo [39,40]. However, the present study also suggests that satisfaction scales cannot truly reflect the complexity of satisfaction (Extended paper-4.0.2.). Improved appearance largely accounted for the sense of MT as “life-changing” and appeared pivotal in facilitating a shift towards a more integrated sense of self (i.e. integration between appearance and identity). This could be understood in a number of ways: as a reduction in the negative self-appraisal, and shame felt towards the appearance of an injury reported in previous literature [5,11,25] (Extended paper-4.0.3-5); as a consequence of the perceived regained freedom which had been lost post-injury [20] (Extended paper-.4.1.1.); or a reduction in the negative reactions of others [11]. These findings are indicative of a directional effect on improved well-being and Quality of Life (QoL). However, this was not specifically measured.

Within this study, participants linked improved appearance with increased confidence, supporting the previous service evaluation of KPF [38], which also reported improved confidence following MT. It also, in part, supports the importance of the role of ‘other’ within the experience and the inherent social nature of appearance and appearance-based judgements [21,32](Extended paper-4.1.2.). This study suggests that improved confidence comprises a combination of factors including regaining normalcy, increasing acceptance of ‘new’ appearance and reducing inter-relational barriers. The findings that regaining a sense of ‘*normal-ish*’ was viewed as ‘amazing’ replicates similarities to the themes: ‘*doing normal things*’, ‘*looking normal*’, ‘*normal health*’ and the ‘*reconstruction of normal*’, identified in a study of breast reconstruction patients [34]. Normalcy seems to include a sense of regaining freedom from the perceived control of the damaged appearance (e.g. impact of camouflage on living a ‘normal’ life). This supports findings which posit that recovery is a process of striving to regain freedom from impacts of the burn [20]. It is possible that those who have acquired a visible difference, either through injury or surgery, attempt to feel ‘normal’ after the incident and suggests

physical appearance and the body play a crucial role in self-identity and inclusion in society [16,19].

The increase in acceptance of appearance following MT supports previous findings which have suggested that recovery from a burn injury is, in part, a balance between acceptance of what could not be changed and efforts to 'change the changeable' [20] (Extended paper-4.1.1.). The ability to alter internal standards and values to minimise the impact of the injury on well-being, happiness and satisfaction is identified as a 'response shift' [52]. It appeared that, for these participants, this viewpoint was achieved via social comparison (i.e. comparing their injuries to those of others [53] (Extended paper-4.1.4.) and also alongside the drive to help and support others who are currently struggling.

To a lesser extent, the findings suggest improved mood, increased confidence and some improvements in close relationships. The examples indicate that individuals felt more able to connect with closer friends and family and/or engage in some enjoyable activities in a different way following MT (e.g. wear a swimsuit on the beach and not cover up, and engage in social media). While these outcomes were noted during the interview process, these were not prominent in their experiences of MT. For example, improved mood was rarely discussed, although it was significant for those who did. Furthermore, the overwhelming positivity in relation to MT may indeed be an indicator of improved mood and well-being. These findings tentatively support the improved QoL scores within the previous KPF service evaluation [38], although again illustrate that quantitative measures may not capture the complexity of the experience. Nonetheless, these findings are suggestive of the notion that body image satisfaction moderates the long-term psychological outcomes following a burn injury [22,23].

Alongside the positive narrative, a contradictory portrayal emerged around the perception that it was not legitimate to want to consider and undergo a treatment to improve appearance or 'outer-beauty', and to do so would elicit negative reactions from others. The results demonstrate dissonance for participants between a perceived pressure to 'fix' their appearance and conform to an 'ideal' model of physical appearance. A sense of pressure was also identified to simultaneously accept and adjust to their altered appearance. This

contradictory narrative has been identified in previous research in which female participants with burns reported both that their injury appearance was “not a problem” but also that it was “not a pretty sight” [21]. The current study also supports the reported notion of an interplay between complex narratives of outer versus inner beauty within the burn literature [19] and the societal influence in defining what is ‘acceptable’ appearance [32]. The most overt demonstration of this conflict was observed in the repeated reporting of difficulties in accessing or communicating the fundamental change experienced, or the “life-changing” importance of improved appearance for these individuals. It was frequently reported, for example, that MT had no impact on day-to-day life. Although activity changes were identified, these were not prominent for participants who appeared to struggle to connect fully with the impact and importance of the changes in their sense of self following an improvement in appearance. It can be postulated that such a response constitutes a form of self-silencing [21,54]. This restriction of self-expression refers to a cognitive schema developed in order to maintain close relationships. This has been generally conceptualised as a female problem as women are socialised to place emphasis on maintaining connected relationships rather than attending to their own needs [54]. The reluctance to express both the positives of improved appearance and the negative role of ‘others’ in their experience may result from conflict between their true experience and feelings and the need to maintain relationships both during the interview process and in their personal lives.

A further example of difficulty experienced in accessing or communicating experiences was highlighted within discussion of the theme of ‘hope’. Prior to the MT, hope, and its management, were central. Participants focused on their aspiration for enhanced well-being through improved appearance, which could be understood as a hope of escape from the shame and negative self-appraisals encountered as a result of their disfigurement [11,25]. Yet, the theme was peppered with indications of how MT might change the perceptions of ‘others’, which could reflect a desire that they would be perceived more positively [28] or simply be less scrutinized by others [32]. This hesitance to discuss the role of others may again constitute a form of self-silencing [54]; by avoiding this topic they might influence how they are

perceived, due to beliefs that others may question the legitimacy of their experience.

An additional aspect of this conflict appears to relate to strained inter-relational experiences. During the MT procedure itself, the main focus related to anxiety and uncertainty and how fear was alleviated through interactions with knowledgeable clinicians (Extended paper-4.2.). The results provide situation-specific examples within the context of burn-treatments involving assumedly knowledgeable professionals. These are indicative of the extent to which individuals continue to be affected by fears of social rejection, avoidant responses and reduce responsiveness from others [24,29–31]. Nonetheless, the current study highlighted that participants perceived MT as an effective, quick, simple treatment that should be offered to burn survivors.

Limitations

The results obtained within this study need to be considered within the context of the limitations of the research.

Unintentionally, all the participants recruited were female so the experiences of male and transgender populations were not considered which limits applicability across genders. However, although males account for 75% of the burn population, females account for 46% of burn patients receiving reconstructive treatments [23] and the KPF's client base is largely and historically female. This representation may reflect that men experience fewer negative impacts from a change in appearance [23,55,56]. However, it may also represent a social narrative that men should place less importance on appearance [57]. Nonetheless, recruitment was limited to one support service and subsequent snowballing which may have influenced the gender of participants and also resulted in some degree of self-selecting bias (such as increased focus on appearance). Crucially, it was highlighted within the interviews that participants may be able to identify other participants from the demographic information collected. Therefore, to maintain confidentiality, the data presented were limited, reducing the study's ability to deliver a truly idiographic, personally contextualized account. This awareness of others' demographic information appeared to be related to recruiting from KPF (the

only charity which offers MT) and a manifestation of the previously identified desire to share stories of their injury and recover [42–44].

As all interviews were completed by telephone, the detail of contextual and non-verbal data collected was compromised - such information may have offered further interpretive information. However, while limited, it has been suggested that telephone interviews offer equally valuable data within IPA studies [58]. Given the reported fear of judgement from others [25] and an interviewer who has not experienced a burn injury, telephone interviews may have allowed participants to feel more confident to engage and disclose sensitive information [59], increasing the extent of data collected. Nonetheless, there may have been raised incidences of socially-desirable responding [60], resulting from the perceived conflict between the relative importance of inner or outer beauty and the assumption that the interviewer could not understand their experience. Future research projects may benefit from consideration of the use of different research methods including video-recording and/or utilising a researcher with burns. However, the effectiveness of these methods to elicit data that is different in depth or quality would also need to be evaluated.

The use of a retrospective design within this study may have increased the potential for recall bias [61] and potentially influenced the meaning made of the participants' experience of MT. For some subjects, significant time had lapsed between the MT and the interview which may also explain the tendency to focus on the long-term impacts rather than issues when waiting for and receiving the MT which had occurred years before.

Clinical Implications

Clinical implications must be considered within the wider narratives of the society and the limitations of the study. Overall, the reported benefits and minimal negative judgements supports previous findings suggesting that increased access to MT via the NHS Burns Services would be beneficial as an additional treatment [38]. This study indicates that MT might help to contribute to the recovery pathway of burn survivors. MT appears to provide a treatment which would seem, within the early stages of its evaluation, to improve psychosocial adjustment, including reduced feelings of shame, improved confidence and increased acceptance of their 'new' appearance. This may

support burn survivors in the process of integrating back into society. It is, however, acknowledged that further investigation is required to examine whether such findings are replicated within larger scale research. Furthermore, funding wider access to MT as a standard, routinely used part of the treatment pathway would help legitimise the procedure, allowing participants to view MT as positively as other medical options.

Burns services may benefit from reviewing the information that is routinely provided to patients, notably regarding early awareness of MT as a treatment option, alongside detailed information and support for feelings of anxiety and hope and the procedure itself (such as providing 'before and after' pictures and figures on success rates). For services offering MT, face-to-face consultations with other patients who have undergone MT alongside clinicians are recommended to permit discussion of these issues and to allay fears of legitimacy. Clinicians may be aided by more overt awareness of relevant, underlying social narratives. These may include factors such as the push and pull of inner versus outer-beauty conundrum, the perceived pressure exerted by society via the patients' own narratives, the perceived beliefs of others regarding what is deemed 'normal' and, finally, the potential for adjustment via exposure to others with similar injuries [62]. It is also recommended that burns services utilise psychologists to help with decision-making and to provide follow up sessions to support patients in processing their experiences. Likewise, those offering MT in other areas such as nipple-areolar reconstruction and lip vitiligo may wish to consider whether similar narratives are impacting on their populations and modify support accordingly. It may become clear that the provision of information about the process of MT requires specific support from psychological input, or for these discussions to be combined with specific psychological interventions, such as CBT to address appearance anxiety [63] (Extended paper-4.3.). However, targeted research would be needed to establish both need and efficacy.

Further Research (Extended paper-4.4.)

This study illustrates benefits for recipients of MT in terms of wellbeing which are voiced in the experience of feeling normal, and of self and societal acceptance. While offering important insights into the complexity of wellbeing,

the DAS24 does not aim to diagnose. Other clinical measures (such as the Hospital Anxiety and Depression Scale [64] or Burn Specific Health Scale [BSHS] [65]) may enable future research findings to more easily fit within diagnostic approaches and pathways currently used to structure mental health services. This may be pertinent for those who are no longer supported by burn services. This could be achieved via the application of longitudinal qualitative or mixed methods approaches with burn survivors before, during and after MT to explore and understand the potential processes and impacts which may occur at different stages of the procedure. Consideration of other appearance-related treatments (such as laser treatments) would also be useful to contextualize the findings.

Further investigation could be employed to give a voice to and better understand the meanings of MT and the context in which they are understood for males and members of LGBTQ and BAME communities who may have differing experiences, perceptions of beauty and social expectations. Exploring potential differences may enable the NHS to provide a more inclusive and individualised service. It would also be beneficial to investigate the views of those who, when offered, decline MT as a treatment to provide a fuller understanding of relevant underlying processes. Additionally, exploration of the potential for these experiences to be reflected in other populations with visible differences could enhance understanding of the impacts of this treatment.

Finally, this study highlighted the push-pull between beauty narratives which influence the decision to go ahead with MT and the subsequent experience. Further research is needed to explore these societal expectations which may be subjugating individuals by influencing them to undergo treatment to fit the 'norm'. This research may also wish to consider a more beneficial narrative to increase inclusion of differing appearances within society. It would be useful to gather further data regarding this potential dynamic from the perspectives of those with and without a burn injury to illuminate the most effective support.

Conclusions

This retrospective study utilising IPA has provided unique, detailed and idiographic psychosocial experiences of MT for those living with a burn injury. It

has identified the need to manage hope of improvement and the value of an accessible treatment which has been reported to generate long-term positive, life-changing impacts. MT would appear to be an accessible and well-regarded treatment for burn injuries, with multifaceted positive impacts for individuals and minimal negative outcomes. While these were not measured, improvements may be observed in psychological and social well-being. These positive consequences appear to be enacted via a combination of psychosocial, cultural and societal factors or narratives central to the participants which, to varying degrees, permit a sense of the regaining of 'normalcy' and an improved sense of being acceptable in society which is experienced as 'life-changing'. This indicates that the procedure should be made more widely available. The findings, however, seem to be set within a context of psychosocial, cultural and societal pressures around the concepts of external and inner beauty, combined with a sense that conforming to these expectations is also not viewed as important or acceptable. This potential paradox appeared to influence participants' ability to access and communicate their experience, which may be crucial for relevant professionals to appreciate when offering support within the clinical field. Therefore, although MT seemingly offers a powerful and important role within the recovery of burn survivors, the wider context and narratives related to appearance must continue to be considered. Given the highlighted complexities, further research is needed and consideration given to the experience of other groups (such as those who choose not to take up medical tattoos), and the role of societal perceptions on the need for improved appearance. Such research would contribute to improvements in MT accessibility, usability, effectiveness and patient satisfaction.

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Extended Paper

1. Introduction

1.0.1. The significant short- and long-term physical and psychological challenges of experiencing a burn injury most commonly include anxiety and depression (Roh, CHung, Kwon, Kim, 2012), grief (Partridge & Robinson, 1995), post-traumatic stress disorder (Van Loey & Van Son, 2003) and sleep disturbances (Boeve et al., 2002). Patients can lose social and occupational roles, change social status and experience adverse social responses (British Burn Association, 2001; Partridge & Robinson, 1995). Patients can also experience loss in confidence, difficulties within social relationships and disengagement in previously enjoyed activities (Ye, 1998). The greatest dysfunction and distress is reported during the first year after hospitalization due to factors such as memories of the accident, family strain and general daily-life disruption caused by the injury (Blades, Jones and Munster, 1979; Patterson et al., 1993; Sheffield et al., 1988).

~~1.0.2. Visible differences occur from a variety of health conditions, alongside injuries and following surgery (e.g. cleft palate, breast surgery, vitiligo, burn injury) and can have a profound impact on those affected. Some individuals with visible differences adapt well (Partridge, 1990; Rumsey, 2002) although approximately 30 to 50% of outpatients have reported high levels of anxiety and social avoidance, alongside a reduced quality of life (QoL) (Rumsey and Harcourt, 2002). This is a developing area of research and is frequently limited to only one population with a visible difference. Two detailed reviews of relevant literature have been completed. Thompson and Kent (2001) provided~~

an overview of observations of adjustments to disfigurement and the processes involved with being visibly different. Rumsey and Harcourt (2004) reviewed psychosocial implications and considered the complex influence of physical, cultural and psychosocial factors on adjustment. Following this the Appearance Research Collaboration (ARC) (2014) complete an extensive review to identify the psychosocial factors and processes contributing to successful adjustment to disfiguring conditions. The review consisted a large scale questionnaire-based cross-sectional study involving participants with a range of disfiguring conditions (n=1265), two longitudinal studies (n=360), a qualitative interview study of stability and change in adjustment (n= 26) and nine follow-on studies employing a range of methodologies to focus in more depth on specific topics: positive adjustment; black & minority ethnic community views; South Asians with vitiligo; social comparison processes; appearance concern, hostility and social situations; scale development for intimate behaviours; women with limb prostheses; appearance and rheumatoid arthritis; general practitioners' beliefs, experiences and training needs. The review concluded that the adjustment to disfiguring conditions, such as burn injuries, is a complex dynamic, context specific, multi-factorial process. The review's synthesis of findings suggest positive adjustment was defined by low levels of social anxiety, social avoidance, negative affect, general anxiety and depression and included the psychological characteristics of higher levels of optimism, greater feelings of social acceptance and satisfaction with social support, reduced of concern about negative evaluations by others, and a self-system with lower levels of salience and valence afforded to appearance related information. Other factors included how easily the difference could be disguised, role of functional disability, gender, age ethnicity, religion and culture. Within three studies a number of individuals self-reported personal growth, reporting a number of strategies that appeared to work well, including pragmatism and 'getting on with it' in the face of challenges, acceptance and determination, and engaging with problems and difficulties rather than avoiding them again. Given the complexities of this area a comprehensive discussion of the psychological theory underpinning adjustment is beyond the scope of this thesis, but is provided by the ARC review (2014). Also, given the exploratory nature of this study and the IPA aims to voice the idiosyncratic experiences of MT following

burn injuries efforts were made to avoid preconceptions in relation to 'successfulness' of adjustment and the decision to have, and experience of, MT.

1.0.3. Clinical Psychologist are a fundamental in supporting the psychosocial adjustment to burn injuries. Given the role of salience and valence afforded to appearance-related information and other beliefs about judgment and social support (ARC, 2014) Cognitive Behavioural Therapy (CBT) would understand psychosocial adjustment, including emotional and behavioural reactions, as being mediated by the person's appraisal or beliefs of the injury, their appearance, and society. It is possible that a number of the mediating factors such as age, culture, gender and ethnicity highlighted in the ARC review (2014) are enacted via their impacts on the beliefs held by those individuals. This is reflected within the burn population where the literature highlights the influence of society norms on how individuals evaluate their scarring (Thompson & Kent, 2001). However, a recent systematic review of 16 studies into the psychosocial interventions for adults with visible differences (Norman & Moss, 2015) concluded that there is very limited evidence to support the efficacy of CBT for supporting adults with visible differences. However, there is still insufficient information to draw firm conclusions. While this review highlighted that individuals with visible differences did not find the idea of CBT associated with their appearance stigmatizing, it may be that there is significant supporting evidence for the beliefs which are leading to distress (e.g. other people will stare at me, looks are important). Narrative Therapy (Payne, M. (2006). Narrative therapy. Sage.) may offer an alternative approach by considering the role of dominant narratives within society. Dominant narratives can subjugate individuals into behaving in accordance to those narratives. For example, if the dominate narrative portrays attractiveness and/or 'normal' appearance by photoshopped imagines of a subsection of society (celebrities) then those who no not meet that standards are likely to feel they are not 'normal' or 'attractive'. They are also likely to feel pressured to make efforts to achieve those standards, thus proliferating the dominate narrative of 'normal' or 'attractive' appearance. Narrative Therapy believes that individuals all have their own narratives and would argue these differences explain why different people have difference narratives in relation to their burn injury and what this means to

~~them. Narrative therapy suggests difficulties arise when an individual's story conflicts with the dominate narrative such as the appearance of a burn injury not meeting 'normal' appearance. Yet, instead of challenging beliefs Narrative therapy would encourage an individual with a burn injury to consider and explore societies dominate narratives that influence their feelings towards their injury and support the individual to redefine their relationships with the dominate narrative to reduce the subjugation (e.g. the need to match the dominate narrative). Norman & Moss's (2015) review did not identify any studies on the use of Narrative Therapy interventions for adults with visible differences.~~

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1.0.4. Several studies have considered the impact of burn injuries and scarring. Brown et al. (1985) recruited individuals with scarring treated by a specialist scar service to explore ratings of QoL. Themes related to scarring were identified and included emotional wellbeing (low confidence, anxiety and low mood), social functioning (difficulties with relationships, communication, and

leisure activities), physical discomfort (pain and itching) and acceptability of self and others (dissatisfaction and stigma). Alongside consideration of potential interventions, Van Loey and Van Son (2003) offered a detailed account of the psychopathology and psychological problems encountered by a significant minority of patients with burn scars, including depression, PTSD, anxiety, neuropsychological, sexual and social interaction problems, and the impacts on QoL.

1.0.5. Appearance acts as a pre-discursive form of interaction and it allows identification of the participants, the relative social values attached to their positions, moods, and attitudes or possible courses of action (Stone, 1970). In part, appearance can be thought of a phase in social interactions which establishes identification of the participants (Stone, 1970), so we can tell who someone is by their appearance. If appearance changes dramatically, it may no longer be possible to ascertain identity. It has been argued that identity indicates a placement within a set of social-structural relations, often taking the form of identities in role, status or relations that play out through social interactions (Stone, 1970; Weigert & Gecas, 2003). The role of appearance in identity has been considered across many social groups with the focus being on minority groups, perhaps due to the perception by minorities that they do not fit within social norms (Hutson, 2010).

1.0.6. It has been suggested that the concept of self is defined primarily in aesthetic terms considering how one looks rather than in terms of what one does (Negrin, 2008). This is reflected in the plethora of products and technologies for modifying the body, such as diet pills, exercise programs, and cosmetic surgery and tattoos aimed to improve appearance (Negrin, 2008). Therefore, it appears identity is a complex phenomenon which cannot be separated from either personal or societal aspects. Sharatt et al. (2019) investigated the individual and social experiences of twenty-two adults (six men) living with a visible difference through interviews which were analysed using thematic analysis. It was highlighted that participants were concerned about the negative reactions and judgements of others and these often underpinned the individual difficulties they faced. Personal appearance was felt to be a projection of the self into the world and that 'looks' proffer something fundamental about

the individual. The participants also reported that having a visible difference created a sense of lack of privacy in that they voiced feeling 'others' felt they had some sort of right to closely examine their disfigurement (Sharratt et al., 2019). Finally, the subjects reflected a tendency to compare their own appearance with others to find comparative normality. This was most frequently done to consider whether the injury could have been worse, and appearance could have been more severely affected. The researchers identified the important role of society in defining the concepts of 'normal' and 'acceptable' for those with visible differences.

1.0.7. Scarring can lead to unwanted and stigmatising attention from others - individuals with visible difference can feel they are 'on show' to the public (Sharratt et al., 2019). For those with a burn injury, scarring can be observed by others particularly when located on the face, head or body if not hidden by clothes or make-up. Individuals frequently report both strangers and known others stare at their injuries (British Burn Association, 2001; Sharratt et al., 2019) and it has been shown that individuals with a visible facial difference are stared at longer than those without (Halioua, Williams, Murray, Skalko, Vogel song, 2011a). Staring is a powerful form of expressing our response to others (Garland-Thomson, 2009) and can communicate curiosity, surprise, disgust, and hostility. Staring is a strong reaction to others and is frequently viewed as rudeness within western societies. However, it is also a response to novelty and to the unexpected (Garland-Thomson, 2009). Therefore, it is possible that the increased frequency of staring could be viewed as intensification in negative, hostile or curious communications which would likely have significant impact on those with a burn injury.

1.0.8. Tattooing is traditionally in the form of a recognisable pattern or design. However, the medical application of tattooing first appeared in 1835 to restore natural colour to the skin in cases of congenital vascular nevi (congenital or acquired blood vessel abnormalities or birthmarks) and has since been utilised in a variety of ways (Vassileva & Hristakieva, 2007). Micropigmentation, the more frequently adopted term in the USA, conveys tattooing used for cosmetic reasons to improve appearance, including permanent make-up (e.g. eyelid tattooing and changing the shape of, or

simulating, lips and eyebrows) (Steinberg & Winkelman, 2001). Dermatography is the method introduced by European clinicians to designate the art of tattooing applied to permanently correct cosmetically disabling disorders, including burns (van der Velden et al., 1995). It consists of implantation of different colours through several consecutive treatments to obtain a full colour match of the surrounding skin.

1.0.9. The Katie Piper Foundation (KPF) was established in 2009. It is the sole charity in the UK dedicated to rehabilitation and restoration services for adult burns survivors and those living with severe trauma scarring (Charity Commission, 2018). The charity's vision is "to have a world where scars do not limit a person's function, social inclusion or sense of wellbeing" (KPF, 2020). Prior to 2019, the KPF offered MT to its clients but this treatment option is now no longer offered. Currently, the service offers access to residential burn and rehabilitation centres, hair transplant surgery and hair replacement systems. This change has removed the opportunity for many to seek MT without charge.

1.0.10. Limited research data is available regarding the concept of normality for those with visible differences although this has been explored in relation to sexual behaviours (Tiefer, 1994). Tiefer (1994) posits that there are at least five ways to define normalcy in relation to sexual behaviours: subjectively, statistically, idealistically, culturally and clinically. Subjective normality describes individuals who consider themselves 'normal'. Statistical normality refers to the statistical norm or average although this is unlikely to be 'normal' for many. Idealistic normality refers to the concept of perfection whereas cultural normality reflects the norms of individual cultures. Clinical normality describes what medical professionals would describe as healthy, with behaviours that 'deviate from healthy being considered abnormal' (Tiefer, 1994). It is acknowledged these categories cannot be independent of each other. While these categories related to sexual acts, the wide range of definitions of normal are evident. It is possible that similar concepts of 'normal' influence the adjustment of those with a burn injury.

2. Method

2.0.1. All research involving burns survivors can be considered sensitive as it requires participants to recall a traumatic event that has potential long-

lasting and wide-ranging psychosocial impacts (Attoe & Pounds-Cornish, 2015; R. Kornhaber et al., 2014). Furthermore, this focus of investigation is becoming increasingly complex as new reconstructive treatments become more readily available, extending the scope for treatment but, critically, also widening the possibilities for differing treatment experiences. Therefore, a qualitative research design was most appropriate and better suited to managing the inherent sensitivity of the issues whilst revealing the complexity of the experience. It is anticipated that findings gained will enhance understanding detailed within existing literature by providing critical insights into the psychosocial effects of MT.

~~2.0.2. Interpretive Phenomenological Analysis's (IPA) foundation in phenomenology are what drives the importance of the focus on experience and perception of experience. (Smith, Flowers & Larkin, 2009). IPA's is underpinned by the concept that every individual is embedded and immersed in a world of objects and relationships, language and culture, projects and concerns. Fundamentally lived experiences are a unique personal unfurling of perspectives and meaning, but are created within their relationships to the world and others. IPA aims to understand other people's relationship to the world by interpretation of their attempts to make meaning of their experiences (Smith, 2009). This requires the consideration of hermeneutics (the theory of interpretation). IPA incorporates the idea that research is shaped by the data and the researcher including the impact that fore-structure experiences and knowledge inevitable has (i.e. bracketing is only partially achievable and any results are the researchers interpretation of the participants interpretation of the phenomena). This is crucial for IPA as it both acknowledges the inevitable impact of the researcher within the interpretations and allows the potential for meaningful insights that exceed and subsume the explicit claims of the participants. Another key aspect for is IPA the use of the hermeneutic circle over linear thinking i.e. to understand and give part of an experience you must consider the whole, and to understand the whole you must look at the parts which fundamentally guide the development of themes and demands the research to move back and forth throughout analysis to offer different perspectives on the part-whole coherence of the themes.~~

Therefore, IPA is a qualitative research approach dedicated to the examination of how people make sense of major life experiences (Smith, Flowers & Larkin, 2009). While sustaining a burn injury itself would be viewed explicitly as a major life experience, this study would argue that the recovery from such a trauma, including treatments for appearance, would be equally important for the individual. IPA is particularly suited to uncovering issues related to the experiences and context of psychological distress and also focuses on exploring the experience in its own terms rather than examining predefined hypothesis (Smith et al., 2009). This approach would appear useful within the field of MT as there is limited focused research; it allows the facilitation of exploratory studies, but also permits the depth of analysis required to appreciate the complexities of the lived experience of adjusting to a burn injury.

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2.0.3. Other qualitative methodologies for research were considered for their individual merits but it was assessed these would be unable to provide either the vital ideographic approach or the detail required to permit ascription of personal meaning and sense-making of those who have shared a MT experience. Grounded Theory was considered as a research method as it could potentially identify an explanatory level account of MT (such as factors, impacts and influences) (Strauss & Corbin, 1994). However, this approach would primarily focus on the process of change as a result of MT rather than the lived experience of those undergoing the procedure. Furthermore, the study did not aim to generate a theory. Additionally, of consideration, MT is a relatively new treatment for burn injuries which has only recently been offered within a limited number of burn services so, as a result, the accessible population is currently limited but is likely to increase within the NHS. To ensure the study was feasible in terms of recruitment, it was concluded that recruiting until the collected themes reached saturation (Camic, Rhodes & Yardley, 2003) may not be realistic at the time of the study (e.g. thematic analysis, framework analysis). Crucially, methodological approaches which would necessitate a larger sample size would inevitably lack the depth of examination that would be permissible

with an IPA approach and subsequently not fully give voice to these individuals' experiences of MT (Smith et al., 2009).

2.0.4. Therefore, IPA appeared the most appropriate methodology to ensure achievement of the research objectives, as it would permit fuller understanding of the complex and subjective patient experiences and context of any psychological distress following MT. IPA is also compatible with a critical realist stance as it aims to develop deeper levels of explanation, understand individual processes and identify structures at the core of events to provide understanding of the reality individuals experience (Miles & Huberman, 1994).

~~Following analysis, the data and themes identified difficulties in communicating the lived experiences related to MT. Therefore, another approach to be considered in future would be discourse analysis which emphasises the contextual meaning of language and how people use language to specific effect (e.g. build trust) (Johnstone, 2017). While IPA allows the analysis of such information as demonstrated within this study, discourse analysis may offer further insights into the complexities of communicating the experience of MT.~~
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2.0.5. Epistemology frames the way individuals make sense of the knowledge produced and the standpoint taken towards the nature of knowledge (Riley & Reason, 2015). Those who adhere to the principles of critical realism accept that reality exists but believe that individuals can never identify or understand it with certainty due to the limitation of human intellectual mechanisms (Egon & Lincoln, 1994; Sims Schouten, Riley, Willig, 2007). Oliver (2012) suggests that critical realism is the bridge between the positive idea that there is a reality external to humans and the socially constructed meanings they place on reality. Critical realists emphasize that, in order to test theories, there must be structures and processes (e.g. the process of adapting to MT) against

which to reference them (Bhaskar, 1978); there must be methods to consider and explore the efficacy of any clinical and academic implications of research. The goals of critical realism are to develop deeper levels of explanation, understand individual or social processes and identify structures at the core of events to provide understanding of the reality we experience (Miles & Huberman, 1994). These aims are reflected in the underpinnings and objectives of this study – to explore in detail the individuals' experiences of MT following a burn injury to understand and produce new knowledge from the author's interpretations of their interpretations of the experience. Therefore, a critical realist framework was adopted. To ensure alignment with the critical realist epistemological stance (Trochim & Donnelly, 2001), the study will aim to understand individual or social processes and identify possible core factors or experience (Miles & Huberman, 1994) and, thereby, develop an understanding of the reality experienced.

2.0.6. The Katie Piper Foundation intended to advertise the research on its website, social media sites and in newsletters using an adaptation of the research invitation (RI; Appendix C). However, due to a lack of uptake, participants were recruited via a contact list of participants involved in previous research. RI, Participant Information Sheet (PIS; Appendix D) and demographic questions (Appendix F) were emailed to the first 8 individuals who expressed interest in the study. These participants were subsequently contacted to arrange either a face-to-face or Skype/phone interview. This process was repeated until eight participants had been contacted to arrange and confirm an interview. All participants opted for telephone interviews. ~~To ensure consistency with the sample size of other IPA studies, the sample size was not extended (Smith et al., 2009). In addition, IPA does not attempt to generate theory nor reach data saturation due to its focus on rich idiosyncratic experience (Smith et al., 2009). Therefore, eight participants was assess to be able to provide an appropriate volume of data to manage for a detailed IPA.~~ To ensure consistency with the sample size of other IPA studies, the sample size was not extended (Smith et al., 2009). In addition, IPA does not attempt to generate theory nor reach data saturation due to its focus on rich idiosyncratic experience (Smith et al., 2009). Therefore, eight participants was assessed to be able to provide an

appropriate volume of data to manage for a detailed IPA. Once the eight participants had been sourced, potential participants were contacted and thanked for their interest and informed that the study had met the maximum participant limit.

2.1. Inclusion and Exclusion Criteria

2.1.1. The inclusion and exclusion criteria for participants are presented in Table 8.

Table 8: Inclusion and Exclusion Criteria for Participants

<i>Inclusion Criteria</i>	<i>Exclusion Criteria</i>
Adult (18+ years)	The burn injury was a direct result of deliberate self-harm/suicide attempt
The participant has suffered a burn injury	The participant has significant cognitive impairment or a severe and enduring mental health problem that would affect the interview process
The participant has undergone medical tattooing prior to interviews	The participant is not fluent in English
The participant is able to give informed consent	

~~Due to the author not having experienced a burn injury, the specific location of the burn injury i.e. facial burn was not an inclusion or exclusion criteria. This was to avoid the introduction of the authors potential bias that location was fundamental within with the experience of medical tattooing and to prevent the exclusion of important experiences of medical tattooing such as those identified within the results e.g. being able to go to the beach. During analysis location of the burn was considered, but did not appear to influence the contribution to the themes identified.~~

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2.1.2. Previous studies of individuals with burns have highlighted that those who have deliberately caused their injury may have a different experience of the treatment in terms of prior mental health difficulties, their own perceptions of responsibility, questioning whether they are ‘deserving’ of treatment and the potential for future self-harm (Pham, King, Palmieri, Greenhalgh, 2003). They also represent a minority of the total burns’ population (Wallace & Pegg, 1999). Therefore, this group was excluded.

2.1.3. Clinically, older adults constitute a significant proportion of those with burn injuries related to mobility difficulties and memory and cognitive impairments (Davidge & Fish, 2008). Due to the potential impact that cognitive impairment (at any age) could have on patient engagement in interviews, this was applied as an exclusion criterion. As cognitive screening of all participants would be impractical given funding constraints and ethical concerns (such as participant burden), participants were screened out based on known diagnoses, such as those with dementia, a learning disability or brain injury. Fortunately, the frequent contact with NHS services as part of the patient’s burn care would be able to reveal any such impairments prior to participation in this study.

2.1.4. Individuals who are not fluent in English would also be excluded due to financial constraints preventing the use of translators.

2.1.5. Due to the importance of prioritising participants’ well-being, ethical guidelines set out by the Health & Care and Professional Council (HCPC 2016) and (BPS 2009) were met and adhered to throughout the research. Ethical approval was granted by the University of Nottingham’s Ethical Committee. The ethical considerations included:

Informed Consent - To gain informed consent, participants were provided with a PIS (Appendix D). To address research risks of coercion, there was a planned time lapse between provision of the information and taking consent. This ensured participants could receive the information sheet by post and asked to make contact if interested in involvement. Due to participants’ preference for telephone interviews, the ethical approval was revised to allow oral consent, and the oral consent script was reviewed and agreed by the University of Nottingham’s Ethics Committee. Consent for participation was accepted after

the researcher conducting the interview had explained the PIS to establish that the participant understood its content and had been given an opportunity to ask questions. Oral consent was recorded within the interview recordings.

Withdrawal - In keeping with participants' rights to withdraw, the process was made explicit on the PIS and Consent Form (CF: Appendix E). Participants were notified of their right to withdraw from the interviews at any time without adverse consequences relating to their care (or otherwise). In order to provide a realistic and transparent deadline, participants were notified of their right to withdraw their data from the study up to one week after the interview, after which point data was anonymised and withdrawal would not be possible.

Confidentiality: Data & Data Retention - In the CF, written confirmation of confidentiality was given. This detailed that all data collected would be anonymised from the point of transcription. The transcription service utilised signed a confidentiality agreement. All personal details which were subsequently reported were anonymised or changed where necessary to prevent identification of participants. Subsequent publication and dissemination of the thesis will clearly state that participants' details have been changed. In particular, sensitivity was applied to circumstances surrounding the burn and whether, if disclosed, these details could also identify the participant. However, if participants had raised concerns that indicated risk to themselves or others, they were informed this would need to be acted upon appropriately and confidentiality may have to be breached. Wherever possible, participants would have been spoken to before confidentiality was breached. These circumstances did not arise during the research.

Giving Advice / Support - It was recognised that participants could have potentially used the data collection process to gain information, reassurance or opinion on their care or treatment. The researcher ensured reconfirmation of the nature of her research role at the start of interviews. It was agreed that if a participant requested advice, they would be informed that no advice or ongoing support could be offered during the course of the research (other than basic emotional support during the course of data collection only) and would be advised to contact the Katie Piper Foundation and / or the professionals already involved in their care. These events did not occur during the interviews.

Protection from Harm - This study was considered in line with the published BPS guidance on types of research which “would normally be considered as involving more than minimal risk” (p.13). Although this research is not considered to fall within any categories of increased risk, it is recognised that, by disclosing personal accounts of trauma and difficulty, participants may have experienced distress. This was acknowledged prior to the data collection process (in the PIS) and was responded to appropriately, as above. At the end of interviews, all participants were asked explicitly about their emotional responses and encouraged to explore options to manage these, if appropriate, such as through social support, appropriate resources and signposting.

Debriefing - All participants were provided with a written Debrief Sheet at the end of interviews and given an opportunity to ask questions. Contact details for both the researcher and the University of Nottingham were also provided should further questions arise at a later stage.

Risk management - Consideration was given to the risks posed by lone working with close reference to the University of Nottingham’s Lone Worker Policy and the Susie Lamplugh Trust Good Practice Guidelines (<http://www.suzylamplugh.org/>) including informing a member of the research team of the interview address (in a sealed envelope to be opened, if needed) and expected finish time. Lone working did not occur during the interviews.

2.1.6. A small number of participants is appropriate for IPA methodology which takes a detailed and ideographic approach to analysis, rather than seeking saturation. It is focused on detailed accounts of individuals’ experiences and does not seek to generalise findings to broader populations (Pietkiewicz & Smith, 2012). Six to eight subjects allowed a degree of flexibility to cope with participant withdrawal or insufficiently detailed interview matter (see 2.0.6). It was decided that, in these situations, such data would be included in analyses but the required number of additional participants would be recruited (up to eight).

2.1.7. Inclusion of pilot interview – Following an evaluation by all authors of data relevance, depth and detail, the pilot interview that was conducted was deemed

to be of suitable quality to be included in the study. It was also concluded that the interview questions were appropriate to elicit the information required.

2.1.8. Materials/Resources - The resources required to complete and store the interviews comprised a telephone, audio-recording equipment and encrypted audio-recording storage (memory stick). One copy of the PIS, oral consent script, interview schedule and DS were used as prompts or scripts during the interviews. There were no other paper resources as all communications were in electronic format, and consent was taken orally.

2.2. Interview Procedure

2.2.1. The interview procedure is summarized in Table 9

Table 9: Interview Procedure

	<i>Procedure</i>
Contacting Participants	Interview time was arranged by telephone (or preferred contact) with the participant. Preferred location (either at home or the University of Nottingham, or via telephone/Skype interview) was established. Confirmation of appointment details was emailed or texted to the participant.
Interview	The researcher attended interviews with: • Audio-recording equipment • Encrypted USB device • Interview Schedule, Oral Consent Script, PIS, CF and DS At the start of each interview: • Participants were reminded of information within the PIS and oral consent taken. • The researcher explained her role and answered any subsequent questions • Participants completed DF and DAS 24 orally. Commencement of the interview – all interviews were audio-recorded. Interviews would be suspended or terminated on the request of the participant or if the researcher deemed this was appropriate (e.g. a participant failed to comply with the protocol).
Debrief	Following the interview, each participant was provided with the DS given orally to enquire about wellbeing, the impact of the interview and signposting for additional support. The researcher ensured there was an opportunity for participant questions.

Note. PIS = Participant Information Sheet (Appendix B); CF = Consent Form (Appendix C); DS = Debrief Sheet (Appendix D); DF = Demographics Form (Appendix E)

2.2.2. Once an expression of interest in participation had been made, the participants were contacted via telephone and/or email to organise an appropriate time for the interview. The researcher contacted each participant

one day before the arranged time (via an agreed method of either text or email) to ensure its suitability.

2.2.3. At the agreed time, the researcher called the participant and, if the call was not answered, a second call was made 10 minutes later. If the participant was still unavailable, the researcher would leave a voicemail message to rearrange the interview. If the participant contacted the researcher, the research would arrange to call the participant back immediately. Once it was agreed the participant was free to complete the interview, and was happy to do so, the researcher clarified whether the information presented within the PIS could be recalled. If required, the PIS was summarized to the participant as part of the process of obtaining oral informed consent

2.2.4. All aspects of the data collection were completed orally. The participants were advised the interview could be paused or stopped at any point if needed. If the phone call had to be stopped prematurely, it was agreed that the researcher would phone back after 10 minutes. It was also made clear that if a participant identified or showed signs of requiring increased support, recommendation would be made to contact professionals involved in their care (e.g. GP) or the Katie Piper Foundation, as appropriate.

2.2.5. The researcher presented the demographic questions orally and adequate time was given for response.

2.2.6. Participants rated their appearance concerns using the DAS24 which was presented orally by the researcher who could provide clarification if uncertainty was raised. This scale was completed to provide supplementary information to triangulate the qualitative data gathered and aid understanding of the individuals interviewed and the sample overall during data analysis. It was a means by which to consider whether qualitative interview data reflected the individual's reports on the DAS24. Interpretations of the data and emergent themes were grounded in consideration of the DAS24 scores across the sample. This was achieved by referral to the DAS24 scores as the themes developed. Within the burn population, the DAS24 is a frequently used standard clinical measure to assess appearance-related distress. Therefore, DAS24

scores were collected to provide context for clinicians who will have knowledge of how this sample relates to the populations within which they work.

2.2.7. The interview process permitted participants sufficient time to discuss the impacts of the injury to contextualize their experiences and the data gathered. The interview questions explored the (1) Impact of the burn injury – questions included: How did your burns/scars/hair loss affect how you felt about yourself prior to the medical tattooing?, and prompts such as - What impacts did this have on your body image?; and (2) Medical Tattooing – questions included: What were your hopes/expectations?, Can you describe to me the process you went through to get medical tattooing?, How does your tattoo affect everyday life?, What do others think about your medical tattooing? How has it changed how others react to you? and prompts including: How did the MT impact on appearance?, Can you tell me more about that?, and Can you give me an example of that?

2.2.8. Following the interview, participants were thanked and referred back to the PIS entitled: “What happens when the study stops?”. This was again summarised orally and participants were signposted to further appropriate support. Participants could request a copy of the published findings, if desired, and were informed these would be made accessible by the KPF via email and sent directly to those who were not in contact with the charity. Participant responses were accurately documented. Finally, participants were informed that, apart from receipt of a letter of thanks and the documented results, there would be no further contact with the researcher relating to the study.

2.3. Transcription and Analysis Procedures

The transcription and analysis procedures are presented in Table 10.

Table 10: Transcription and Analysis Procedures

<i>Transcription</i>
Interviews uploaded from recording equipment to computer as temporary files.
Interviews saved on encrypted memory stick, then uploaded onto an NHS computer.
Interviews transcribed via a transcription service. The transcription service used was required to sign a confidentiality agreement before undertaking the work.
Transcribed interviews were then stored following university and trust guidelines.
<i>Analyses</i>
Extraction of themes:
Transcripts read several times and annotated (close to free textual analyses)
Initial list of themes collated
Clustering of themes
Table of themes from each participant
Master table of themes from the group
Supervision:
Each interview informally evaluated in conjunction with the named academic supervisor to discuss relevance, depth and detail for the purposes of the current study and requirements for further data collection.

2.3.1 The transcription service was recommended by the University of Nottingham due to positive feedback gained from previous researchers in relation to accuracy, professionalism and speediness.

2.4 Stages of IPA Analysis (Smith et al., 2009)

(1) Each transcript was read and re-read to permit familiarisation with the data. This stage ensured that the participant is the focus of analysis. The first author listened to each recording alongside its transcript at least three times so the most striking aspects could be highlighted and pertinent observational notes made in a notebook.

(2) Transcripts were annotated with exploratory notes to generate ideas and questions about the way the account was constructed and potential meanings for the participant. The first author completed such annotations without the constraints imposed by dividing the text into units and utilised descriptive, linguistic and conceptual comments.

(3) Interpretation and thematic grouping of the exploratory comments were used to create emerging themes. The transcripts were divided into meaningful units, usually of one sentence. The author moved from a participant-led analysis to an interpretive-led approach. However, the focus remained on the participants' lived experiences.

(4) Comparison and contrasting of themes were used to create a coherent structure. Patterns and connections between the emergent themes were explored with consideration of abstraction, subsumption, polarization, contextualisation, numeration and function to map the emerging themes.

(5) Stages 1 to 4 in the IPA analysis were repeated for each case;

(6) Themes were explored across cases. Supervision was utilised to ensure the analysis moved from descriptive to interpretive levels.

2.4.1. The researcher utilised a reflective diary and supervision to explore the possible impacts of not possessing a shared experience of a burn injury or medical tattooing.

2.4.2. The method of bracketing is used within qualitative research to mitigate the potentially deleterious effects of preconceptions that may taint the research process (Tufford & Newman, 2012). However, in IPA, it is acknowledged that pre-understanding cannot be eliminated or "bracketed" (Koch, 1995). This method permits the close investigation of experiences through the researcher's perspective of the participants' interpretation rather than the assumption that the research is exploring the experience directly. Nonetheless, the author used reflective cycles to acknowledge and explore the impact of prior knowledge, expectations and the impact of previous analyses (Smith et al., 2009). Furthermore, the author ensured adequate time between each analysis to reduce the impact of one upon the other. It had to be clearly appreciated that, although the author shows a research interest in the psychological processes related to appearance, she has not experienced a burn injury.

~~The following are extracts from the author's reflective diary (Appendix K) reflect varying processes used to identify, manage and interpret the impacts of the authors lived experience during analysis (i.e. double hermeneutics the process of the researcher's sense making of the participants' sense making.)~~

~~Date: 10.6.19: Coding interviews:~~

~~(1) Self-awareness: Noticing that I am being influenced by coding previous interviews and concerns I am not being true to that individual's thoughts 'What if I am doing this wrong?'. Emotions 'fear' and 'frustration'.~~

~~(2)(1) Description: Coding alone: Noticed that I was using code 'identity' when perhaps I should have been using 'self' or another descriptor due to previous use of identity. Became uncertain that this was too interpretive at this stage or not right for this person.~~

~~(3)(1) Reflections: I feel pressure to code this correctly and reflect the participants' comments well and meaningfully to ensure the research is accurate and helpful both academically and to service users. The situation made me feel unskilled.~~

~~(4)(1) Influences: Having to pass my thesis, my internal assumption appearance will be linked to identity might influence what I put, I am having thoughts which question my ability and assuming inability to be independent. However, feedback after supervision concluded that coding looked appropriate. Consideration that supervision should influence my confidence in the results. IPA methodology means that I am going through a process and this takes time and development. Reminding myself that names or labels are just words that can be altered until the language provides the best understanding.~~

~~(5)(1) Evaluation: I cannot help but be influenced by interviews that I have coded or my assumptions but I can be aware of them and continue to challenge them by focusing on the transcript and asking myself 'What it this person saying?'. Went well: noticed the influence of the other interviews, thought about feedback and sought guidance from IPA methodology.~~

~~(6)(1) Learning: I am going to continue coding and discuss wordings further in supervision.~~

~~Date 4.10.19: Themes~~

~~For this extract, I decided to take a narrative informed approach to my reflections to help me maintain the story focus of understanding and interpreting participants' experiences, and also consider how my own narratives and stories are impacting on my interpretation of the themes.~~

~~Firstly, I am finding this process difficult and exhausting. Therefore, I have decided to pace this process to ensure I can fully focus on the data to prevent myself for making less accurate interpretations due to fatigue. The second experience I have noticed~~

~~that the interpretation process is testing my ability to hold and focus on larger amounts of information. I feel like I am holding 8 people in my head and I can identify that their experiences are overlapping, but I fear that I am conflating experiences rather than creating truly unique stories for them all. The data and process of IPA is overwhelming, but I remember from teaching and my reading that this is normal and a good sign. However, the need to reflect is clear.~~

~~From my perspective, it seems participants are all experiencing similar processes and views of MT — that it is fantastic to look better. It appears that this process has impacts that they cannot even describe to me as it is so inherently important to look normal. This could be understood as MT being an important part of a recovery pathway which should be offered as a standard treatment. However, I am more drawn to the influence of societal narratives. It is important to note that my personal preference and psychological stance is biased towards the power of such narratives and, as such, I am likely to see what I understand as narratives within all contexts, but given my personal conflict with narratives around appearance, these will be very notable to me. This part of my understanding is questioning the ‘correctness’ of saying having eyebrows or not having scars is the only way to look normal. Yet, I acknowledge I too have a conflict with dieting due to the pressure to look ‘normal’ by the standards of beauty (which isn’t normal). IPA acknowledges the role of the author and that all interpretations would be my own. But it will be essential to refer back to interviews where participants have spoken about the expectations of others and the negative reactions to their injuries to assure the themes truly represent the data. I have also booked in a supervision session to discuss the developing and emerging themes to discuss this further. I will reflect again following this discussion.~~ The following are extracts from the author’s reflective diary (Appendix K) reflect varying processes used to identify, manage and interpret the impacts of the authors lived experience during analysis (i.e. double hermeneutics - the process of the researcher’s sense making of the participants’ sense making.)

Date: 10.6.19: Coding interviews:

(1) Self-awareness: Noticing that I am being influenced by coding previous interviews and concerns I am not being true to that individual's thoughts – 'What if I am doing this wrong?'. Emotions – 'fear' and 'frustration'.

(2) Description: Coding alone: Noticed that I was using code 'identity' when perhaps I should have been using 'self' or another descriptor due to previous use of identity. Became uncertain that this was too interpretive at this stage or not right for this person.

(3) Reflections: I feel pressure to code this correctly and reflect the participants' comments well and meaningfully to ensure the research is accurate and helpful both academically and to service users. The situation made me feel unskilled.

(4) Influences: Having to pass my thesis, my internal assumption appearance will be linked to identity might influence what I put. I am having thoughts which question my ability and assuming inability to be independent. However, feedback after supervision concluded that coding looked appropriate. Consideration that supervision should influence my confidence in the results. IPA methodology means that I am going through a process and this takes time and development. Reminding myself that names or labels are just words that can be altered until the language provides the best understanding.

(5) Evaluation: I cannot help but be influenced by interviews that I have coded or my assumptions but I can be aware of them and continue to challenge them by focusing on the transcript and asking myself 'What is this person saying?'. Went well: noticed the influence of the other interviews, thought about feedback and sought guidance from IPA methodology.

(6) Learning: I am going to continue coding and discuss wordings further in supervision.

Date 4:10:19: Themes

For this extract, I decided to take a narrative-informed approach to my reflections to help me maintain the story focus of understanding and interpreting participants' experiences, and also consider how my own narratives and stories are impacting on my interpretation of the themes.

Firstly, I am finding this process difficult and exhausting. Therefore, I have decided to pace this process to ensure I can fully focus on the data to prevent myself for making less accurate interpretations due to fatigue. The second experience - I have noticed that the interpretation process is testing my ability to hold and focus on larger amounts

of information. I feel like I am holding 8 people in my head and I can identify that their experiences are overlapping, but I fear that I am conflating experiences rather than creating truly unique stories for them all. The data and process of IPA is overwhelming, but I remember from teaching and my reading that this is normal and a good sign. However, the need to reflect is clear.

From my perspective, it seems participants are all experiencing similar processes and views of MT – that it is fantastic to look better. It appears that this process has impacts that they cannot even describe to me as it is so inherently important to look normal. This could be understood as MT being an important part of a recovery pathway which should be offered as a standard treatment. However, I am more drawn to the influence of societal narratives. It is important to note that my personal preference and psychological stance is biased towards the power of such narratives and, as such, I am likely to see what I understand as narratives within all contexts, but given my personal conflict with narratives around appearance, these will be very notable to me. This part of my understanding is questioning the ‘correctness’ of saying having eyebrows or not having scars is the only way to look normal. Yet, I acknowledge I too have a conflict with dieting due to the pressure to look ‘normal’ by the standards of beauty (which isn’t normal). IPA acknowledges the role of the author and that all interpretations would be my own. But it will be essential to refer back to interviews where participants have spoken about the expectations of others and the negative reactions to their injuries to assure the themes truly represent the data. I have also booked in a supervision session to discuss the developing and emerging themes to discuss this further. I will reflect again following this discussion.

2.4.3 During supervision, assessments of the researcher’s coding and the interpretations which arose from the data were completed via group discussion and reflection and with direction from IPA guidelines (Smith et al., 2009).

3. Results

3.1 Conflict about Legitimacy

3.1.1. As a result of the barriers in communication with those who have not had personal experience of a burn injury, the primary source of emotional and instrumental support for participants in relation to MT was provided from within the ‘burn community’ rather than from friends and family - few participants

reported direct support from their families. Helen's reasoning for not seeking support from her family alluded to the impression that non-burn survivors are unable to offer validating support:

"I decided to go on my own, ... and I think someone else there ... talking, trying to make me feel better but actually, they are just getting in my head space."

Milly's account highlighted what appeared to be a tendency to only seek support from the 'burn community' comprising individuals who could more fully appreciate the impacts of the damage to appearance. (In addition to its members, many of KPF's support staff have also personally experienced a burn injury):

"[when asked if she sought support from family or friends] No, no, I just spoke to [A member of the KPF with a burn injury] about it. ... she was so good... very helpful, you know, it's somebody that actually cares ..."

3.1.2 Although participants did report brief conversations with specific individuals (e.g. children, partner, certain friend), these discussions were usually brief, and functionary (i.e. informing the individual they had chosen to have a MT).

"I just told my children" (Sara),

"Yes, I talked to my daughter about it" (Lucy),

"I think I mentioned it to a few friends" (Emmy).

When directly questioned, most participants reflected that they had received positive reactions and supportive comments when they chose to share their decision to undergo the procedure. Yet, no participant voiced seeking any input or support in relation to thinking through the decision to have MT. Considering the reported significance of the MT, this lack of discussion with family and friends perhaps suggests difficulty in facilitating open discussions about the underlying reasoning for MT or the hopes and expectations MT may have held for these individuals. Milly's account illustrated this positive response:

"I discussed it with my mum and my friends. And they just said, well if that's what you want and you're going to feel better, then it's entirely your choice to do so. They were, everybody was a hundred percent, a hundred and ten percent behind me."

Lily's experience, however, highlighted that not all reactions were positive. This is perhaps indicative of the reactions the other participants sought to avoid:

"So when I said to her, I'm going to have this medical tattooing, (mum said) what are you messing about with yourself for? You're alright as you are, just leave it alone.... She didn't want me to do it. And I've been back a few times and each time she's had the same response about it..."

3.1.3. Interestingly, although it appeared there were family members and friends who were perceived to understand and sympathise, support was not sought from them during MT sessions. Penelope's account highlights that offers of support were made but she felt a strong desire to be solely independent at this time:

"I went to [KPF] before going and they actually offered, my mum offered to come with me, I had a friend offer to come with me, but it was something that I wanted to do..., like something for me to overcome, ... going into London on my own and having this treatment done."

This highlights the importance, for her, of regaining control and independence but this may also suggest the provision of support for a MT is not perceived as legitimate.

3.1.4. Penny highlighted that family and friends reported they were not aware of her scars and continued to value her as they had done before the burn was sustained. While the validation of her internal worth was a positive experience, it caused her to question the necessity of undergoing the procedure. It may also confirm the suggested narrative that appearance should not be a concern and she should be accepting of her new, altered appearance:

"No, because my friends aren't looking at my scars and stuff... my partner says as well, that he doesn't really see the scars, you know. It's what I am inside that matters to my close friends and family."

3.2 Managing Hope

3.2.1 Intensity of hope was experienced by those who acquired their injuries many years before discovering MT. Milly, who was burned during childhood and did not remember a time before this injury, highlighted her intense hope by voicing both excitement and impatience to undergo the procedure:

"As soon as, ... I was informed that I could have this done, I just thought, I just can't wait, I was so excited, I just couldn't wait to get it done."

Positive expectations were also experienced by those who were made aware of MT in the early stages of recovery. Penelope stated:

"Yes, that glimpse of hope was a huge thing. ... there's something to actually look forward to in all of this like horrific cloud hanging over me".

3.2.3 Participants also reported hope for increased confidence. Sara, a participant who found it difficult to express her experience, was asked what she hoped the improvement in appearance would bring and simply replied "Confidence". The simplicity in this statement reflected the voices of all participants and suggests that appearance felt integral to confidence - the hope for improved appearance included hope for improved confidence. It also appeared that the hope for increased confidence was linked to anticipation for reduced need for camouflage in both make-up and clothing.

3.2.4 Others hoped for improved reactions from strangers such as a reduction in incidents of being stared at and perceived as "frightening", "disgusting" or as abnormal – "a freak". Helen, who had extensive scars on her legs, also focused on the hope that improved appearance would reduce how evident perceptible the scars were to others:

“... it’s mainly the pigmentation... there are some that are ... pure white, where the colour’s gone. And I thought, if they can get that covered up, they won’t be so noticeable.”

However, some like Emmy, reported their sole desire to improve appearance:

“Well just looking like a face ... I never put any of my thought process onto how much more different my life would be. ”

It is possible that pressures within her community to “fix” her appearance and meet the “Bollywood” expectation of beauty conflicted with the realisation that this would now be impossible. Yet, indirectly, like others, Emmy alluded to the desire of improved confidence and inter-relational experiences:

“So I’m carrying all these labels associated with... my scars. So things I grew up with, for example, were like, well you’re never going to get married because who’s going to look at you? No man is ever going to accept you the way you look.”

3.2.5. Similarly, Lucy’s emphatic, yet hesitant, description highlighted the centrality of appearance within her intense hope and the qualification of her expectations with the suffix in “normal-ish”:

“... people would not see what they’re seeing, they’d see something a bit, well just not see anything ... just see normal-ish ... they’d just see me, a person, not a person that’s scarred and burned.”

Emmy also indicated intense hope when recollecting her desire for the permanency of professional make-up:

“I’ve ... taken pictures and was like, wow, imagine... I thought why can’t they do a fixing spray, so they never ever come off?”

This hope resonates with the experiences of other participants who also reported struggling to use camouflage effectively and independently. Like Emmy, Milly voiced feelings of positive anticipation and also of relief at the prospect of no longer needing to apply daily make-up:

"I couldn't believe it, ... all I wanted done is my eyebrows making normal, ... And I couldn't believe it, that I could have that done,... I was just so happy that my eyebrows, I wouldn't have to draw them on anymore ...".

3.2.6. These intrinsic attempts to limit hope to only looking "a little bit" better or "more" like themselves took various forms across participants. For Lucy, the limitation was framed as an appreciation that the actual outcome could never meet her desired outcome:

"Just saying, ..., it would be nice to have some shape back" but I don't think they'll ever be like they were because, you know, they can't be. But even a bit better is better...."

Similarly, Emmy talked about reminding herself MT may not be a feasible procedure for her:

"I was kind of prepping myself for the fact, don't be too disappointed if they can't do it, it's OK. You've done without for all this time, it's fine."

Even Penelope, whose positive outlook appeared to have bolstered her recovery, remained fearful of having hope:

"The thought of having my hopes built up, of having them and then they just fade overnight, ..., that would literally, be a kick in the teeth."

Lucy simply stated:

"but I don't think they'll ever be like they were because, you know, they can't be."

3.2.7. Helen reflected on the need to use self-talk to limit hope and its negative impacts:

"You've got to prepare yourself for that because, obviously, my scars are quite old and they're quite deep. So there's always that chance that it might not work... So I had to try and think that, it was really hard though because I was like, oh it's going to be amazing. But yes, no, yes, I had to prepare myself for that, which was not very nice."

Similarly, Penelope reflected on the self-dialogue she used to both limit and maintain hope:

"I think ... I probably thought was What if it doesn't, because they say, it doesn't always take... to be fair, I was like, it can't get worse than what it is".

However, Lilly, who was very nervous about the procedure, stated she needed to avoid thinking about the MT in case she changed her mind.

"No, I tried not to think about it, to be honest. I tried to put it out of the back of my mind and not even think about it, so I didn't talk myself out of it."

3.2.8. Penny's direct responses appeared to differ with others as she maintained she did not have any expectations and felt no anxiety:

"I don't really know what expectations I had. (pause).. It's a bit difficult really to talk about expectations. I don't think I really had any. ...[when asked about anxiety] No, no. I just let them get on with it, yes."

However, it was clear within other sections of her interview, she was also demonstrating narrative inconsistencies demonstrated by others:

"You are going to look good after so it's worth the pain".

3.2.9. Again, Emmy illustrated clearly the intensification of the need to limit hope. On attending the MT appointment, her attempts to limit hopes and expectations were often expressed as the outright fear that MT would not be feasible and, again, she utilised self-talk.

" When I did get there, I was prepping myself ... don't be too disappointed if they can't do it"

Penelope also voiced fears that the procedure would not be successful:

"what if it doesn't, because they say, it doesn't always take."

For others, such as Lucy, the fear that MT would not be successful was more subtle, fearing the impact would be minimal:

"I just thought, I'm going to have an improvement. It may not be a lot but whatever it is, it will be some sort of improvement."

3.2.10. It is noted that, while most participants focused on appearance, others did this more indirectly by considering the practical advantages of MT such as not having to apply make-up daily.

3.3 The Process

3.3.1. For Lilly, fear was triggered by being uncertain about what the clinic would be like:

"... it's like an ordinary business park ... just, a flat roofed building with a white door and a buzzer. ... I didn't know what the hell I was letting myself in for..., do I press [the buzzer] or do I run away?"

3.3.2. For Lucy, whose interview reflected consistent wariness of the judgment of others, her feelings of fear were related to the sense of disparity between her appearance and the expectations for beauty within the clinic (ex2.2):

"I was [terrified], ... [the clinic is] quite intimidating because it's a different world ..., I don't do this makeup and body beautiful thing."

3.3.3. Similarly, Sara's account of feeling uncomfortable at the clinic illustrated anxiety related to the fear of negative reactions but to a lesser degree:

"I was not feeling comfortable ... I don't have much expectation [of what the people will be like], so it's not comfortable"

3.3.4. Penelope also reflected upon the possibility of the MT being unsuccessful, particularly if the clinician did not have the expertise to work with scars. She reflected that the lack of knowledge led to concerns about the risk that more irreparable damage may be caused:

"Yes, and that's when I kind of realised ...when I thought, oh it can't be worse, there was still that niggling of, actually, it could be. They could not only muck it up... I kind of felt, once you've tattooed something, it's even harder to have to tattoo it again."

3.3.5. When asked about anxiety, Penny simple stated:

"No, no.... No, I just let them get on with it".

3.3.6. Like others, Lilly reported she had not taken off clothing in front of anyone yet highlighted how clinicians facilitated her ability to overcome this fear:

" ... the burns unit people ... were so lovely, it made me feel comfortable to be able to take my jeans off and let them see."

Penelope's anxiety also reduced when she knew her clinician had worked with scars before –

" And I think a huge thing for me, was going to someone who had experience dealing with scars. ... [none experienced tattoo artists are] not going to have a clue, ... it's got to be done differently, ... that was a huge thing."

3.3.7. For those who had MTs to recreate specific features (e.g. eyebrows), Milly's comment typified how the process was straightforward:

"...she draws on with a pencil first and matches ... the colour that will suit your features, ... she shows you in the mirror ... Then she just cracks on with it."

However, Helen reflected upon her experience of the skin pigmentation tattoo on her arms and legs which caused more physical trauma than her facial tattoos:

"It's physically tiring ... because I had both my legs and my arms done"

3.3.8. While pain was considered within decision-making and participants' experiences, the brevity of Milly's discussions on pain suggested it was not central to the process:

"Well I'm not going to lie, it was [painful], ... it was very painful ... But it doesn't, it only lasts for, ... like maybe half a day, if that. And then, you know, you just forget about it"

Similarly, Penny reflected that the experience of pain was also considered within the context of results being more important:

"You know you're going to look good afterwards, so it's worth, ... putting up with a bit of pain"

3.4 Impact of MT

3.4.1. Lucy described the unexpected and undesirable appearance of her face immediately post-tattooing as follows:

"... it's quite funny because when you come out, ... it's dead dark and your lips are swollen and dead bright. ... I looked like one of these old women that had just bright red lipstick on and [eyebrows] painted black"

3.4.2. Helen, who had not been warned of post-procedural consequences, voiced fluctuations in her feelings and, for the first time, required support from a personal relationship:

"Definitely think, oh my god, what have I done?... ,... I sent him pictures of it and he was like, just think how it will be once it's all healed And I was like, yes, yes, it will be good "

For others, like Sara, support again was provided by the clinician:

"At first I didn't think it looked good but she talked to me, she said, 'no, after a few days you will see the result'"

3.4.3. Similarly, Lucy voiced being overwhelmed the moment she looked in the mirror for the first time:

"she just gave me the mirror and I thought, oh my god, I couldn't believe it.... all I saw were these eyebrows and lips and they were normal.... Oh I thought, wow, this is going to be good, and it was and ten times better than I expected, it was absolutely amazing."

It is perhaps understandable that, given the efforts to temper hopes, participants appeared surprised by their satisfaction with the results and the immensity of the impact of MT they instantly felt. Helen, who had described her fantasy of being 'fixed', reflected her surprise at the impact of the MT:

" I was kind of in awe. I was like, wow, I didn't really think that it was going to do anything but I can see changing ... I was so happy,

like this is going to work, this is great, this is going to change my life ... and I felt normal, and that sounds ridiculous ..., it's incredible."

3.4.4. Other participants voiced experiencing this life-changing impact in slightly different ways:

"It gave me everything back. It gave me my life back." (Lucy)

"Yes, yes, and they have, it's been a godsend, you know."
(Milly)

"I was just, I was so happy, like this is going to work, this is great, this is going to change my life." (Helen)

3.4.5. Positive language used to reflect the enormity of the results included: *"huge"* (Penelope), *"fantastic"* (Helen), *"A hundred percent"* (Sara), *"tremendous"* (Lucy) and *"really happy"* (Milly). These words and synonyms were used repeatedly throughout the interviews and participants frequently returned to mention the results of the MT regardless of the topic of conversation.

3.4.6. Helen described how improved appearance and confidence had further impacted on improving wellbeing:

"Oh definitely, yes. Yes, it changed how I felt about myself. Obviously, having more confidence but that touches into feeling, you know, prettier and happier and just, not feeling so negative about myself, which is massive, it's such a big deal."

Similarly, Penny reflected simply how she would recommend MT due to the resultant improved sense of wellbeing:

"Like yes, the main thing was like how it's made me feel and, you know, would I recommend it? For sure, like yes. Because if I could let somebody experience even an ounce of what I've experienced, then it's definitely got to be worth it."

3.4.7. Another example of the difficult participants had in expressing the impact of MT came from Emmy who reported life-changing consequences of having a face and the apparent regaining of her sense of identity reflected in the

statement – “*I almost owned my name and said, this is what [I] looks like.*”. So, surprisingly, when asked what changes it had made to her life, she stated:

"On a day-to-day basis it's not really done anything, no."

This again highlights the apparent conflict in or hesitancy to label improved appearance as a legitimate standalone change in day-to-day experience. Lucy also found it hard to voice the impacts of the MT. When explored during interview, she reflected she had not considered her experience prior to the interview:

"things you wouldn't normally think about on a day to day basis, without somebody sort of giving you a nudge"

3.4.8. Penelope, who had been a very confident person prior to her injury, provided a relatable insight into the confidence MT had brought:

" When you go and buy that dress that fits you and makes you look amazing, you feel a hundred, like a million dollars in this dress, that's how I feel having my lips and eyebrows done."

3.4.9. The consequences of both reduced barriers and fewer difficulties in interpersonal relationships after MT was discussed by many participants but they focused on these less. There was reduced need to hide scarring which was now hidden by the tattoo, an increased sense of positive interactions and improved abilities to relate and share experiences and feelings with friends. Lilly discussed the removal of the barriers created by her ‘horrific’ appearance:

"Oh my god, it's a game-changer better... unless somebody got up close and stared, they wouldn't actually know. Whereas, before, it was pretty horrific."

Penny focused on the positive feedback and improved interactions due to MT:

"[my daughter] thought they were great. Everybody was, you know, when people first see them they always pass a comment on them."

For some participants, the reduction in barriers was more subtle, such as being able to discuss the injury with friends and the reclaimed experience of taking pride in their appearance. Emmy talked about re-engaging with friends:

"... now I can talk to my friends about eyebrows, or when they go to get their eyebrows done.. I can sort of, I get it now,... I've got an eyebrow appointment as well... it's being able to connect to my girlfriends on a different level."

Many voiced a strong belief that the decision to undergo MT was for self-benefit and was not an attempt to influence others' reactions. Yet, all participants inadvertently discussed MT's role in reducing, but not removing, the negative reactions of others. This suggests a level of conflict around it not being acceptable to care about what others think about your appearance. Helen reflected upon the legitimacy of MT as a personal choice which was not intended to influence the reactions of others:

"I don't think that [others would] noticed anything different...But that's OK, I don't care what they're thinking, in a way. It's all about, I can see the difference and I feel better about myself, so I'm now happier."

3.4.10. All participants expressed difficulties in accessing and/or communicating the impacts of their MT, which was perhaps exacerbated by the presumption the interviewer could not understand their personal experiences. However, during the interviews, all provided examples of how MT had positively impacted upon them when they were not being directly questioned about these aspects:

"... it's silly, because you're dead excited, you've got these lovely lips again" (Lucy)

"... now I can talk to my friends about eyebrows, I can sort of, I get it now,... I've got an eyebrow appointment as well... it's being able to connect to my girlfriends on a different level." (Emmy)

I knew it looked good from the moment that she showed me it. And from that moment, you know, confidence had gone, you know up, I nearly said to Karen, I said, at least I look normal. (Milly)

The difficulties with providing clear examples may again reflect continuing doubt in the legitimacy of the experience they are portraying, as demonstrated by some language used (e.g. “it’s silly”, or “it sounds crazy”). Furthermore, Lily’s extract may highlight the possibility of a shift towards being able to feel validation from her friends and family following her MT.

3.4.11. Another powerful statement was produced by Helen who reflected upon regaining the ability to look at herself in the mirror:

"I can like look at myself in a mirror and not completely hate myself. It's better than what it was. Before I couldn't even look at myself in the mirror... it's just changed just how I feel about myself and my confidence and it's just amazing. I don't really know how to say anything else. It's just, it's amazing "

This perceived reclaiming of humanity was similar to Emmy’s earlier quote about being able to feel truly herself when looking at her MT:

"as soon as I saw my face, I looked like a face now. I looked, I almost owned my name and said, this is what [I] looks like."

For Helen, whose MT was on her arms and legs, the focus was on no longer feeling as though she was held back by the scars:

"Just like wearing clothes that I want to wear, like everyone else wears. And it's just the most amazing feeling, just to feel a bit free and not held back by all of this."

Also, Lilly spoke about how MT created a nipple which gave her more sense of completeness:

"... when they created my nipple, that was like, oh my goodness, that, I think, gives you more confidence. I felt more womanly, you know, a bit more complete. That was actually really lovely"

4. Discussion

4.0.1. Physical appearance is of great importance in a sociocultural context that places a high premium on physical attractiveness (Thombs, Lawrence, Magyar-Russell, Bresnick and Fauerbach, 2008). Perceived physical

attractiveness is associated with many valuable personal characteristics and social advantages (Eagly, Ashmore, Makhijani, Longo, 1991; Langlois et al., 2000). Research findings suggest that attractive children and adults are judged and treated more positively than those who are perceived to be unattractive (Langlois et al., 2000). Attractive people are perceived to be healthier (Weeden & Sabini, 2005), more competent (Eagly et al., 1991), have more positive personality characteristics (Eagly et al., 1991) and more likely to succeed academically (Ritts, Patterson and Tubbs, 1992) than unattractive people. Furthermore, they are more likely to be helped by strangers (Benson et al., 1976), be treated more leniently in judicial situations (Mazzella & Feingold, 1994) and have the advantage in hiring, promotion and job performance evaluations (Halioua, Williams, Murray, Skalko and Vogelsong, 2011b). Those with a visible difference, on the other hand, report negative experiences as previously described (Rumsey & Harcourt, 2004). MT aims to improve appearance via reconstruction of features or skin pigmentation. Although the perceived attractiveness of this 'new' appearance was not specifically explored, many reported an improvement in appearance.

4.0.2. Satisfaction scales are frequently utilised within clinical practice and evaluations. Yet, there is limited research on the utility and validity of such scales, with most being developed specifically for each individual study. Similarly, there is large variation in the QoL measures applied within research. For example, a systematic review which considered QoL in paediatric clinical trials identified 14 different QoL measures within the 18 trials (S. A. Clarke & Eiser, 2004). Furthermore, QoL measures frequently have different foci (e.g. physical functioning, feelings of health and vitality and psychosocial functioning). As a result, care must be exercised when selecting and applying a QoL measure and considering the conclusions drawn. Within academic burns literature, variations of the Burn Specific Health Scale (BSHS) are frequently utilised to evaluate QoL. Each of the scales has shown high levels of reliability, with α -values ranging from 0.82 to 0.94 (Kildal, Andersson and Gerdin, 2002). Although this measure was not utilised, this study highlights that standardised QoL measures may not reflect the important factors for the participants but instead reflect the ones imposed upon them. While these scales provide useful

information, they cannot access how individuals make sense of their experience or give voice to novel factors which have yet to be considered within research.

4.0.3. Self-esteem is a fundamental component of self-concept and worth of self (Harter, 1999) and refers to a person's positive or negative appreciation to the different roles and domains of life (Markus, 1987). Body image esteem or satisfaction is also a multidimensional concept that relates to perceptions about one's physical appearance and the degree to which a person is satisfied with his/her appearance (Cash, Santos and Williams, 2005). A close relationship between appearance and self-concept have been documented within the general population (Harter, 1999) and the interdependence of these constructs for people with visible differences has been supported within a range of studies (Kent & Thompson, 2002). It has been widely evidenced that there is an inverse relationship between personal self-esteem and psychological distress (Greenberg et al., 1992). Personal self-esteem also has been theorised to moderate the relationship between various stressors and psychological distress (Corning, 2002).

4.0.4. Research findings confirm that visible differences, including burn injuries, lead to lowered self-confidence and negative self-image across the lifespan (Rumsey & Harcourt, 2004). A person's subjective perception of how noticeable their difference is to others is a better predictor of psychological and body image disturbance than the assessment of an observer or clinician (Harris, 1997). Those who have a burn injury frequently report negative self-appraisals and shame (Fauerbach et al., 2002; Kornhaber et al., 2018) although there is evidence to suggest the male gendered burn survivors experience less difficulties with self-esteem and poor positive body image (Orr, Reznikoff and Smith, 1989).

4.0.5. Shame may be viewed as a maladaptive emotion associated with exposure and with a concomitant need to hide. It could, therefore, be considered a negative evaluation of self (Duncan & Cacciatore, 2015). Feelings of shame primarily manifest in the concept of one's body image which include social, cultural and parental perspectives (Kornhaber et al., 2018) and frequently result in participants feeling pressure to conceal their scars. There is also evidence to suggest relatives of burn survivors feel ashamed by the burn

survivor's appearance. Additional cultural-specific judgements on appearance (Kornhaber, et al., 2018) may be likely to support the perceived pressure to use camouflage. The themes identified within this study supported the concept of, and the importance of, a perceived pressure to cover scars from others within the experience of MT. However, published research shows some burn survivors do not experience shame (Kornhaber et al., 2018). Similarly, this was understood as a level of acceptance but did not appear to require MT to facilitate this (Hunter et al., 2013). There is also evidence that American adolescents with burn injuries who attended an organised 'support' burn camp felt relief when they no longer needed to cover-up their scars as they felt safe from judgement (Cox, Call, Williams and Reeves, 2004). This reflects the finding within this study that participants felt those within the burn community were the only people who could understand their experience and highlights the importance of regaining freedom from the pressure to cover-up scars. This study also spotlighted that continued exposure of scars within this 'safe' community allowed some participants to feel more able to expose their scars when they returned home (Cox et al., 2004). This suggests that it may not be necessary to improve appearance for those who have survived a burn injury in order for them to regain freedom from their injuries.

4.0.6. Two participants were from minority groups. The cultural differences did not impact on the development of the themes, as the differences voiced focused more significantly on the impact of the burn injury itself rather than the experience of medical tattooing. The data may also tentatively suggest that certain cultural narratives place increased pressure on individuals to address their altered appearance. For example, one participant felt pressured to relocate to the UK partly to seek treatment for her burn injury, and partly due to her appearance no longer being accepted. It is possible that such cultural pressures will influence individuals motivation to seek MT, and the increase the hope that MT will improve appearance to reduce the feelings of shame or rejection (Gilbert, 2000; Sharratt et al. 2019). The data found within this study suggests the need for further consideration of the impact of societal narratives (e.g. Bollywood verse Hollywood) on the psychosocial adjustment following a burn injury.

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4.1 Regaining Freedom

4.1.1 In Norway, Moi & Gjengedal (2008) studied 14 individuals (men=11) to explore life experiences after a burn injury and concluded that participants expended significant effort to create coherence in their disrupted personal life stories. As with the data gathered in this study, Moi and Gjengedal (2008) reflected that the participants' burn injuries were sudden and unexpected causing disruption to their lives for many years. It was reported that the accidental burn trauma and its treatment altered their perspectives on life and, in order to improve every day experiences, they needed to strike a balance between accepting what could not be changed, such as physical damage to nerves or restricted movement and striving to alter that over which they had control (Moi & Gjengedal, 2008). These researchers highlighted that this was a process that began during hospitalisation during which time the participants had felt completely dependent on others. It would also appear that, within the contextualising data collected in this study, regaining freedom from multiple factors is central including freedom from dependence on others and from physical constraints. MT would, therefore, appear to have a role to play in facilitating recovery from the psychological impacts of a burn injury.

4.1.2. There is a fundamental role of ‘others’ in the experience of living. It appears the neurotypical brain is innately designed to make humans social beings (Frith, 2013), including the ‘mirror neuron system’ which is a brain network activated when an individual observes the actions of ‘others’ (Jeon & Lee, 2018). The role of ‘others’ in shaping individuals’ experiences starts at birth when infants rely on their primary caregiver to understand and interact with the world around them (Bowlby, 1979). Evidence even suggests that positive interaction with others is essential for ‘healthy’ brain development. whereas negative or limited interactions can be extremely detrimental (Hughes, 2004). This fundamental importance of others is also reflected in the description of humans as a ‘ultra-social’ species with the desire to learn from and cooperate with each other (Boyd & Richerson, 2009; Tomasello & Vaish, 2013).

4.1.3. The importance of the role of ‘others’ has been researched within numerous academic fields, particularly psychology and those focusing on wellbeing. It seems, for example, that shame, depression and social anxiety are highly correlated with feelings of inferiority (Gilbert, 2000) in line with social rank theory which argues that emotions and moods are significantly influenced by the perceptions of one’s social status/rank (Gilbert 1992). When the role of ‘others’ is considered together with the literature on appearance, it appears those who are considered more attractive are ‘better’ (social judgment) (Thombs et al., 2008). As a result, visible differences may be accompanied by social challenges. It is likely that social factors are influential to the experience of MT for those with a burn injury, as suggested by the work of Sharratt et al. (2019). Yet, a comprehensive understanding of the processes by which this is affected remains elusive. It has been suggested that an integrated theory considering models of social anxiety and body image schema, sociological models of stigma and social skills training could be valuable in developing further understanding (Kent, 2000).

4.1.4. Social comparison theory was posited by Festinger (1954) who suggested that humans are driven to evaluate their opinions and abilities and driven by a desire to learn about themselves through comparison with others. However, most individuals’ awareness of, or willingness to admit to, social comparison is limited (Schoeneman, 1981). It is argued that there are three

underlying motives for comparison: self-evaluation ('How am I doing?' 'What should I think or feel?'), self-improvement (learning about abilities, and, in doing so, improve them) and self-enhancement (enhance self-esteem or self-concepts).

4.1.5. Two types of social comparisons have been postulated: upward comparisons or comparing ourselves to those we perceived to be 'better' than we are, and downward comparisons, or comparing ourselves to those we perceived to be 'worse'. The desire or need for self-enhancement can affect the amount and direction of comparison (i.e. upward versus downward comparison) in addition to its impact (Wills, 1991). This study highlighted that participants were able to discuss their use of downward social comparison as a method by which they could recognise positive aspects of their appearance. However, the interview transcriptions suggest there may also be an unspoken influence of upward comparison which impacts upon those who have experienced a burn injury.

4.1.6. Difficulties and anxiety in social situations are among the most frequently reported issues by individuals with disfiguring conditions (Kornhaber et al., 2014). Many people with a burn injury experience at least temporary difficulties in social or occupational engagement (Blakeney et al., 2005; Partridge, 1990; Robinson et al., 1996) and up to half of survivors experience chronic and pervasive social strain (Blakeney, Partridge, & Rumsey, 2007). This anxiety can be maintained by avoidant coping strategies, such as escaping stressful encounters (Fauerbach et al., 2002; Kent, 2000). This, in turn, can create and maintain phobic anxiety specific to social situations including those in which burn survivors may need to expose their scars (Newell & Marks, 2000). Therefore, a burn injury can increase self-consciousness, social anxiety, and anticipation of rejection (Kapp-Simon & McGuire, 1997; Kornhaber et al., 2014), poor social skills and a tendency to attribute negative social events to the injury (Robinson, 1997).

4.2 Limitations

4.2.1 Alongside the potential limitations of the use of an interviewer without experience of a burn injury, there is the commonly encountered limitation in qualitative research due to the potential ambiguities which are

inherent in the human language. While the interviewer utilized clarifying questions to prevent the assumption of meaning, such difficulty cannot be removed completely. The IPA methodology acknowledges this challenge and views results as the author's interpretations of the participants' interpretations and, as a result, no feedback on the themes was sought from participants within this study. Thus, it is possible that presented interpretations may not resonate as 'true' for participants. It has to be concluded, therefore, that although offering insights into the experience of MT following a burn injury, future investigations would allow these results to be interpreted in a wider body of research.

4.2.2 Within qualitative approaches in research, findings cannot be extended to wider populations. As the data is not quantitative, conclusions drawn from this study relate solely to the participants involved and generalised conclusions have to be tentative in nature (Smith et al., 2009) and the clinical implications which can be drawn are limited. However, qualitative research does permit for fine distinctions to be drawn from the data set (such as surrounding the potential components of improved confidence); the data does not have to be restricted by predefined categories and expectations. IPA also usefully acknowledges the inevitable impact of the researcher's knowledge and expectations.

4.3. Clinical Implications

4.3.1 While there is evidence to support the use of CBT within the burns population in relation to appearance anxiety (Clarke, Thompson, Jenkinson, Rumsey & Newell, 2013), there are other psychological approaches which may be beneficial following careful consideration and evaluation. Narrative therapy, for example, adopts an interpretive method rather than assuming underlying structure or that dysfunction determines behaviours (Carr, 1998). It suggests that the self and reality are socially constructed, through language, from moment to moment (Payne, 2002) and that individuals use narratives to develop and sustain a sense of self and purpose from diverse experiences (Singer, 2004). Additionally, narrative therapy actively scrutinizes knowledge and power (White & Epston, 1990) and how individuals are subtly, or overtly, regulated by the normalising gaze/dominant discourses of society. The current study identifies powerful societal narratives which appear to impact on

adjustment such as experiences of losing identity, fears that others cannot appreciate their experience, and the sense of the pathway of recovery being a story to share with others. However, the theoretical underpinnings of a narrative therapy approach conflict with standard evaluation methodology and, additionally, there is limited research to evidence its effectiveness. Nonetheless, therapists working within burn services may wish to consider the potential benefits of a narrative approach when discussing appearance-based treatments.

4.3.2. It has been suggested that, potentially, acceptance and commitment therapy could be considered in relation to supporting those with visible differences (Zucchelli, Donnelly, Williamson & Hooper, 2018). Similarly, compassion focused therapy (Gilbert, 2009) may be beneficial as self-compassion has been demonstrated to moderate the inverse relationships between body-related threats and body appreciation in those with body dissatisfaction (Homan & Tylka, 2015). The efficacy of such interventions with burn survivors would need to be evidenced and any required modifications required clearly presented.

4.4. Future Research

4.4.1. It will be necessary to assess the effectiveness of MT using longitudinal research methods, and notably, whether concomitant psychological interventions enhance the effectiveness of the procedure on improving body satisfaction and overall well-being. It is suggested that consideration of issues of hope, identity, self-esteem, and the role and influence of others will be useful. The use of a case study design within burn services may be an effective way of implementing research within the population as it would permit the application of appropriate interventions based upon the psychological formulations for each individual.

4.4.2. This study indicates that participants were striving to regain a sense of 'normality' and MT facilitated this. However, due to notable variations in perceptions of normality (Denford et al., 2011; Tiefer, 1994), misunderstandings between patients and practitioners may occur when reconstruction options such as MT are being considered. Subsequently, this may result in inappropriate advice, unrealistic expectations and reduced

satisfaction levels. It will be essential to consider how burn survivors view normality to enhance practitioners' ability to understand patients' goals and motivations within their desire to be 'normal'. This may lead to more effective communications and management of expectations so patients can make fully informed and confident decisions about MT and patient experience will be improved.

4.4.3. Longitudinal research to consider the issues of feelings of loss of control and normalcy and how these are influenced in the recovery from a burn injury may be useful to contextualise MT and other treatments within the recovery process.

4.4.4. Research considering the use of social comparison within the adjustment process may highlight how this process may facilitate or hinder adjustment to those with a burn injury.

4.5 Strengths of Research

~~4.5.1. This study has provided a powerful insight into the lived experience, common themes and narratives of those who have chosen to seek MT as a treatment for their burn injury. The results highlight the complex contradictory narratives between life-changing effects of MT and societal pressure concerning outward appearance. It has demonstrated that while the focus of MT is on appearance for these participants MT provided much more, including a perception of 'normality' and inclusion that outweighed appearance. Thereby, highlighting the possibilities of MT in improving psychosocial adjustment if offered more widely within the NHS. Furthermore, the detailed insight into the experience of MT supports clinician's ability to support those who have experienced a burn injury in decision making regarding their treatment.~~

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5. Conclusions

5.1 Critical Reflective Component

5.1.1 This section will provide a critical reflection on the process of undertaking this research. It will be written in first person to give voice to the author's experience and learning.

5.2 Paucity of Previous Research

5.2.1. The paucity of published research findings relating to MT created challenges in the development of research design and goals. At the time of initial study design, no published and peer-reviewed research of MT was available that could have provided focus for the current study and guide suggestions for appropriate design. Subsequently, therefore, the aims of the study had to be more wide-reaching to reflect this. Additionally, although I had previously completed qualitative research, I found the progression to doctorate level research somewhat daunting and challenging. Nonetheless, I felt driven by the awareness that MT constitutes an essential part of the battery of treatments available to those recovering from burns. Therefore, its short- and long-term psychological and social impacts and cost-effectiveness, for instance, must be stringently evaluated, particularly if offered routinely through the NHS. In this case, it would be vital to consider the validity of the presumed assumption that 'improving' appearance was inherently a beneficial outcome. My personal interests in the dominant narratives surrounding beauty, which have been coined as the 'beauty myth' (Wolf, 1991), influenced me to question this premise and consider addressing the lack of research in burn victims and within the wider population of individuals with visible differences. Consequently, I have become more confident in my ability to consider research in areas in which

there is negligible investigation. I have been able to consider supportive, pertinent literature in related fields such as around the concept of normalcy and within other populations who have or might undergo MT.

5.2.2. I have become aware of the benefits of explorative qualitative studies and how they can offer valuable insights into the complexities of lived experiences. This is particularly beneficial within the arena of clinical psychology, as many clinical areas are still developing and evolving and remain under-researched. This includes the impact of narratives related to appearance on individuals who do not, or cannot, meet those expectations and also in populations such as looked-after children and new diagnostic categories such as complex post-traumatic stress disorder.

5.3 Recruitment

5.3.1 Recruitment of subjects proved challenging within this study. As a relatively new treatment for burn injuries, MT has only been offered to a small proportion of individuals through a limited number of burn services throughout England. Consequently, possible numbers for recruitment would also be limited. Alternative avenues for recruitment were considered including approaching relevant charities and private companies offering the procedure. Although this would have been beneficial in relation to the speed of ethical approval, there would be inherent difficulties of advertising for interview participants through such avenues. It would be particularly challenging for private companies due to data protection issues; it would be problematic for data to be used for a purpose other than that agreed to within consent documentation i.e. contacting patients about research. Charities, however, regularly remain in contact with their clients via events and newsletters for which consent has been gained. Nevertheless, as there is only one UK charity (KPF) that supports victims of burn injuries, options for recruitment were limited. Fortunately, one supervisor had established contacts within the KPF and had worked effectively with the organisation to undertake previous research studies. However, this recruitment strategy resulted in compromised ability to produce a 'true' IPA study (by being fully idiographic) due to ethical issues with anonymity. Unfortunately, recruitment via the KPF created an unexpected difficulty in maintaining anonymity for participants. Through the interview process it became clear that,

as participants regularly shared their stories, it would be likely that those within KPF would be able to identify participants from the demographic information collected. This created a conflict between ensuring essential confidentiality and providing a truly individualised account of experiences.

5.3.2 This experience reinforced that the exploration of possible recruitment options is crucial but also restricted options do not mean that recruitment is impossible. However, unforeseen limitations can always occur. The conflict between anonymity and research design made me consider and develop ethical knowledge and understanding and clarify my personal stance. In future research and practice, I will continue to prioritise ethical choices and acknowledge the limitation this may place upon research and practice (e.g. protecting confidentiality and the central importance of informed consent). However, in the future, I will ensure I take greater time to consider options around the possibility of recruitment from a wider pool and to discuss limitations that may be pertinent for the charities or organisations, particularly when working with smaller populations.

5.3.3 I have developed skills in considering how data should be presented to ensure anonymity (such as through the creation of tables for participants' information to present visual demographic details to provide context for interpretation of the results). This method of presentation facilitated both my learning and appreciation of the need for consideration of the audience of the research; alongside accurate representation of the data collected, it was useful to concentrate on the key points that I would like to be the 'take-home' message.

5.3.4 It is my feeling that I have developed as a researcher; encountering and managing unexpected challenges and conflicts has supported me to be increasingly resilient and also adaptable. These attributes will be beneficial in both future research and day-to-day clinical practice.

5.4 Qualitative and IPA Approach

5.4.1 I had limited previous experience of utilising an exploratory qualitative approach in research to gain an understanding of underlying reasons, opinions and motivations. Consequently, I have developed my

knowledge, skills and understanding of this approach, particularly through decisions on appropriate design study and application of an IPA methodology. This was facilitated via supervision and resources provided from the additional authors. Additionally, I contacted other relevant academics with knowledge of relevant studies. I have come to appreciate the importance of seeking support from experts in the field to facilitate improved knowledge and inspire a wider consideration of relevant information, design and analysis.

5.5 Epistemological Stance

5.5.1 A critical realist perspective is not perhaps a traditional epistemological stance when completing an IPA study. However, I could not take this stance as it did not feel genuine to my beliefs about understanding and using knowledge. This meant I had reservations about how realistic it would be to apply this. The research aimed ultimately to offer informative and insightful data to clinical practice and trigger future research. Consequently, I hoped the findings generated would be of tangible benefit to those who have experienced a burn injury. This again felt at variance with a pure social constructionist stance. However, I am significantly influenced by narrative approaches which also are positioned within the social constructionist stance. Therefore, I felt conflicted about the appropriate stance with which to approach the research problem. The process of conflict resolution here highlighted to me the necessity of reflections and reference to published literature. In this way, I was able to consider and ultimately choose to approach the research from a critical realist stance which acknowledges humans/individuals can never identify or understand all experiences with certainty due to the limitation of human intellectual mechanisms (Guba & Lincoln, 1994; Sims-Schouten, Riley & Willig, 2007) but also accepts that reality exist. This stance, thereby, allows the testing of theories, by accepting that there must be structures and processes against which to reference them (Bhaskar, 1978). It allows for the consideration and exploration of the efficacy of any clinical and academic implications of research. This was deemed an appropriate stance which could truly be in line with my beliefs about how individuals make sense of the world (i.e. there is a reality but individuals form narratives to understand their experiences). I have also learnt how important it is for me that research questions and approaches feel

‘authentic’ and will consider such fundamentals in future research and my clinical practice.

5.6 Impact of Research

5.6.1 While this study was able to provide insights into MT, it also raised issues that were not related directly to the aims of the study. This was of great interest to me and generated further questions around the complexity of appearance, societal roles, and beauty expectations. I hope the findings of this project will stimulate interest and subsequent research to generate further data which can be applied to improve well-being, particularly for those in vulnerable groups. However, on a personal level, I have come to appreciate that one might enter a research project with a set of expectations but complete the study with a greatly differing mind-set and understanding. This awareness will be beneficial to me in the completion of future research as it will help ensure I remain open-minded and flexible. It has also highlighted the benefit of maintaining regular reflection to consider how increased knowledge supplements, alters or conflicts with your belief system and how this may impact on your approach to research. The process of reflection directed me to seek increased levels of support from peers and colleagues which then permitted external perspectives to be compared to my own. I feel that this was a means by which to reduce my personal biases and will utilise this for monitoring personal influences in the future.

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Appendices

Appendix B: Copy of the Ethical Approval Confirmation



**University of
Nottingham**
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences Research Ethics Committee

c/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

2nd October 2018

Catherine Tyerman

Doctorate in Clinical Psychology Student
c/o Dr Danielle De Boos
Assistant Professor/Clinical Psychologist
Division of Psychiatry and Applied Psychology
School of Medicine University of Nottingham,
YANG Fujia Building,
B Floor, Jubilee Campus,
Wollaton Road, Nottingham
NG8 1BB

Dear Ms Tyerman

Ethics Reference No: 12-1804 – please always quote	
Study Title: The Experiences of Medical Tattooing in Adults following Burn Injuries: An Interpretative Phenomenological Analysis.	
Short Title: Experiences of Medical Tattooing	
Chief Investigator/Supervisor: Dr Danielle De Boos, Assistant Professor, Division of Psychiatry and Applied Psychology, School of Medicine.	
Lead Investigators/student: Catherine Tyerman, DClinPsy	
Other Key Investigators: Dr Anna Tickle, Associate Tutor, Doctorate in Clinical Psychology, Division of Psychiatry and Applied Psychology, School of Medicine, Laura Shepherd, Clinical Psychologist, Burns Unit, Nottingham University Hospitals NHS Trust, City Hospital Campus.	
Type of Study: PG Student, qualitative, interviews	
Proposed Start Date: 01/01/2018	Proposed End Date: 01/09/2019 21 mths
No of Subjects: 8	Age: 18+years

Thank you for notifying the Committee of amendment no 2: 01.10.2018 as detailed and the following documents were received:

- Oral Consent procedure and documents for telephone interviews to ensure that a record of consent is kept version 1.0: 01.10.2018.

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A favourable opinion has been given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Professor Ravi Mahajan

Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix C: Research Advert



‘The Experiences of Medical Tattooing for Adult Patients with Burn Injuries: An IPA Analysis’

I am hoping you can take part in an exciting study I am completing as part of my doctorate (DClinPsy) at Nottingham University

The Research: I am interested in talking to patients with burn injuries about their experience of medical tattooing. We are hoping this research will give us a better understanding of how you and others experience medical tattooing (e.g. why you wanted it, how it felt to have it, what effects it has had on your life) which in turn will help us offer improved support and evaluate the psychological benefits of medical tattooing.

This research involves meeting with patients, like yourself, to ask about your experience following your burn injury and through the medical tattooing process. This will involve one interview with me - Catherine Tyerman - that may last up to two hours – refreshments will be provided. If you take part, I will be asking questions about your views of the medical tattoo, the process and how you adapted to the tattoo.

Interviews will be arranged at your convenience, and can be completed at your home, at the Nottingham Burns’ Service or, if you, prefer over telephone or Skype.

Who can take part? – English-speaking men and women who are over 18, who have had at least one medical tattooing procedure related to their burn injury caused by an accident or injury.

If you are interested, please contact: Catherine Tyerman on C.Tyerman@nhs.net or the KPF

Appendix D: Participant Information Sheet



Participant Information Sheet

Research Study: 'The Experiences of Medical Tattooing for Adult Patients with Burn Injuries

Name of Researcher(s): [Catherine Tyerman](#)

We would like to invite you to take part in our research study.

Before you decide, we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have during our initial phone meeting, or you can contact us (details provided below). Talk to others about the study if you wish. Please do ask us if there is anything that is not clear.

What is the purpose of the study?

Medical tattooing is a procedure offered as part of the recovery for burn injuries. Its aim is to improve the appearance of scarring or damage caused by the injury. Currently there is little information on the psychological or social effects of this procedure. We do not know, for instance, how the procedure affects a person's wellbeing, relationships and work.

Therefore, as this type of procedure is more frequently offered, it is crucial to know how individuals like yourself experienced medical tattooing, why you chose to have undergo it and how it has influenced your lives.

The results will be vital to professionals - giving us first-hand information on the positives and negatives of going through the procedure and the effects it has on individuals' wellbeing and life generally. This will inform us on when and to whom we should offer the procedure, allow us to provide better support for those going through it and integrate it fully with the support that is currently offered.

Furthermore, it will give insight into how individuals feel about treatments which aim to improve appearance, and how these fit with other treatments such as psychological or occupational therapies.

Why have I been invited?

You are being invited to take part because our records suggest that you have had a medical tattoo, and so your experience is important to us. We are inviting eight participants like you to take part.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Even if you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your care or legal rights.

What will happen to me if I take part?

The project involves one interview.

Having received this information and agreed to be contacted in relation to this research, I will contact you to discuss several points:

- Whether you would prefer a face-to-face, or telephone/Skype interview.
- If you would prefer a face-to-face interview, I will ask if you would prefer the interview to be held at your home or the University of Nottingham.
- I will also arrange a convenient time for the interview to be held – the interview can be up to two hours, so it would be helpful to have a morning or afternoon free.

Following this discussion, confirmation of the agreed method, location, date and time of the interview will be emailed or posted to you.

On the date of the interview, we will meet where arranged. On that day:

- We will discuss the information in this form.
- I will talk you through consent (you will get a copy of this).

If you give consent:

- You will be asked to complete some information about yourself.
- I will discuss my role in the research.
- There will be time for you to ask any questions.

Following this you will:

- Complete a semi-structured interview related to your experience of having a medical tattoo. For example, questions will consider:

Why you chose to have a medical tattoo – your injury, what effects it had on your life and how you felt about any scarring.

How you experienced having the tattoo itself –, how much support did you receive and was it painful?

What has been your experience following the tattoo, how did you feel after the tattoo, how do you feel about it now, how did others perceive the tattoo and whether you would recommend it to others

Finally, after the interview, we will discuss how you are feeling and thoughts you have about the interview.

You will have time to ask any questions and further information about the study will be offered. You will also be given information on support which is available if you feel you need this following the interview. You will be asked if you would like a copy of the published results, which will be posted or emailed to you following the submission of the thesis. Following this, there will be no further contact with the researcher/about the research.

Pre- Interview

I will contact you to arrange:

- either a face-to-face interview or a Skype interview
- where the interview will be held
- a convenient time for the interview
- and I will answer any questions you may have



Day of the Interview

We will discuss:

- the information in this form
- consent
- my role in the interview



The Interview

If you wish to continue, we will ask you to complete

- a consent form – one for me and one for you
- a short questionnaire about yourself
- a semi-structured interview about your medical tattoo and



After the Interview

You will

- receive a full debrief
- receive information on available support

At this point contact will be terminated except from receiving letter of thanks and a method of requesting the published results when available

Expenses and payments

Unfortunately, you will not be paid to participate in the study. However, there are several options for interviews:

1. Interviews can be conducted at your convenience in a meeting room at the University of Nottingham. Where possible they can be arranged on the same day as follow-up appointments. Refreshments will also be provided.
2. The researcher can complete the interview at your home.
3. Interviews can be completed over the phone or via Skype to reduce travel time and costs.

What are the benefits of taking part?

We really appreciate your help in this study.

Currently, there is little information on what people think and expect from medical tattooing or how individuals experience the process of the procedure. The information you will be able to provide us is vital in developing our understanding of the experience of medical tattooing.

You will provide us with further information on experiences and impacts of medical tattoos e.g. the areas of your life in which it has made a difference and in what kind of ways. This information is crucial in providing a full service to people who have experienced burns and also provides important information around our understanding of recovery from burn injuries. This information may ultimately, reduce recovery times and improve long-term wellbeing. Providing further information will allow clinicians to understand how to support people through the process more fully.

What are the possible disadvantages and risks of taking part?

There is the possibility that taking part in these interviews may cause you to experience a range of emotions as you may talk through experiences you found hard. (see: What will happen to me?). The researcher is not able to offer advice or on-going support during the research, other than basic emotional support during the interview such as giving you suitable breaks. However, you will be signposted to organizations where you can seek appropriate support following any or all interviews, if needed.

Unfortunately, due to financial constraints, no more than £14 mileage costs can be covered.

What happens when the research study stops?

Following the interview, there will be no contact in relation to the study until you receive a copy of the published results (if you have requested to receive this).

What if there is a problem?

If you have any concerns about any aspect of this study, you should ask to speak to myself, the researcher, and I will do my best to answer your questions. My contact details are given at the end of this information sheet.

If you remain unhappy and wish to complain formally, you can do this by contacting Danielle De Boos: Address: Doctorate of Clinical Psychology, School of Medicine, University of Nottingham, YANG Fujia Building, B Floor, Jubilee Campus, Wollaton Road, Nottingham NG8 1BB, UK.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in strictest confidence.

If you join the study, we will use information collected from you during the course of the research. All information will be kept strictly confidential stored in a secure and locked office, and on a password protected database at the University of Nottingham. Any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in locked offices in swipe-card secured buildings, and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx>.

Authorised persons of the University of Nottingham who are organising the research may be given access to the data for monitoring and/or audit of the study to ensure we are complying with guidelines. All will have a duty of confidentiality to you as a research participant.

Information about you which leaves the research unit will have your name and address removed and a unique code will be used so that you cannot be recognised from it.

Your contact information (address, telephone number) will be kept by the University of Nottingham for one year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it.

All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say in the interview is confidential, should you disclose anything to us that puts you or anyone else at any risk it would be necessary to report this to the appropriate persons. Wherever possible, we would discuss this with you in advance and keep you informed.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason should you wish to do so, we recommend doing this within one week of completing the interview. After that point if you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Involvement of the General Practitioner/Family doctor (GP)

Your GP does not need to be notified of your participation.

What will happen to the results of the research study?

The results of this study will be written up as part of my doctoral thesis and then published within a relevant scientific journal, and within support groups' newsletters. The results will also be provided to Burns' Services across the East Midlands.

When you receive your letter of thanks following the interview, this will indicate when and where you can get access to the publication. It is important to note you will not be identifiable in any report or publication.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded as part of the trainee's Doctorate in Clinical Psychology.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS ref no: 12-1804).

Further information and contact details

Catherine Tyerman

Address: Doctorate of Clinical Psychology, School of Medicine, University of Nottingham, YANG Fujia Building, B Floor, Jubilee Campus, Wollaton Road, Nottingham NG8 1BB, UK

Email: msxcjt@nottingham.ac.uk/C.Tyerman@nhs.net

Appendix E: Scripts for Oral Consent

Hi, this is Catherine Tyerman from the University of Nottingham. I have been put in touch with you by the Katie Piper Foundation as you have previously agreed to take part in my research about 'The Experiences of Medical Tattooing for Adult Patients with Burn Injuries'

Thank you for talking with me today

Before we start I would just like to confirm you received the Participant information Sheet and have had a chance to read this? Do you have any questions?

I wanted to talk to you about the project I gave you information about before. To recap, the broad aims of my project are to explore your experience of medical tattoo – the good things and the bad things of how you found this experience, and what it meant to you..

Are you interested in taking part in the project?...

That's great. I just wanted to go over again some of details of the project to make sure you understand what's involved for you. These were that:

- It's a project about the experiences of medical tattooing for Adult Patients with Burn Injuries and it's being used for my thesis for my doctorate in clinical psychology
- If you take part, we will complete an interview over the phone which will last between an hour and an hour and a half approximately.
- This interview may be distressing as I'll be asking you about your medical tattooing, but as part of this will talk briefly about your burn injury. If you do find this difficult we can take a break and I will call you back – we will agree a time for this if and when it happens.
- You don't have to say yes to the project; you can ask me any questions you want before or throughout; you can also withdraw at any stage.
- You know that Nottingham University's Ethics committee has approved this work
I won't keep any of your details for longer than necessary, and any data used with my thesis will be completely anonymised.
- The phone call will be audio record and transcribed as part of the research - The transcription services will sign a confidentiality agreement prior to undertaking the work.
- You have the right to withdraw your data from the study up to one week after the interview. You understand that, should you withdraw after one week, then the information collected so far cannot be erased and that this information may still be used in the project analysis.
- You're aware that my written work will be published online

Are you still willing to take part? ...So if you're happy with all of that, and have no more questions, let's start.

If they have not read the PIS

Hi, this is Catherine Tyerman from the University of Nottingham. I have been put in touch with you by the Katie Piper Foundation as you have previously agreed to take part in my research about 'The Experiences of Medical Tattooing for Adult Patients with Burn Injuries'

Thank you for talking with me today

Before we start I would just like to confirm you received the Participant information Sheet and have had a chance to read this? Do you have any questions?

(if the answer is no)

No problem let me talk this through with you now...

I'm currently a trainee psychologist at the University of Nottingham. My research is on Burn survivors' experience of medical tattooing.

In my study, I want to explore burn survivors' experience of medical tattooing. As you are aware medical tattooing is a procedure offered as part of the recovery for burn injuries. Its aim is to improve the appearance of scarring or damage caused by the injury. However, currently there is little information on the psychological or social effects of this procedure. We do not know, for instance, how the procedure affects a person's wellbeing, relationships and work. I am hoping to find out some of this information.

If you choose to take part in the interview: We will go on to have a conversation where I will ask a whole range of questions about your experience of medical tattooing – so questions like:

Why you chose to have a medical tattoo – your injury, what effects it had on your life and how you felt about any scarring.

How you experienced having the tattoo itself – how much support did you receive and was it painful?

What has been your experience following the tattoo, how did you feel after the tattoo, how do you feel about it now, how did others perceive the tattoo and whether you would recommend it to others

Finally, after the interview, we will discuss how you are feeling and thoughts you have about the interview.

You will have time to ask any questions and further information about the study will be offered. You will also be given information on support which is available if you feel you need this following the interview.

If you agree to participate in this project, the research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. Further, the research will also be written up for articles to be published in academic and public journals. You will be asked if you would like a copy of the published results, which will be posted or

emailed to you following the submission of the thesis. Following this, there will be no further contact with the researcher/about the research.

The personal information you will share with me will not be passed to any third party.

This research is anonymous, which means that in my publications, your name will not be used, unless you insist on the opposite. This is completely voluntary, and we can stop any time you like. During the interview, I will use an audio recorder to make sure I'm getting an accurate record of your thoughts. The interview will then be transcribed by a company who have signed a confidentiality agreement. You have the right to withdraw your data from the study up to one week after the interview. You understand that, should you withdraw after one week, then the information collected so far cannot be erased and that this information may still be used in the project analysis. This is because the data will have been made anonymous and put together with anonymous data from other participants making it difficult to extract.

This research project has been reviewed and approved by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics committee. If you would like to speak to the University directly, I'll give you their postal address, but is within the PIS form provided. Do feel free to contact me also. My mobile is 07899 683091. You can also reach me at c.tyerman@nhs.net.

And if for any reason you wished to make a formal complaint, you would be able to contact my Supervisor

Dr Danielle De Boos: Address: Doctorate of Clinical Psychology, School of Medicine, University of Nottingham, YANG Fujia Building, B Floor, Jubilee Campus, Wollaton Road, Nottingham NG8 1BB, UK. E-Mail: danielle.deboos@nottingham.ac.uk

and/or

the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Any questions?

Are you still willing to take part? ...So if you're happy with all of that, and have no more questions, let's start.

Appendix F: Demographics Sheet

Research Study: 'The Experiences of Medical Tattooing for Adult Patients with Burn Injuries

Thank you for agreeing to take part in this research.

We are asking for this information as part of the research, so that we have a more detailed understanding of the participants, which will inform our analysis. We are collecting this information from everybody who takes part and we will write about the group collectively, i.e. we will not report your details in isolation, to protect your anonymity. This information will be securely stored at the University of Nottingham, which can only be accessed by the research team. It will be kept for seven years and then destroyed.

Participant no..... Age

Demographics

Ethnicity:

- White British ☐
- White Irish ☐
- Any other White ☐
- White & Black Caribbean ☐
- White & Black African ☐
- White & Asian ☐
- Any other Mixed ☐
- Asian or Asian British ☐
- Chinese ☐
- Other _____ ☐
- Prefer not to say ☐

Marital Status:

- Married/Civil Partnership ☐
- Cohabiting ☐
- Single ☐
- Separated ☐
- Divorced ☐

Religion:

- Atheism ☐
- Buddhism ☐
- Christianity ☐
- Hinduism ☐
- Islam ☐
- Sikhism ☐
- Other ☐
- No religion ☐

Employment:

- Employed full time (30h+) ☐
- Employed part time ☐
- Unemployed ☐
- Full-time student ☐
- Retired ☐
- Full-time homemaker or carer ☐
- Prefer not to say ☐

How did the burn injury occur?

.....
.....
.....
.....

When did the burn occur?

.....
...

How old were you when the burn occurred?

.....

How long was your stay in hospital?

.....

What was the total body surface area of the burn (if known)?

.....

Have you received any psychological support in relation to your injury?

.....

Appendix G: DAS24:

The Das24 is a copyrighted measure. You can obtain a copy of the DAS24 via direct contact with the author from the following website:

<http://www.derriford.info/>

Appendix H: Interview Schedule

A. Impact of burn injury

- a. How did your burns/scars/hair loss affect how you felt about yourself prior to the medical tattooing?
 - i. Appearance – before burn vs after burn
 - ii. Body image
 - iii. Identity/self-concept
 - 1. How would you describe yourself as a person prior to the medical tattooing?
 - 2. Did having a burn injury/scarring/hair loss make a difference to how you viewed yourself prior to medical tattooing?

B. Medical Tattooing

- a. When, where (on the body) and over how many sessions did you have medical tattooing?
- b. Can you describe to me the process you went through to get medical tattooing?
- c. Why did you want medical tattooing?
 - i. What were your hopes/expectations?

Prompt – appearance, social,

- ii. What difference did you believe it would make to your life?
- d. What did other people think about your choice to seek medical tattooing?
- e. What was it like waiting for the medical tattooing?
- f. What support did you receive in relation to getting your medical tattooing?
 - i. Before, during, after – professionals, family, friends, others
- g. What was the process like - having the (first) procedure?
- h. Could you describe what it was like when you first saw how you looked after the medical tattooing?
 - i. How did you feel?
 - ii. What did you think?
- i. What was your experience over the multiple procedures (if appropriate)?

- j. How do you feel about your medical tattoo now?
 - i. did it meet your expectations?
- k. How does your tattoo affect everyday life?
 - i. Psychological wellbeing, work, hobbies/leisure/social activities, relationships
- l. How would you describe what having medical tattooing has meant to you?
 - i. What words come to mind, what images?
- m. What do others think about your medical tattooing? How has it changed how others react to you?
- n. Is there anything you have not told me about your experience of medical tattooing that you think is important?

Appendix I: Debrief

Research Study: 'The Experiences of Medical Tattooing for Adult Patients with Burn Injuries

Thank you for taking part in this research. This study aims to explore how patients understand, view and adapt to medical tattooing. In analysing a collection of patient experiences, we hope to be able to further understand what this experience is like, and how services may further support patients during this time.

Your contribution today has been highly valuable in developing this research.

Should you be feeling worried or in need of additional support, I hope you find the following resources useful.

Should you have any further questions about this research please contact:

Researcher Catherine Tyerman Email: msxcjt@nottingham.ac.uk

University of Nottingham, Department of Clinical Psychology, University of Nottingham, YANG Fujia Building, B Floor, Jubilee Campus, Wollaton Road, Nottingham NG8 1BB, UK.

- If discussing your burns has raised questions, or caused distress, or any thoughts of self-harm, please speak to your G.P. as soon as possible.
- Crisis support is also available from the Samaritans:

Samaritans

08457 909090

If you would like further information and support contact the **Katie Piper Foundation** :
<https://katiepiperfoundation.org.uk/>

Or

Changing Faces

<http://www.changingfaces.org.uk>

A charity which offers information and support to people with disfigurements to the face, hands or body, and their families.

Victim Support

<http://www.victimsupport.org.uk/>

National charity giving free and confidential help to victims of crime, witnesses, their family and friends.

Appendix J: IPA Analysis

Appendix I: Themes, Example Codes and Example Quotes Interview 6

Theme	Emerging Themes	Example codes	Example Quote
Conflict about Legitimacy	MT Less essential	MT – not necessary	<i>“I remember taking one patient and, wrongly I judged the situation ... I never thought that eyebrows for her was a huge thing”</i>
	Narratives around acceptance, efforts to be, and being beautiful	MT - Difficulties communicating appearance difficulties MT Impact – changed relationship with beauty	<i>“...do I sound stupid saying, out of everything, I miss my eyebrows?”</i> <i>“I’ve recently put a post up on social media of me with no makeup, no filter, no nothing, ... you know, just, basically, promoting that, of why people feel they need to put filters on.”</i>
	Perceived Lack of support/ understanding from those without a burn injury	Validation from burn survivors Non-burn survivor can’t understand	<i>“My life wasn’t over because all these people are still living their life”</i> <i>“instant friendship because you’ve got that understanding, which no one else has got.”</i> <i>“Their opinion meant more to me than my own friend’s opinion because they understood”</i>
	Experiences viewed as “Crazy” or “Silly”/ need to justify choice	Use of Language Justification	<i>“it’s crazy because it’s literally, just eyebrow tattooing”</i> <i>“do I sound stupid saying, out of everything, I miss my eyebrows? “</i> <i>“it’s OK to have tattooing or a little something that gives you that boost because that’s, you’re human, you know, everyone needs that little boost in life.”</i>
Management of Hope	Hope	MT Expectation – positive for self	<i>“that glimpse of hope was a huge thing.”</i>
		MT Expectation – Look better to self/to others	<i>“at least if someone looks at me, they’re going to think, she’s got nice eyebrows and not notice the scars as much.”</i> <i>“... then I can look in the mirror and think, I have nice eyebrows. “</i> <i>“I’ve seen the results, was a massive thing for me”</i>
		MT Expectation - Improved sense of self	<i>“step in the right direction of getting the old me back”</i>
	Limitation of hope	MT not possible/wouldn’t last/might go wrong	<i>“I always thought [it would] cost an absolute fortune.”</i> <i>“the thought of having my hopes built up of having them and then they just fade overnight</i>

The Process	Anxiety – fear or judgment	MT Salon -	<i>"It's kind of almost like a beauty sort of place I guess. They're all very glam in there - that was a bit daunting"</i>
		MT – Judgment	<i>"so worried about people judging me on how I looked now"</i>
	Support from expert/ non-judgemental professionals	TA - expert	<i>"experience in doing it with scars"</i>
		TA - Non-judgemental	<i>"I need to pick the right person to do this"</i> <i>"... these like perfectly made up women. But once you get there and they talk to you, they're nothing like, you know, what you kind of envision".</i>
Impacts of MT: 'Normal-ish is Fantastic'	Improve appearance		<i>"my scars weren't very visible"</i> <i>"not be disgusted when I look in a mirror or the second I look in a mirror to do something, find a fault."</i> <i>"result was so much better than I would ever imagine I could have. "</i>
	Improved Confidence	Impact MT - confidence	<i>"it was just a massive, massive, massive confidence boost."</i> <i>"level of confidence just went from zero to a hundred really."</i> <i>"I feel like I've got a new pair of shoes and a nice dress, because that is the level of confidence."</i> <i>"But on a daily basis, I don't feel I need to do that because of my eyebrows and my lips being done"</i>
	Sense of Normalcy	Impact MT – regaining self	<i>"I got a glimpse of the old me"</i>
		Impact MT – feeling normal	<i>"that I can finally be happy in myself, happy in my skin, have that confidence that I thought that I'd never get back."</i>
	Regaining Control/freedom/conference	MT Impact – reduced camouflage	<i>"I do it for me now, not for other people. "</i> <i>"But on a daily basis, I don't feel I need to do that because of my eyebrows and my lips being done"</i>
		MT Impact– regaining self	<i>"I'm still that crazy person, like that has come back"</i> <i>"Having medical tattooing has meant for me, that I can... have that confidence that I thought that I'd never get back."</i>
	Increased Acceptance	Impact MT - Acceptance	<i>"Well yes, because I now don't feel I need to cover my scars. It's helped me, I guess it's helped me accept myself"</i> <i>"But on a daily basis, I don't feel I need to do that because of my eyebrows and my lips being done"</i> <i>"I'll be the one that will put a post up and I've recently put a post up on social media of me with no makeup, no filter, no nothing, and then me with a filter, and saying, you know, just, basically, promoting that, of why people feel they need to put filters on."</i>
	Inter-relational	Impact Others – MT looks good	<i>"She thought it was fantastic"</i>

	Impact social - Confidence	<i>"I think it gave me the confidence to be able to have that sort of relationship."</i> <i>"I took my makeup off in front of him and I think I had the confidence to do that because I had my eyebrows done and my lips"</i>
	Impact Others- Less important for them	<i>"I doubt other people think, oh wow, her eyebrows really stand out today"</i>
Limitations	MT Limitations - Not fixed for everything	<i>"I think I still get quite anxious of how people perceive me."</i> <i>"I'm further down the line of my recovery, my facial scars aren't so prominent, they're not so lumpy. I've had laser, they're a lot smoother"</i>
Life- changing	Use of Language	<i>"it was just a massive, massive, massive confidence boost. "</i> <i>"Huge, huge change."</i> <i>"you look amazing, you feel a hundred, like a million dollars in this dress, that's how I feel having my lips and eyebrows done"</i>

Appendix K: Excerpt of Reflective Diary

Date 23.2.19: Interviews

(1) Self-awareness: Struggling within an interview – thoughts: ‘I don’t think we are communicating well’, ‘I am not sure she fully understands me’, ‘I cannot always hear what she is saying’. Emotions: ‘distress’

(2) Description: Interview with participant and myself over the phone. Phone line was bad but we had tried before and we could not improve it. She wanted to participate so agreed to continue. I wasn’t sure this was the best plan but she had made a lot of effort to participate so I continued with the interview. At some points the interviewee gave me important information but at other points I wasn’t sure she understood what I was saying and I struggled with her use of English (it was her second language) and her accent made interpretations difficult over the phone. The interview ended up being very short and I asked a high proportion of closed questions to clarify her meaning. However, this had a significant impact on the data.

(3) Reflections: I wanted to deliver a good interview but I also didn’t want to refuse the participant as a result of my assumptions about language. I decided to continue as it felt correct and appropriate to continue the conversation as there may still be information worth gathering. Consequently, the participant was able to engage and her viewpoint was heard and recorded to potentially add to the research.

(4) Influences: Ethical considerations- the participant had offered information about her experience and it felt ethically correct to finish once started; Qualitative research – the data should be rich; Internal – I feel unreasonable saying stop due to my difficulties in understanding the participant; Scientific – if the data is limited due to difficulties in language, the data is not giving the participant full representation; Inclusion - exclusion criteria – while the invitation requested participants to be fluent in English – this is subjective without assessment. I relied on participant’s self-report and did not assess. This perhaps means I should have excluded this participant following the interview. On reviewing the interview, there was useful data that could be analysed

(5) Evaluation: I could have clarified language more explicitly, I could have insisted on a face-to-face interview, I could have terminated the interview, I could have kept generating open questions even though I was unable to track the conversation, I could have asked someone else to do the interview. Went well: She engaged in the process and did provide some useful data. Less good: I couldn’t always understand what she was saying so the data is not of high quality and will need to be carefully analysed – if it can be

(6) Learning: I am going to discuss in supervision, practice open questioning techniques, ask about proficiency in English prior to interview, it was a good experience of a difficult interview that will guide future interviews.

Date: 10.6.19: **Coding interviews:**

(7) Self-awareness: Noticing that I am being influenced by coding previous interviews and concerns I am not being true to that individual's thoughts – 'What if I am doing this wrong?'. Emotions – 'fear' and 'frustration'.

(8) Description: Coding alone: Noticed that I was using code 'identity' when perhaps I should have been using 'self' or another descriptor due to previous use of identity. Became uncertain that this was too interpretive at this stage or not right for this person.

(9) Reflections: I feel pressure to code this correctly and reflect the participants' comments well and meaningfully to ensure the research is accurate and helpful both academically and to service users. The situation made me feel unskilled.

(10) Influences: Having to pass my thesis, my internal assumption appearance will be linked to identity might influence what I put, I am having thoughts which question my ability and assuming inability to be independent. However, feedback after supervision concluded that coding looked appropriate. Consideration that supervision should influence my confidence in the results. IPA methodology means that I am going through a process and this takes time and development. Reminding myself that names or labels are just words that can be altered until the language provides the best understanding.

(11) Evaluation: I cannot help but be influenced by interviews that I have coded or my assumptions but I can be aware of them and continue to challenge them by focusing on the transcript and asking myself 'What it this person saying?'. Went well: noticed the influence of the other interviews, thought about feedback and sought guidance from IPA methodology.

(12) Learning: I am going to continue coding and discuss wordings further in supervision.

Date 4:10:19: Themes

For this extract, I decided to take a narrative-informed approach to my reflections to help me maintain the story focus of understanding and interpreting participants'

experiences, and also consider how my own narratives and stories are impacting on my interpretation of the themes.

Firstly, I am finding this process difficult and exhausting. Therefore, I have decided to pace this process to ensure I can fully focus on the data to prevent myself for making less accurate interpretations due to fatigue. The second experience - I have noticed that the interpretation process is testing my ability to hold and focus on larger amounts of information. I feel like I am holding 8 people in my head and I can identify that their experiences are overlapping, but I fear that I am conflating experiences rather than creating truly unique stories for them all. The data and process of IPA is overwhelming, but I remember from teaching and my reading that this is normal and a good sign. However, the need to reflect is clear.

From my perspective, it seems participants are all experiencing similar processes and views of MT – that it is fantastic to look better. It appears that this process has impacts that they cannot even describe to me as it is so inherently important to look normal. This could be understood as MT being an important part of a recovery pathway which should be offered as a standard treatment. However, I am more drawn to the influence of societal narratives. It is important to note that my personal preference and psychological stance is biased towards the power of such narratives and, as such, I am likely to see what I understand as narratives within all contexts, but given my personal conflict with narratives around appearance, these will be very notable to me. This part of my understanding is questioning the ‘correctness’ of saying having eyebrows or not having scars is the only way to look normal. Yet, I acknowledge I too have a conflict with dieting due to the pressure to look ‘normal’ by the standards of beauty (which isn’t normal). IPA acknowledges the role of the author and that all interpretations would be my own. But it will be essential to refer back to interviews where participants have spoken about the expectations of others and the negative reactions to their injuries to assure the themes truly represent the data. I have also booked in a supervision session to discuss the developing and emerging themes to discuss this further. I will reflect again following this discussion.

Appendix L: Chosen Journal

For the journal article: The Journal of the International Society for Burn Injuries. The guidance can be found at:

<https://www.elsevier.com/journals/burns/0305-4179?generatepdf=true>. Key point: (1) No word limit; therefore 8000-word limit excluding abstract, figures, tables, and references is assumed (2) Reference style: Elsevier Journal

For the systematic review: The Journal of the International Society for Burn Injuries guidelines were also followed:

<https://www.elsevier.com/journals/burns/0305-4179/guide-for-authors>. Key point: (1) No word limit; therefore 6000-word limit excluding abstract, figures, tables, and references is assumed (2) Reference style: Elsevier Journal

Poster Presentation

