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Health-Related Quality of Life in adolescent survivors of burns: Agreement on self-reported and mothers' and fathers' perspectives

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ABSTRACT

Aim: This study examined the agreement on self-reported Health-Related Quality of Life (HRQOL) between adolescents with burns and their mother's and father's observation at 6 and 18 months after the burn. Moreover, factors potentially influencing discrepancies between the adolescent and proxy reports were examined.

Methods: Children with burns (11–18 years old) and their mother and father were invited to participate. A total of 54 adolescents aged 11 years or older filled out the American Burn Association/Shriners Hospitals for Children Burn Outcomes Questionnaire (BOQ). Descriptive and correlational analyses were performed.

Results: The physical functioning scores showed to be optimal in almost all participants (99%) and across the three informants. Adolescents reported better functioning than their fathers and mothers on most of the scales. On average the correlations between self-reports and proxy reports were moderate to good. Higher parental traumatic stress scores were linked to less favorable parent-reported burn outcomes.

Conclusion: Overall, this study showed that a large proportion of the parents had similar views on the adolescents physical functioning, but disparities emerged also, mainly in psychosocial scales. The discrepancies between self- and parent reports should be discussed when they have a role in treatment decisions. Preferably, besides parent-reports,

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adolescents' self-reports should be included in clinical assessments and treatment decisions, as parental traumatic stress symptoms are a possible factor influencing parental observations.

1. Introduction

According to the World Health Organization, around 96,000 people under the age of 20 years died as a result of fire related burns in 2004 [1]. The estimates for 2011 for disability-adjusted life years (DALYs) for fire, heat and hot substances in the World were 4,218,680 cases for boys 0–14 years olds and 3,603,873 for girls in the same age group [2]. These figures show that burns are a major concern in the health area, because they can lead to an incapacitating condition accompanied by deep pain, and frequently, by long-term sequellae [3]. Functional outcome studies in pediatric burn populations confirm poorer levels of functioning associated with burn severity, face burns, lower appearance scores, and higher emotional and behavioral problems [4–6]. Costs for patients with burns are high as all domains of functioning can be affected, thus optimization of cost-effectiveness of burn care is needed [7,8]. It emphasizes the call for documenting Health-Related Quality of Life (HRQOL) in the aftermath of a burn, particularly in children, as they have a whole life in front of them.

The many definitions of HRQOL all refer to a broad multidimensional concept that includes self-reported measures of physical and mental health [9]. The American Burn Association/Shriners Hospitals for children Burn Outcomes Questionnaire (BOQ) is the only age-specific instrument to measure HRQOL in pediatric burn patients [10]. It includes both physical and psychological functioning directly linked to the burn event and a child and parent version are available. Studies investigating the agreement among the adolescent and the parents using the BOQ showed inter-agreement correlations between .40 and .92 [10], indicating there is considerable variation in agreement across the scales.

Cross-informant variation in HRQOL studies is a common finding [11]. Several studies have shown that scores across multiple informants do not perfectly match [12,13]. It has been advocated that the perspective of the child may differ from the parent, but that they are equally valid, as they both provide important information [14]. It has also been reported that cross-informant variation can vary depending on the domain of interest. Agreement was lower for social and psychological domains of functioning compared to physical domains, because the latter is better observable. Therefore both perspectives should be obtained if possible. However, there may be situations in which only a proxy-report can be obtained, for example because the child is too young or the severity of the illness limits the capability to provide self-reports [13]. Sometimes parents take a dominant role in the decision-making about health care use for their child. In all cases, it would be helpful to better understand the discrepancy between the perspectives.

In burn research, on the BOQ scale-level, marked discrepancies between self and other observations appear that are worth investigation [10]. The appearance scale, measuring scar-related aspects, was found to show poor agreement between the adolescent and the parent in the available studies [10,15]. Appearance has been found to be suboptimal as reported by parents years after the burn event [16] and showed to be negatively associated with family conflict and achievement orientation [17], illustrating important relationships with the family environment.

Discrepancies between child- and parent reports may be explained by the existence of parental traumatic stress symptoms. Parental post-traumatic stress symptoms are reported to be a common consequence in the aftermath of a burn event [18,19]. The scars which are directly linked to the burn event may act as a reminder and therefore may play a role in parental observations [20]. Moreover, parental traumatic stress symptoms were also observed to be associated with a higher level of burn-related concerns in the parent [21]. Therefore, we hypothesize that parents with higher traumatic stress levels overreport the problem level relative to the adolescent's report, which may be especially the case in relation to the appearance scale.

Most of the studies have examined the agreement between the adolescent and either the mother or the father report [10,15,22,23] and concluded that similar estimates of burn recovery for the adolescents and one of their parents were found for most of the scales. One study reported statistically significant differences between parent's and adolescent's scores in the appearance, itch and school reentry domains [15]. An issue unaddressed is the agreement between both parents of a child, so it is unknown whether the mother and the father from the same family have the same perception on the functioning of their child with burns.

This study considers two underaddressed issues when using HRQOL parental ratings of children with burns. The first aim of this study was to report on the HRQOL outcome in adolescents with burns and to compare self-reported HRQOL of the adolescent with burns and the proxy estimation of both the mother and father at 6 and 18 months after the burn. Based on the existing literature, it was expected that agreement on observable domains of physical problems would be higher across informants than agreement on psychosocial domains. The second aim was to investigate whether a higher parental problem level relative to the adolescent's score was associated with parental post-traumatic stress symptoms. It is expected that parents troubled with post-traumatic stress symptoms observe more problems in their child.