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The burn outcome questionnaires: Patient and family reported outcome metrics for children of all ages

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1. Letter to the Editor

Recently, Griffiths et al published a review of available pediatric patient reported outcome measures (PROMs) for use in pediatric burn survivors. [1] This work, entitled, 'A systematic review of patient reported outcome measures (PROMs) used in child and adolescent burn research,' notes that the Children's Burn Outcome Questionnaire (formally known as the Burn Outcome Questionnaire for ages 11–18, $BOQ_{11–18}$) is the only burn-specific pediatric patient-reported outcome measure available. The $BOQ_{11–18}$ [2,3] is one of several instruments developed as part of the Shriners Hospitals for Children/American Burns Association program, the Burn Outcome Questionnaires (BOQs). We submit that it is limiting to restrict the assessment of pediatric burn outcomes by requiring only reports from the patients themselves and not including reports obtained from their parents or caretakers. This restriction disenfranchises younger and pre-verbal children. There are currently four separate BOQ instruments, the $BOQ_{0–5}$ [4], (administered to the parents of the burn survivors, ages 0 up to 5 years of age), $BOQ_{5–18}$, (also administered to the parents of the burn survivors ages 5_18 years) [2,3], $BOQ_{11–18}$, (administered to teen burn survivors, ages 11–18) [2,3], and the Young Adult Burn Outcome Questionnaire (YABOQ, administered to burn survivors ages 19–30) [5]. These instruments take into account normal expected growth for physical and mental development through the use of age-specific reference groups, a powerful and unique aspect of the BOQs not available in the other burn-specific measures. The progression of the questionnaires through the different stages of childhood allows for assessment of burn outcomes from infants to young adults. Additionally, Meyers et al [3] reported excellent correlations between outcomes among the rich range of domains reported by the teenagers using the $BOQ_{11–18}$ and their outcomes reported by their parents using the $BOQ_{5–18}$.

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The psychometric properties of the BOQs have been well established. Griffith et al correctly state that the items in the $BOQ_{11–18}$ were generated from a review of the instrument literature and by expert clinician input [1]. In order to clarify some finer nuances of the psychometric testing outlined in the Griffith article, we would like to make the following points: (1) A conceptual framework for each BOQ was developed based upon well-established frameworks. This included work from the Medical Outcomes Study that included patient reported outcome assessment tools [6]. Quality of life was further defined by the conceptual work of Wilson and Cleary [7]. (2) Pilot studies with interviews were conducted in order to develop the item content of the BOQs. This included interviews with adolescent burn survivors and their parents [2]. (3) Item redundancy was assessed using item deletion techniques with Cronbach alpha statistics [2]. (4) Assessments included exploratory and confirmatory factor analysis of items reflecting the different domains [2–5]. (5) Missing data techniques included specific algorithms for dealing with imputation of missing values to evaluate biases among items that were not present [2–5,8]. Finally, the experience of over 1200 burn survivors and their families completing the pediatric BOQ instruments are solid evidence for the acceptability and feasibility of the instruments in the clinical setting. For the BOQ instruments, all of these psychometric tests, including item total correlations, criterion validity and responsiveness were tested [2–5]. These properties are evident from the clinical correlations confirmed in the Dalroy [2], Kazis [4] and Ryan [5] articles, as well as work detailing differences in outcomes related to burn size [9,10] and critical area burns [11–13].

Finally, the clinical utility of the BOQs is becoming increasingly apparent. They have been used to define the course of recovery of burned children over time using recovery curve methodologies [8]. The BOQs have been used to discern differences in multidimensional outcomes related to important clinical characteristics. This allows identification of populations at risk for poor outcomes and in need of greater support. Benchmarking allows for use of the BOQ data for performance improvement purposes and best practices. More recently, the innovative use of these disease-specific PROMs, combined with real-time feedback to the patient, parent and clinician benchmarked to population expectations over time from injury, makes possible the personalization of burn follow-up care [14,15]. Information regarding expected outcomes can be conveyed visually to aid in the assessment of the patient’s condition. The BOQs are currently the most well-studied and clinically developed PROMs for use in children with burn injuries. Future work involving the further development of the BOQs as well as the development of new pediatric instruments [16] for the assessment of burn-specific outcomes and the implementation of sophisticated technologies such as computer adaptive testing [17] applied to burn recovery assessment are exciting new directions in this field.

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