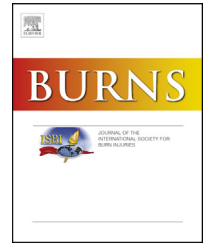


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Review

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

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ABSTRACT

Background: A significant burn can severely impact 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 burned 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 databases, Pubmed, Scopus, 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 230 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 burns 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. 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.

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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 influences 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 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 "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 [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 burns.

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