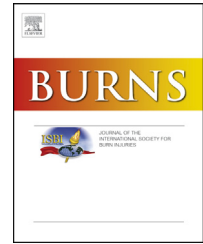


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# Patient experiences of burn scars in adults and children and development of a health-related quality of life conceptual model: A qualitative study<sup>☆</sup>

Megan Simons<sup>a,b,\*</sup>, Nathaniel Price<sup>a</sup>, Roy Kimble<sup>b,c,d</sup>, Zephania Tyack<sup>b</sup>

<sup>a</sup> Department of Occupational Therapy, Lady Cilento Children's Hospital, 501 Stanley St, South Brisbane, South Brisbane 4101, QLD, Australia

<sup>b</sup> Centre for Burns and Trauma Research, Child Health Research Centre, Level 7, 46 Graham Street, South Brisbane 4101, QLD, Australia

<sup>c</sup> Department of Paediatric Surgery, Urology, Neonatal Surgery, Burns and Trauma, Lady Cilento Children's Hospital, Brisbane 4101, QLD, Australia

<sup>d</sup> School of Medicine, The University of Queensland, St Lucia 4067, QLD, Australia

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## ABSTRACT

**Purpose:** The aim of this study was to understand the impact of burn scars on health-related quality of life (HRQOL) from the perspective of adults and children with burn scars, and caregivers to inform the development of a conceptual model of burn scar HRQOL.

**Method:** Twenty-one participants (adults and children) with burn scars and nine caregivers participated in semi-structured, face-to-face interviews between 2012 and 2013. During the interviews, participants were asked to describe features about their (or their child's) burn scars and its impact on everyday life. Two coders conducted thematic analysis, with consensus achieved through discussion and review with a third coder. The literature on HRQOL models was then reviewed to further inform the development of a conceptual model of burn scar HRQOL.

**Results:** Five themes emerged from the qualitative data: 'physical and sensory symptoms', 'impact of burn scar interventions', 'impact of burn scar symptoms', 'personal factors' and 'change over time'. Caregivers offered further insights into family functioning after burn, and the impacts of burn scars and burn scar interventions on family life. In the conceptual model, symptoms (sensory and physical) of burn scars are considered proximal to HRQOL, with distal indicators including functioning (physical, emotional, social, cognitive), individual factors and the environment. Overall quality of life was affected by HRQOL.

**Conclusion:** Understanding the impact of burn scars on HRQOL and the development of a conceptual model will inform future burn scar research and clinical practice.

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\* Corresponding author at: Lady Cilento Children's Hospital, Department of Occupational Therapy, 501 Stanley Street, South Brisbane, QLD 4101, Australia. Tel.: +61 7 3068 2275.

E-mail addresses: [Megan.Simons@health.qld.gov.au](mailto:Megan.Simons@health.qld.gov.au) (M. Simons), [Nathaniel.Price@health.qld.gov.au](mailto:Nathaniel.Price@health.qld.gov.au) (N. Price), [royk@uq.edu.au](mailto:royk@uq.edu.au) (R. Kimble), [z.tyack@uq.edu.au](mailto:z.tyack@uq.edu.au), [zephania.tyack@gofarm.com.au](mailto:zephania.tyack@gofarm.com.au) (Z. Tyack).

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## 1. Introduction

Health-related quality of life (HRQOL), according to the World Health Organization definition of health, is a state of complete positive physical, mental and social well-being [1]. Understanding the impact of burn scarring and its treatment, from the perspective of the patient, is at the core of reporting HRQOL [2]. Burn scars are a result of injury to the dermis, believed to arise as a result of prolonged wound healing [3]. Complications arising as a result of burn scarring may include contracture [4], itch [5], changes to the skin's thermoregulation [6,7] and discomfort associated with treatments for the burn scar [8]. Under the banner of HRQOL, the American Burn Association recently released a consensus statement that the ultimate clinical goal was a functional outcome with which the patient was satisfied, regardless if a residual impairment persisted [9].

Few studies exist regarding the impact of burn scars on HRQOL [10–12]. Lower HRQOL has been reported for adolescents with mature burn scars in social functioning and perceived physical appearance using a generic measure of quality of life (PedsQL) and a subscale (perceived physical appearance) validated for a cancer population (PedsQL Cancer Module). Social functioning and perceived physical appearance changed significantly over 8 weeks with a cosmetic camouflage intervention for scars [10]. Furthermore, a negative correlation has been found between the total score of the Patient Observer Scar Assessment Scale (POSAS—patient scale) and HRQOL measured using the World Health Organization Quality of Life scale (WHOQOL-BREF) ( $r = -0.93$ ,  $p < 0.001$ ) [12]. Participants in that study were adults with grafted areas ( $N = 26$ ) who had sustained burns to greater than 25% total body surface area (TBSA) at one year after discharge. Sveen et al. [11], using a burn-specific HRQOL measure (American Burn Association/Shriners Hospitals for Children Burns Outcomes Questionnaire), reported lower HRQOL up to 9 years after burn for appearance and emotional health for children aged 5 to 18 years, and behavior and family disruption for children aged up to 4 years. Individual burn characteristics (such as percent of full thickness total body surface area, length of stay) and the presence of visible scars were associated with lower HRQOL. In adults, length of stay (as an indicator of burn severity) affected HRQOL up to seven years after burn using a standardized instrument (EQ-5D) to measure health outcome [13]. Improvements were reported by both adults with burns, and their family members, in HRQOL over time using the EQ-5D, particularly in the dimensions of mobility and anxiety/depression [13,14]. Unemployment and pre-existing disease has also been found to impact on HRQOL using the 36-item Short Form Health Survey (SF-36) for adults with burn scars [15]. Of the available qualitative studies of people with burn scars, most have studied homogenous groups such as adolescents with visible scarring [16], children who underwent skin grafting after burn [17] and adults with more than 20% TBSA burned [18]. Thus work is needed to understand the impact of scarring on HRQOL in a more heterogeneous group.

Currently there is no burn-scar specific conceptual model that focuses on the impact of burn scars on HRQOL. Other burn models, such as The Model of Outcome for Children Post-Burn

[19,20] do include the impact of scarring (measured as an impairment to body structure and function). However, as they examine scarring in the broader context of the burn injury, these models are likely to include outcomes that are not specific to burn scar HRQOL. Few models consider changes over time that impact HRQOL. Two global HRQOL models exist although these are not disease-specific. These include Wilson and Cleary's model [21] and Ferran's adaptation of Wilson and Cleary's model [22]. Wilson and Cleary's model includes five central domains: biological, symptoms, function, general health perception, and overall HRQOL. Ferrans et al. [22] adapted the Wilson and Cleary model to explicitly include characteristics of the individual and characteristics of the environment but kept the same five central domains. Although the International Classification of Functioning, Disability and Health (ICF) has been described as a HRQOL model [23], it was not designed as a HRQOL model per se, rather as a classification framework for functioning, disability and health.

A number of gaps exist in global models of HRQOL to-date that can inform the development of a burn-scar specific HRQOL conceptual model. Most of the HRQOL models reviewed by Bakas et al. [23] in their systematic review focused on the influence of symptoms not on the influence of interventions. Further, both the Wilson and Cleary and Ferrans models were designed to reflect the HRQOL of individuals rather than families, communities, or cultures [23]. Whilst the ICF has the potential to have broader application to these groups, the ICF model has been criticised for not examining pre-morbid functioning, not capturing the complexity of quality of life [24]; and classifying people against what is normal [25]. Thus global models to date have gaps in their applicability to groups (e.g. families), the inclusion of the impact of treatments, and the ability to represent what is important for individuals as part of social or cultural groups. Given that the ultimate goal of many health professionals working with people with burn scars is to improve HRQOL, this area warrants further investigation. Therefore, this study aimed to understand the impact of burn scars on HRQOL from the perspective of adults and children with burn scars, and caregivers to inform the development of a conceptual model of burn scar HRQOL.

## 2. Materials and methods

### 2.1. Research design

This study was the first phase of work being undertaken to develop a burn scar HRQOL measure [26]. A cross-sectional design using purposive sampling was employed. Semi-structured interviews were completed with people with burns scarring aged over eight years and with caregivers of children aged below eight years. Eight years was set as the lower limit for self-report because children of that age were expected to be able to describe HRQOL and events or experiences that had potentially occurred in the past [27].

### 2.2. Participants

This study sampled people with burns scars or caregivers of children with burn scars who received ongoing treatment for

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