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**Published version**

KORNHABER, Rachel, CHILDS, Charmaine and CLEARY, Michelle (2018). Experiences of guilt, shame and blame in those affected by burns trauma : a qualitative systematic review. *Burns*, 44 (5), 1026-1039.

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**Experiences of guilt, shame and blame in those affected by burns trauma: A qualitative systematic review.**

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## **Abstract**

**Background.** A burn injury can severely impact upon the lives of survivors and their carers. This systematic review sought to incorporate the experiences of guilt, blame and shame across the lifespan for burn survivors, their families as well as the experiences of the parents of burn injured children

**Methods.** A systematic review of qualitative studies on the experiences and perspectives of guilt, blame and shame by those affected by burn trauma across the lifespan. The search engine databases, Pubmed, EMBASE, CINAHL, PsychINFO were systematically searched. Authors independently rated the reporting of the qualitative studies included. Thematic synthesis was used to analyse the data. The search identified 232 papers. Eighteen research papers met the study inclusion criteria.

**Results.** Guilt and ruminations of guilt, blame attribution and shame and body image were identified during thematic analysis as pivotal factors across the lifespan for burn survivors, their families as well as the experiences of the parents of burn injured children. Accounts presented, suggest that the impact of burn injury on the lives of the survivor and family covers a diverse spectrum of impact; personal cultural and societal.

**Conclusion.** From the findings of the literature searches and the post-burn experiences described in this review there is a gap in the psychological care for burn survivors and their caregivers that needs to be targeted and closed. This is specifically relevant around issues of parental guilt and blame, ruminations of guilt and shame as well as body image. These findings may not be new to burns professionals but the key message is that management of these issues fall short of

delivering comprehensive post trauma care. Identifying and highlighting the importance of residual psychosocial problems will ultimately influence positive outcomes for burn survivors.

**Keywords:** burns; guilt; social support; attribution; qualitative; systematic review

## **1. Introduction**

A burn injury can severely impact upon the lives of survivors and their carers [1]. Although severe burns are accompanied by perturbations in physiology, the advances in surgery, skin repair, optimum analgesia and fluid resuscitation over recent decades now means that patients with burns covering in excess of 90% of the body surface area can survive their injury [2]. This remarkable change in survival however brings catastrophic emotional sequelae for the patient and the family [3].

It might be fair to say that the solutions available to assist in a person's full recovery and adaptation to society remains a significant challenge after burn trauma. This is due, in the main, to the heterogeneity of the coping strategies, resilience and, importantly, family support that the individual brings to his/her recovery programme. Whilst medical care protocols and treatment pathways can be standardised, the rehabilitation of a burn survivor is complex. It requires support for the effects of factors which interplay between physical, emotional, psychological and societal factors and which in turn impact upon a person's quality of life. Furthermore, as rehabilitation is unlikely to bring a return to a former self, especially if there are changes to appearance, so rehabilitation, both physical and psychological is likely protracted [4]. Testimonies of burn survivors show that their experience of being burned is not only associated with the effects of the burn but also by altered body image and scarring [5]. Disfigurement is a common occurrence, especially after facial and hand burns. However, loss of function due to

contracture, amputation, with or without nerve involvement will exacerbate the body image changes [6, 7].

Following a similar trajectory to the patient, is the readjustment required for family members as the consequences of the burn injury "spill over" to spouse, children, friends and the wider family and social and work networks [3, 8]. Depression, anxiety, low self-esteem and difficulties with social functioning [7, 9] can become a long term problem. Some severely burned patients 'develop clinically-significant psychological disturbances such as somatization and phobic anxiety' (p. 677) [10].

Burns can result from accidents, so it is not uncommon for negative thoughts of guilt, blame and shame to follow. This might be expected if the burn victim is a child, injured as a result of parental inattention or even deliberate harm. These moral emotions are deemed important for social functioning and the development of interpersonal relationships as they are a regulator that encourages an equilibrium between an individual's impulses [11]. However, dysregulation of these 'moral emotions' such as self-blame, guilt and shame, can result in mood and anxiety disorders [11, 12]. Guilt and shame are both negative self-conscious emotions [13] conceptualized as unpleasant feelings and accompanied by a belief that one should have acted otherwise [14]. Guilt implies the notion of empathy toward another and a concern that emerges from poor judgement where harm is caused. Whereas shame is embedded in a negative self-focused emotion [15] of self-perception as well as the 'perceptions' of others [11]. Furthermore, the concept of guilt and shame are referred to by Rosaldo [16] as the 'guardians of social norms and the foundations of a moral order' (p. 148). Whilst there is a wealth of research focusing on the psychosocial impact of burns in survivors and their families for example Post-traumatic Stress Disorder (PTSD) [17, 18], experiences of burn scars [19], psychosocial adjustment

following a burn injury [20] and the perceived support in parents of children with burns [21], much less is known about the experiences of guilt, blame and shame. This review sought to synthesise the experiences of guilt, blame and shame across the lifespan for burn survivors, their families as well as the experiences of the parents of burn injured children. To our knowledge, this is the first systematic review of the literature that focuses on the experiences that constitute moral emotions in those affected by burn injury.

## **2. Methods**

### 2.1 Review process

The review was guided by Thomas and Harden [see 22] method for thematic analysis of qualitative research. The authors also followed the Enhancing Transparency of Reporting the Synthesis of Qualitative research (ENTREQ) guidelines, which provides a framework for reporting of systematic reviews [23, 24]. The ENTREQ guidelines consist of 21 reported items [24].

### 2.2 Search strategy

A comprehensive literature search was conducted in October 2016 using five electronic databases: Pubmed, Scopus, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Embase and PsycINFO. Boolean connectors AND, OR and NOT were utilised to combine the following search terms: guilt\*, shame, blame, burn\*, qualitative and experience\*. In the initial search, 309 papers were identified after removal of duplicates. Titles and abstracts not relevant to the purpose of the review were then removed. Reference lists of remaining studies were reviewed and two further studies were identified. The researchers contacted two authors to confirm data sets. An additional paper was identified by means of hand searching. In total, 18

research papers met the inclusion criteria for the review (See Figure 1). Two independent reviewers (MC and RK) screened all abstracts, and reviewed the full texts of all studies deemed potentially relevant.

### 2.3 Inclusion and exclusion criteria

Studies included met the following criteria: (a) original qualitative research articles published in English and in peer-reviewed journals; (b) participants were paediatric, adolescent and adult burn survivors, family members or parents of burn injured children; (c) focus on the experience of guilt, blame and shame. Excluded studies were those that used survey data or statistical reporting of the results, abstracts, conference proceedings, theses and editorials as well as secondary sources of research (e.g. reviews).

### 2.4 Quality appraisal

Quality appraisal of included studies was undertaken by two members of the research team (MC and RK) utilising the Critical Appraisal Skills Programme for Qualitative Studies Checklist [25] (<http://www.casp-uk.net/>). All 18 studies met the quality criteria for inclusion.

### 2.5 Data abstraction and synthesis

Data were abstracted and synthesised using thematic analysis [22]. In the findings of each paper, participant quotes and accompanying text were noted. These were coded and the core concepts and themes discerned and reviewed by the team. Translation and synthesis of identified concepts across all studies was performed by means of grouping similar concepts. To ensure all data was captured and integrated into themes all included studies were re-read. All authors then reviewed the preliminary synthesis ensuring that key concepts were captured.

Data extracted from the eighteen studies included: author(s), year, country, aim, sample and study population, methods and key findings and reviewed by members of the research team for accuracy (see Table 1).

### **3. Findings**

#### **3.1 Study characteristics**

This systematic review incorporated the experiences of guilt, blame and shame across the lifespan for burn survivors (n =187), their families as well as the experiences of the parents of burn injured children (n=154). Studies were conducted across eight countries; Australia [26-30], China [31], Brazil [32, 33], Malawi [34], Sweden [35], India [36, 37], Canada [38-40], United States of America [9, 41] and the United Kingdom [42]. As a result of inconsistencies in reporting of key data such as the extent of the burn, total body surface area (TBSA) and participant age in the included studies, details are provided where possible (Table 1).

The qualitative approaches used included phenomenology (four studies) [26-30] with one study having two data sets [28, 29], ethnography (two studies) [32, 33], grounded theory (four studies) [31, 36, 37, 42] with one study reporting different findings [36, 37], and narrative/thematic analysis (seven studies) [9, 35, 38-41].

#### **3.2 Synthesis**

Data were synthesised and organised into the following three themes: *guilt and ruminations of guilt, blame attribution* and *shame and body image*. These themes are discussed with selected participant quotes used to illustrate each theme.



### 3.3 Guilt and ruminations on guilt

Parents with feelings of guilt were identified across several of the included studies [29, 34-37, 42]. Horridge et al. [42] who examined the parental processes that influence children returning to school, found that guilt, as well as stress and anxiety experienced by parents concerning the burn and the recovery process led parents to question their own ability to be effective and protect their child against harm and this is reflected in this excerpt from a parent:

*If I hadn't allowed him to be here, if I hadn't have been waxing my mum's legs and I'd had the kids in for their tea and they were watching a DVD, it wouldn't have happened would it? (p.633)*

This is echoed by Ravindran et al. [36] who reported that family and health professionals reprimanded them for not being responsible parents stating “They are not fit to parent” (p. 790). As a consequence, parents blamed themselves which led to feelings of guilt for not being a good parent.

Participants in the study by Martin et al. [27] expressed feelings of guilt concerning their seeking of emotional support from family and close friends around them. However, being hindered by feelings of guilt was exacerbated by the impact the burn injury would have on their family and friends with one participant stating “it's about the effect it causes on your family and friends” (p.80) [27].

McGarry et al. [29] stated that dressing changes were a source of anxiety for parents. This intensified feelings of guilt when parents listened to their child scream during painful procedures and as they struggled to comfort their child:

*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? Because I was the one with the tea, ultimately, and I just thought, if I didn't have the tea... If, if ... what if? (p.44)*

A child's own expressions of guilt were attributed to their burn injury [28]. Some of the children in McGarry's et al. [28] study provided descriptions of how their own guilt related to the impact this had on parents and siblings. One child in particular expressed feelings of guilt concerning the lack of time parents had in the role of burn care causing arguments among family members:

*Because now I think that my Mum's stressed because she has to help me and well, if my Mum, like, say, if we went to tennis camp and my mum wasn't there, my sisters had to help and sometimes they would not do as good a job as my Mum did, and then we argue about it. (p. 611)*

Adding to the child's emotional burden was how they perceived their parent's guilty feelings concerning their burn injury. McGarry et al. [28] describes how the child would comfort their parent reassuring them that it was not their fault:

*I kept telling Dad it wasn't his fault and not to be upset. Because he was saying it was his fault that I was in there. (p. 611)*

Challenges were often experienced for those recovering from a burn injury. Stergiou-Kita et al. [38] explored the challenges of returning to work after an electrical burn injury. Feelings of guilt, blame and responsibility for the injury and the challenges experienced on returning to the place where the injury occurred were evident. Johnson et al.[26] also report expressed feelings of guilt concerning returning to work and the difficulties experienced with accepting one's inabilities to

return to gainful employment. For men specifically, Thakrar et al.[39] reported expressions of guilt which were not only distressing but interfered with survivors' lives.

*Well I think about it, feel kind of guilty about, about my roommate that he died. I don't know where that guilt is coming from because I know I didn't start the fire, but I allowed the drinking . . . I think about it every day. I find that I don't talk. I hardly say any words at all during the day. I'm constantly dwelling on the trauma that I went through. (p. 1669)*

Expressions of guilt from relatives of burn survivors was reported by Rossi et al. [33]. This was attributed to a sense of responsibility and accountability as expressed by this relative of a burn survivor:

*The day before, I had burned ants using alcohol, and then, the next day, she did the same thing and burned herself. I was her teacher [Relative]. I burned this girl; it's my fault. I keep thinking, she will never have a boyfriend. (p.41)*

Another of Rossi et al's. [33] participants summed it up as “we keep feeling guilty” (p. 41).

In McGarry et al.'s study [29] “many parents described constantly ruminating on thoughts of guilt” (p.46). Parents who blamed themselves for their child's burn injury experienced intense guilt as expressed by this parent [29]:

*I don't think I've ever felt so guilty about something ...I thought, I let this happen, how could I do that? (p.46).*

This sentiment was also expressed in another study [34] in which a parent expressed guilt and self-blame arising from their child's burn injury, and questions kept repeating in their mind:

*It is my fault my child is here. I feel as though I was not caring for him properly. What will his future be like with all these scars? Will he have emotional problems? These questions keep repeating in my mind. (p.605)*

The guilt, and rumination that was experienced by family with regards to the burn and the healing process resulted in many questioning and doubting their abilities as parents and making relatively minor decisions [42].

### **3.4 Blame attribution**

Of the studies focusing on parents and their burn injured child, three studies found that blame was a prime issue identified across the care trajectory [29, 36, 37]. Parents of a child who sustained a burn injury were reported as attributing blame to either themselves or others. McGarry et al. [29] aptly points out that parents who blamed others for the accident experienced feelings of resentment and anger while those who blamed themselves led to feelings of guilt. Furthermore, parents who blamed someone else harboured anger and subsequently were unable to work through their resentment. This was observed with the mother of a 13-year-old boy McGarry et al.'s [29] studying stating:

*I was so angry, I couldn't even look at his Dad. It took me weeks. I was scared if I spoke to him I would say, 'It was your fault, you shouldn't have done this, you shouldn't have bought the bikes' ... I was just so scared that if I actually spoke to him, it would all just come blurring out. (p. 45-46)*

These feelings of blame are also reported by Ravindran et al. [37] with parents internalising the blame with resultant feelings of guilt. Parents encountered both emotional and psychological trauma because of what their child was enduring. Intense feelings of guilt were experienced by

parents who blamed themselves for the accident as opposed to blaming others. They described how they ruminated on guilty thoughts. McGarry et al. [29] have highlighted a mother's ruminations of guilt:

*I don't think I've ever felt so guilty about something ...I thought, I let this happen, how could I do that? (p. 46)*

Parents who blamed themselves began questioning their own competence and ability to be a parent. Subsequently, they were reluctant to share their story with others for fear that they themselves would be judged. McGarry et al. [29] reports the feelings of a mother of a five-year-old boy:

*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. (p. 46)*

This is also reflected by Ravindran et al. [37] where parents endured the blame from both members of their own family and health care professionals asking "How did you allow this?" (p. 592) questioning and undermining their competence as parents. In particular, Ravindran et al. [36] found that enduring the blame was experienced as four distinct stages: "internalizing blame, submitting to blame, rising above blame, and avoiding blame" (p. 790). Working through these stages was fundamental to the parent's capacity to continue parenting their child. Attributions of blame within Ravindran et al.'s [36] study did not manifest with parents apportioning blame. However, family members, healthcare professionals, the burn injured child and others including

neighbours and strangers did apportion blame to the parent/s. In particular, mothers in Ravindran et al. [36] study were the focus of blame from the family members as highlight by a mother.

*Then aunt [mother-in-law] phoned to everyone. . . Everyone came. My mom, my dad, my younger brother. Mm. (with a teary voice) yes all of them came and all of them were yelling at me, ‘Don’t you know how to look after the child? Why do you have a child? Is the child important or cooking is important?’ (p. 789)*

Furthermore, Ravindran et al. [36] highlights the fact that parents blamed each other for their child’s burn causing disunity, years after the initial injury:

*Even now [after four years of injury event] I fight with him [husband]. Because of you only it happened like this, you left the toy there. Trying to grab that only she was burned. I say like this and he will blame me for not looking after her carefully. (p. 789)*

Health professionals were also found to be a source of blame that parents endured during the hospitalisation period. This was found to be particularly difficult for parents as they expected that health professionals would be caring and empathetic to their needs. However, blaming manifested in aggressive questioning of parents including statements as Ravindran et al. [36] identified with the father of a burn injured child:

*The nurses will blame as if we have done this on purpose...you have done like this for a child who was well. (p. 789)*

However, Ravindran et al. [36] illustrates a parents’ insight into health professional’s attitudes highlights this very point of blame attribution with a father stating:

*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" like that saying and also showing in their behaviour were things I did not like. (p. 790)*

Ravindran et al. [36] also encountered in their narratives blame attribution from their own child. However, parents continued to care for their child but within the social context of a devalued parent that was embedded with enduring blame. Others within the community including neighbours apportioned blame to the parents and at times the family unit with an aunt of a burn injured child from Ravindran et al.'s [36] study recalling:

*No one walked by simply. Even those who were walking on the road, looked at the child and asked, "How did this happen to this child? How did you leave him? Where were you gone? Why did you not come away running?" Only the crows and birds did not ask. (p. 790)*

Burns survivors required time to digest their feelings of blame and responsibility to make sense of the accident and reflect on what could have been done differently to avoid the accident. These reflections are highlighted by a participant in Stergiou-Kita et al.'s [38] study concerning their workplace environment:

*I was trying to figure out what went wrong. I mean, I'm a licensed switcher. I have all kinds of safety training. I can work in substations [and] high voltage doesn't scare me. I know the dangers. I've been trained, for me to have this accident. People were just*

*stunned....They were counting on my experience, my knowledge to get me through this. They have changed their procedures [now and] will not allow people to work on inverters during the daylight hours. Because there's no safe way of shutting them down. That I blame the CSA (Canadian Standards Association) [for]. CSA approved the system and you cannot shut it down during daylight hours safely. (p. 502)*

Others viewed their burn injury as a punishment as an act of God clearly defined here by participants in Rossi et al's [32] study:

*When I suffered the burn accident, I put the pan on the stove and I said 'My God, everyday the same thing, nothing changes!' Then, now I think that it was a warning of God, because I said that thing. (p. 716)*

Another of Rossi et al's [32] participants also viewed their injury as a punishment for reasons of abandonment:

*I think that it was a punishment because I abandoned my religion. (p. 716)*

McLean et al.[30] also found similar findings to Stergiou-Kita et al.[38] whereby participants felt the need to make sense of the accident. McLean et al. [30] states that all participants in their study reported reflecting attributions of blame from various sources:

*I was probably under the influence. (p. 382)*

Another of McLean et al.'s [30] participants apportioned blame to just an accident:

*You wouldn't choose to do this to yourself; That's all [...] just an accident yeah (p. 382)*



### 3.5 Shame and body image

Feelings of shame and embarrassment were evident in several of the included studies [9, 31, 33, 35, 40, 41]. Feelings of shame primarily manifested in the concept of one's body image which included social, cultural and parental perspectives. Cox et al.[9] and Hunter et al. [40] in particular revealed burn survivors perspectives concerning their appearance. Cox's et al.[9] study focused on adolescent burn survivors impact of attending a burn camp on their body image. The adolescents in Cox's et al. [9] study felt the need to conceal their scars from society but expressed their relief at not having to cover up their scars whilst at camp where they felt safe from any judgement. One participant stated she could bear "scars and all" (p.145) without experiencing any shameful feelings:

*I don't have to hide anything or cover anything up when you're at camp. Can't nobody criticize nobody about how they look, 'cause everybody got some type of scar on their body...so, that's another thing, you don't have to try to hide anything from nobody...or cover your scars. . .that's why I came back. (p. 145)*

Furthermore, the same participant states how the burn survivor camps facilitated addressing ongoing issues of body image experienced by those with severe burn scars:

*I used to wear a lot of pants, or jeans or whatever. . . the more I come back to camp the more comfortable I feel with showing my arms. . .or showing my legs and then when I get out there in . . .the real world, I go back home, it makes me more comfortable there. (p. 145)*

In Hunter's et al. study [40] feelings of shame concerning their appearance and dissatisfaction with their body emerged:

*And I wanted to wear sometimes like the shorter cute summer dresses but now I have to go for the longer ones (1) 'cause I have some scars on the legs too ((laughing)). But yeah, otherwise as long as I could cover up I feel a bit better because I'm like, even if it's going to be really hot outside but I rather not show my scars. (p. 1593)*

In contrast, the other narrative in Hunter's et al. [40] study demonstrated that some women were not at all ashamed to show their scars in public reflecting the level of acceptance experienced concerning their body image change.

*It doesn't matter that I have to wear this. It doesn't matter that when I don't wear this, it's still going to be a big scar. It doesn't change how I see myself. It doesn't change how I feel about myself. It doesn't change how the people that matter to me, see me, you know. That's-what a stranger thinks of me, I don't care. I really just don't give a damn what they think. It's not their problem; they don't have to live with it. It's mine. I don't find it a problem. It hasn't changed how I feel about myself. (p. 1592)*

A relatives feelings of shame and embarrassment featured prominently in the study conducted by Rossi et al. [33]. Relatives expressed a range of shameful feelings revolving around the experience of having to live with a burn survivor forever and this was perceived as a traumatic experience. One relative expressed the following:

*My God! I feel embarrassed. I stay in all day. I won't even go out into the street. Now, my neighbors go to my house to ask how T's face and skin are. I feel that they apparently want the child's face to be scarred. They also want to come to the hospital to visit only because of curiosity, to tell others what T's face is like. (p. 41)*

Another relative from Rossi's et al.[33] study was concerned about the importance of covering their scars so they were not visible to others; hiding his injury and the associated shame:

*When he goes home, a lot of people will go there to see him. Will he be able to wear a T-shirt? Because people will see the ugly arm, I thought if he puts clothes on, that would hide it a little, no one will ask about it. (p. 41)*

Parents expressions of shame was evident in Oster's et al. [35] and Williams's et al. [41] studies. A parent in the study conducted by Oster et al. [35] expressed feelings of shame concerning their ability to manage their child's refusal of treatment. Refusing to adhere to pressure garment therapy for their scars impacts their future appearance as this parent stated:

*...I'm reminded about it all the time, even more so when I talk about him, how he looks, and I probably think ahead a little, how he's going to look, since this is growing with him. (p. 608)*

Williams et al. [41] described a fathers shame about his son's appearance as the son recalled his father relaying the fact that "he couldn't handle it how (I) looked" and further stated that "It's a shame that he has to look like that". (p.70)

From a cultural perspective, Ren et al. [31] discussed the notion of losing face. The face which is also referred to as "Mianzi" in Chinese culture, represents a physical, social, emotional and moral portrait. The face is the most significant element of social interaction in China representing social appearance and one's behaviours [31]. As the face denotes the domains of social status, prestige, respect, the concept of honour and dignity, losings one's face brings feelings of shame and guilt [31]. Therefore, within the Chinese cultural perspective, appearance

is of prime importance with one participant expressing concerns about returning to their home town after the burn injury:

*I am unique in our town; I would not like to go back being afraid of other peoples' judgment. Anyway, it is ok for me, but I do not want my family members to lose face. . .*  
(p. 1858)

Others in Ren's et al. [31] study felt ashamed of their appearance due to their perceptions of what others would think of their scars. This was expressed as culturally related shame, and perceptions of social rejection:

*I always use a separate room in the public bathroom. I feel ashamed to expose myself because I am afraid that other people may think I have a bad disease.* (p. 1858)

#### **4. Discussion**

The purpose of the review was to 'drill down' to the nature of three key emotional and psychological experiences that can follow the physical trauma of a burn injury, be it a child, an adult and, or, family member of the injured individual. In many ways, 'individual' sets the scope for a perspective on post-traumatic sequelae, for each person responds in a unique way to the **injury** and this brings about a complexity in our understanding of the problem. Furthermore, the problems which we have as our focus in this review, guilt, shame and blame are not fixed. They are dynamic features shaped by internal and external influences; the unique views of self as well as the perspectives and impact of 'others'. However, by taking steps to synthesise these experiences, albeit in just a sample from the burn population and in a systematic way we provide a rich perspective of what it is like, to be a survivor, returning to society. This is an important area in burns trauma care that merits further exploration and follow up. Evidence suggests that

when feelings of guilt, shame or blame are experienced, the psychological problems that can follow; feelings of anxiety, depression or personal shame are all candidate factors feeding in to the development of post-traumatic stress [43, 44].

From the perspective of guilt as a post-traumatic sequelae, the health concerns are that it is frequently seen in individuals encountering PTSD and depression [45]. Within the context of burn injury in children, Rizzone et al [46] state that symptoms of post-traumatic stress are disruptive, and for the parent, it affects their capacity to care for their child. By contrast, Dagleish et al. [47] claims that guilt may have a positive benefit facilitating the ability to engage in a constructive way to improve the relationship and to influence the ability to manage feelings of anger. Guilt might therefore play an adaptive and emotion-centred role when considering social and interpersonal adjustment [47].

Shame on the other hand may be seen as a maladaptive emotion associated with 'exposure' and with a concomitant need to hide. In this way it is more likely to be considered a negative evaluation of oneself [43]. Shame is known to be a complex debilitating emotion that is related to guilt, humiliation, feelings of demoralisation, degradation and remorse with the capacity to impair recovery [48]. The findings in this review suggest that shame, manifested in an altered body image, impacts upon burn survivors as well as the carers. In particular, burn survivors with significant disfigurement, report feelings of shame and humiliation such that the person lives in a state of psychological distress and so adopts avoidance behaviours [49]. Subsequently, shame and guilt often transcend into feelings of worthlessness and hopelessness followed by depression [50]. Our findings suggest that such negative emotions have adverse effects for the survivor and family. This makes shame, a problem which needs to be addressed from a health professional's perspective, yet from the limited number of papers published, shame is a problem, which has

received little attention and thus an overlooked problem. We have therefore focused on the signals of being ashamed and how they are voiced from the perspective of the burn survivor and their carers and how this is reflected as altered body image and including the cultural aspect of 'losing face'. A shameful response reflects the perception of oneself as flawed involving manifestations of vulnerability [51]. Furthermore, Wilson et al. [52] supports the notion that post-traumatic shame is deeply embedded in a person's feelings and in particular, losing face. Shame can be viewed as a two-pronged consequence of trauma, first as the primary emotion arising at the time of the traumatic event and then again as a secondary emotion emerging later when those affected by trauma search for meaning via an attributional process [53]. However, by contrast we have shown that some burn survivors are not always ashamed, at least of the physical consequence of injury, able and willing to show their scars in public. From the perspective of 'self' then there can be a degree of being comfortable with their body image, albeit a different one and this finding may support Wilson et al. [52] in discussing the concept of counterphobic forms of shamelessness developed to delay fear, humiliation and feelings of vulnerability; possibly a 'badge' of the seriousness of the trauma felt by the patient?

When it comes to blame, burn survivors blamed others or a 'higher power' for their injury indicating a shift in accountability and responsibility. Parents either blamed themselves or others or were the recipient of blame. The subject of blame attribution has stimulated much debate within the published literature and the evidence concerning adaptation after the injury and the attribution of blame remain unclear [54]. Startup et al. [55] found that self-blame was associated with a lesser risk of PTSD and with less post traumatic symptoms. Furthermore, Islam et al. [54] found that those who blamed themselves for their injury had significantly lower anxiety and depression scores than those who blamed others. Therefore, personal responsibility for one's

injuries may provide a sense of psychological comfort [54]. Parents blaming themselves was highlighted as an important issue in this review. This has also been reported within the spinal cord injury literature with Murray et al's. [56] finding parents of children affected by spinal cord injury, blamed themselves for the accident.

By focusing on three key "negative" emotions (guilt, shame and blame) reported after a burn injury, it is likely that the reader is familiar with one or more from personal experience. It is a part of the human condition that as sentient beings we experience pleasure as well as emotional "pain". Problems occur for people when the negative emotion/s override or take precedent in everyday life. It is clear from the accounts presented, albeit from a relatively small qualitative literature, that feeling guilty, experiencing shame and blame can have both negative and positive influencing impacts during the post-burn rehabilitation period. They are unique, diverse and to an extent largely overlooked in the literature, especially in relation to how health care professionals cope and deal with those where the adverse effects override the positive effects of survivorship.

#### **4.1 Strengths and limitations**

This qualitative systematic review may be limited by the number of original studies that were identified for inclusion. Two included studies made use of the same group of participants further limiting the pool of data within this review [28, 29, 36, 37]. The exclusion of quantitative studies may be viewed as a limitation. However, the richness of the data viewed through a "qualitative lens" provides a unique perspective that is not attainable through quantitative methods. Methodological congruence within the review was another strength. In addition, the experiences and encounters described are comparable with each other. The inclusion of studies with

paediatric, adolescent and adult participants and their caregivers adds to the diversity of experiences with the country of origins representing both developed and developing countries.

The issues of guilt, shame and blame raised in this review may be construed as having limited applicability and transferability to other areas of trauma due to the unique disfigurement endured with a burn injury. However, these emotions are reported in other areas of disease and trauma and importantly, the literature surrounding aspects of guilt, blame and shame are embedded in those affected by sexual abuse which although a form of trauma cannot be viewed with the same perspective as those affected by burns. Despite these limitations, one can make conclusions about the perceptions and experiences of the cohort represented in this review and provide some tentative support for strategies in the early stages of burn rehabilitation to prepare survivors and their family for experiences of guilt, blame and shame to ensure effective self-management and facilitating resilience. Further research is recommended to explore psychological care for burn survivors and their care givers that address the issues of parental guilt and blame, ruminations of guilt and shame and body image.

## **5. Conclusion**

Guilt, shame and blame are commonly experienced by burn survivors, parents of burn injured children and relatives of burn survivors. The experiences described in this review underscores the emotional impact of guilt, shame and blame experienced after a burn trauma injury. For the future, there are opportunities to act upon what we and others have found in our primary research and literature synthesis to reach a new level of translation of research findings to burn care so providing a utility for the knowledge which has been obtained. Thus, one way to progress might include targeting psychosocial care for burn survivors and their caregivers with aims and



endpoints that can be measured for outcomes; patient reported experiences need to be used for the benefit of patients, their families as well as to enrich the care givers. The findings of this study highlight the importance of identifying and recognising individual factors that influence positive outcomes for burn survivors. The knowledge we have obtained by undertaking this systematic review of the literature reveals the nature of a significant, but somewhat overlooked, 'cluster' of emotional problems and experiences that survivors (and family members) express in relation to the burn injury. Our suggestion would be that this consolidated knowledge could be used to provide fieldworkers, therapists and clinicians with an evidence-base to understand, advise and counsel patients to provide therapeutic communication and support during long-term psychological follow up.

### **Conflict of Interest**

None declared

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