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Measuring the impact of burn scarring on health-related quality of life: Development and preliminary content validation of the Brisbane Burn Scar Impact Profile (BBSIP) for children and adults

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ABSTRACT

Introduction: No burn-scar specific, health-related quality of life (HRQOL) measure exists. This study aimed to develop a patient-reported, evaluative HRQOL measure to assess the impact of burn scarring in children and adults.

Method: Semi-structured interviews, content validation surveys, and cognitive interviews were used to develop and test content validity of a new measure – the Brisbane Burn Scar Impact Profile (BBSIP).

Results: Participants comprised Australian adults ($n = 23$) and children ($n = 19$) with burn scarring; caregivers of children with burn scarring ($n = 28$); and international scar management experts ($n = 14$). Items distinct from other burn scar measures emerged. Four versions of the BBSIP were developed; one for children aged 8–18 years, one for adults, one for caregivers (as proxies for children aged less than 8-years), and one for caregivers of children aged 8–18 years. Preliminary content validity of the BBSIP was supported. Final items

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covered physical and sensory symptoms; emotional reactions; impact on social functioning and daily activities; impact of treatment; and environmental factors.

Conclusion: The BBSIP was developed to assess burn-scar specific HRQOL and will be available at <http://www.coolburns.com.au> under a creative commons license. Further testing is underway.

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1. Introduction

Burn scars are a common consequence of a burn injury. The incidence of hypertrophic scarring after burn has been estimated to be between 32% and 72% in a recent systematic review [1]. In children with mature scars lower health-related quality of life (HRQOL) has been reported years after the actual injury in areas such as physical appearance, psychosocial health (in particular school functioning and social functioning), and overall HRQOL [2], compared to a normative population. In adults severe itch has been associated with reduced HRQOL after burn [3]. Lower health-related quality of life has also been found with the presence of visible scars on the face, neck or hands compared to no scars or other scar sites [4]. The sequelae of scar management interventions may also impact on HRQOL in terms of wound breakdowns, lengthy application regimes, abnormal bone growth, and impact on self-care routines [5]. Even small scars may cause psychological distress [6].

There remain many important questions to be answered regarding scarring after burn such as the effectiveness of scar reduction treatments like pressure garments; how scars change and mature over time, and what factors influence changes in scarring. Access to a HRQOL measure specific to burn scarring would facilitate research that answers these questions. The impact of the burn scar cannot be determined based on reports from health professionals alone, or by using objective measures such as colorimeters or spectrophotometers. Currently, no scar rating scale has been designed that addresses HRQOL nor has adequate testing of existing burn scar rating scales been conducted for this purpose [7]. In fact, existing scar rating scales may not be suitable for detecting clinically important change based on their limited focus on physical scar characteristics.

Whilst many objective and subjective measures exist to measure physical characteristics of scarring, no burn-scar specific HRQOL outcome measure currently exists. To date, the predominant focus of outcome measures of burn scarring has been on the physical characteristics of vascularity, pigmentation, height and pliability (e.g., Vancouver Scar Scale and its 11 modified versions; [7]). More recently developed measures, such as the patient scale of the Patient Observer Scar Assessment Scale (POSAS), have also included sensory aspects and other physical characteristics such as irregularity [8]. HRQOL measures (also termed patient-reported outcome measures (PROMs), are arguably the most important method of assessing burn scarring as they reflect the impact of scarring on a person's life experience, not the judgment of a health professional. HRQOL measures should be developed using the target population [9] – in this case people with burn scarring.

A health-related quality of life measure has been defined as one that determines the patient's perspective of the impact of an injury or illness and treatment [10]. No consensus has been reached about the key domains that should be captured in HRQOL measures. In the past, experts have described three key domains of HRQOL measures (i.e. psychological, social, and physical) with some also including spirituality. However, recent work published after the commencement of the present study, found that the three essential domains of HRQOL were self-esteem, self-acceptance, and social contacts [11], based on a three round Delphi consensus of patients and caregivers as well as experts. This recent work resonates with a qualitative study of patient perspectives of the impact of scarring from a wide range of injuries; that identified acceptability of the scar to self and others, and social functioning as two of five main areas that needed to be addressed from the patient's perspective. However, over 40% of the people included in that study had surgical scars, and it is unclear whether any people with burn scars participated [12]. In addition only adults were included. Thus, the ability to generalize Brown et al.'s work to people with burn scars of all ages is limited by evidence that burn scars may be different to other scars (for example, hypertrophic scarring and contractures are more common following burn injury than other trauma [13], and that scarring may be experienced differently across the lifespan [14,15]. Studies of burn scarring using generic measures indicate wide-ranging impacts including psychological, physical, social, and body esteem [2,16,17]. Thus, these aspects appear relevant to the HRQOL of patients with burn scarring but need to be confirmed.

Patient-reported outcome measures specific to burns do exist and include items regarding scarring; however, items were mostly developed by experts or using pools of items from other measures, not by seeking the views of patients. These measures include the Burn Specific Health Scale [18]; Abbreviated Burn Specific Health Scale [19], Young Adult Burn Outcomes Questionnaire [20], American Burn Association/Shriners Hospitals for Children Burn Outcomes Questionnaire [21], and Health Outcomes Questionnaire [22]. While most of these measures include several items specific to burn scarring and appearance, they may not comprehensively cover items that are important to patients and may be too broad to pick up changes unique to those with burn scarring.

This study aimed to: (1) develop the content for an evaluative HRQOL measure to assess the impact of burn scarring in adults and children (i.e., to measure changes in scarring), using patient reports of their experiences; and, (2) conduct preliminary content validation of the items developed including refinement of the items.

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