BURNS 41 (2015) 212–224

Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.elsevier.com/locate/burns

Review

A systematic review of patient reported outcome measures (PROMs) used in child and adolescent burn research

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ARTICLE INFO

Article history:
Accepted 21 July 2014

Keywords:
Systematic review
Patient-reported outcome measures
PROM
Paediatric
Adolescent
Burn

ABSTRACT

Introduction: Patient reported outcome measures (PROMs) can identify important information about patient needs and therapeutic progress. The aim of this review was to identify the PROMs that are being used in child and adolescent burn care and to determine the quality of such scales.

Methods: Computerised and manual bibliographic searches of Medline, Social Sciences Index, Cinahl, Psychinfo, Psycharticles, AMED, and HAPI, were used to identify English-language articles using English-language PROMs from January 2001 to March 2013. The psychometric quality of the PROMs was assessed.

Results: 23 studies met the entry criteria and identified 32 different PROMs (31 generic, 1 burns-specific). Overall, the psychometric quality of the PROMs was low; only two generic scales (the Perceived Stigmatisation Questionnaire and the Social Comfort Scale) and only one burns-specific scale (the Children Burn Outcomes Questionnaire for children aged 5–18) had psychometric evidence relevant to this population.

Conclusions: The majority of PROMs did not have psychometric evidence for their use with child or adolescent burn patients. To appropriately identify the needs and treatment progress of child and adolescent burn patients, new burns-specific PROMs need to be developed and validated to reflect issues that are of importance to this population.

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http://dx.doi.org/10.1016/j.burns.2014.07.018

Contents

1. Introduction

Around 52,200 children and adolescents suffer a burn in the UK each year [1]. Historically such injuries have resulted in high mortality rates, however with advances in medical and surgical treatment, an increasing number of children and adolescents are living with their injuries. Irrespective of a person's age at the time of injury, a burn can have a significant psychosocial impact, both for patients and the family members supporting them. Those affected can struggle with coming to terms with the traumatic event that caused their injuries, while changes in physical appearance, loss of independence, pain and restricted physical abilities can also be hard to cope with [2].

Late childhood and adolescence can be a challenging time, during which most young people experience physical, psychological and social changes. The stress of experiencing a burn and associated treatment during these developmental stages can add further pressure [3], increasing the likelihood of key developmental processes being disrupted [4]. A recent review found that a considerable proportion of young adults burnt as children still experienced anxiety and affective disorders in adulthood [4]. It is therefore important to identify the needs of children and adolescents with burns, in order to ensure that they receive the most appropriate support, with a view to reducing the likelihood of them experiencing difficulties later on.

The National Burn Care Review (2001) [5] raised awareness of the need for improvements in the provision of care for people affected by burns. As well as highlighting the need for routine audits of mortality and morbidity rates and surgical outcomes, the review noted that a systematic assessment of patients' experiences of their care, treatment, scarring and psychosocial functioning after burns was lacking. The review emphasised that the development of new patient reported outcome measures for this population was a priority. Historically patient needs have been identified through the use of clinician reported measures; however these might miss key aspects of the patient experience. Patient-reported outcome measures (PROMs) are preferable, as unlike clinician reported measures, they provide information about patient experiences and satisfaction with care [6].

PROMs are clearly needed in order to appropriately measure outcomes in paediatric and adolescent burn care. However, careful attention must be given to the development and implementation of these measures. A recent review of the psychosocial consequences of burn scars highlighted the lack of PROMs that have been validated with burns patients [7]. Although PROMS may investigate relevant patient experiences, their reliability (e.g. ability to yield consistent scores over time), validity (e.g. ability to measure what it intends to measure) and responsiveness (e.g. capacity to identify changes in scores over time) cannot be assumed without their psychometric qualities being formally tested with child and adolescent burn patients [8].

When PROMS are used by clinicians and researchers in this and related fields, there has been a tendency to use generic (rather than condition specific) measures to assess patient needs. Although generic PROMs are useful for identifying general health outcomes, they do not capture data relating to experiences that are specific to a particular patient population–in this case, paediatric and adolescent burns patients, and may lack the sensitivity to identify changes resulting from treatment. Rumsey and Harcourt [9] have also argued that there is a need to develop psychometrically robust instruments that can be used to evaluate the psychosocial adjustment of children with visible differences such as burns.

Whilst a number of reviews have summarised the types of outcome measures in research focussing on adults with burns [10–12]; none of these reviews have assessed the psychometric qualities of these outcome measures and little attention has been given to outcome measures used in paediatric burn research. Van Baar et al. [13] reviewed the functional consequences of experiencing a burn in adult and paediatric burn care. Although this review included information about the types of measures used in the studies, the psychometric qualities of the measures were not assessed in relation to paediatric burn patients. Similarly Lawrence et al.'s review [7]