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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.

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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.

2. Method

2.1. Participants and procedures

2.1.1. Participants

The study was a prospective cohort study conducted in seven burn centers, of which three are located in the Netherlands (Groningen, Beverwijk and Rotterdam) and four in Belgium (Antwerp, Gent, Brussels, and Leuven). This study is part of a larger research program on post-traumatic stress symptoms and HRQoL in children with burns and their parents. The data inclusion period ranged between November 2007 and July 2011. All children with burns (8–18 years old) admitted to one of these burn centers and their mother and father were invited to participate in the larger study. Exclusion criteria for the study were: insufficient proficiency in Dutch, a child age younger than 8 years, and pre-existing severe mental incapacities in the child. For the purpose of this paper, we selected adolescents aged 11 years or older who had at least one completed BOQ at 6 months or 18 months after the burn. A total of 201 families were eligible for the larger study, of which 146 gave their informed consent. A total of 43 children were younger than 11 and provided no BOQ self-reports, leaving 103 families for this study. Of these, 14 families provided informed consent but did not complete any of the questionnaires, leaving 89 adolescents. Of this group, in 54 families, the adolescents and their mothers, as well as 41 fathers provided valid BOQ scores. Compared to the families that were included in the analyses, those that were not included did not differ with respect to adolescents' age, gender, and percentage of body surface burned.

2.1.2. Procedure

The adolescents and their parents were invited to participate in the study during hospitalization or by telephone after discharge. They were instructed to fill out the questionnaires separately. The questionnaires were sent to their home address by regular mail in separate envelopes. The participants were asked to return the questionnaire to the burn centers within two weeks using a prepaid envelope. If the questionnaires were not returned, the participants received a reminder (e-mail or telephone call). They were asked to fill out the HRQoL questionnaire at 6 months and 18 months after the burn. The study was approved by Ethics Committees in the Netherlands and Belgium.

2.2. Measures

2.2.1. Adolescent and parents characteristics

The following data were collected about the adolescents: gender, age at the time of the burn, etiology of the burn, percentage total body surface area (TBSA) burned, and length of stay in hospital (LOS). Both parents provided information on their gender, age, and level of education.

2.2.2. Burn Outcomes Questionnaire (BOQ 5–18 year old)

The BOQ (5–18) questionnaire was developed for the American Burn Association and the Shriners Hospitals for Children [10] and was previously validated in a Dutch population [22]. The BOQ is composed of 12 scales: upper extremity function,

physical function and sports, transfers and mobility, pain, itch, appearance, compliance, satisfaction with current state, emotional health, family disruption, parental concern, and school reentry. In concert with the original version, the scores were transformed to a 0–100 scale, such that 0 indicates the least optimal score and 100 represents the optimal score. The scales pain, itch, family disruption and parental concern have reversed scores, such that 0 indicates the optimal score.

2.2.3. Impact of event scale

The impact of event scale (IES) [24] was used to assess traumatic stress symptoms in parents. The 15-item self-report scale assesses symptoms of intrusion and avoidance that are linked to the child's burn event. There was a strong correlation between the IES and a clinical interview of post-traumatic stress disorder in an adult patient population with burns [25]. Items were scored on a 4-point scale (0-1-3-5). The total score can range from 0 to 75. Higher scores reflect a higher symptom level. The Dutch version was used in this study [26]. A total IES score of >26 provides an indication of clinically significant stress levels [27].

2.3. Statistical analysis

Descriptive characteristics of scale scores were presented. Paired t-tests were performed to test for statistically significant differences in mean scale scores between adolescent-mother, adolescent-father and mother-father dyads. Pearson correlations between results of the adolescents, mothers, and fathers 6 and 18 months after the burn were performed. Data analysis was done using the statistical package IBM SPSS 21.0.

3. Results

3.1. Characteristics of adolescents with burns and their parents

3.1.1. Adolescents

Of the 89 adolescents included in the study, 54 (61%) completed the BOQ at 6 months and 47 (53%) at 18 months. Of these 54, 40 (74%) participants were boys and 14 (26%) were girls. The mean age at the moment of the burn was 14 years (SD = 2, range 11–17 years). In 64% and 19% of the cases, respectively, flames and scalds were the cause of injury. The mean TBSA burned was 10 percent (SD = 13, range 1–72) and length of stay in hospital was on average 19 days (SD = 30, range 1–180).

3.1.2. Parents

Of the 89 families, 54 mothers (61%) and 41 fathers (45%) completed the questionnaire at 6 months. Eighteen months after the burn, 46 mothers (52%) and 34 fathers (38%) filled out the questionnaire. The mean age was 44 years (SD = 6) in mothers and 46 years (SD = 6) in fathers.

3.2. Health-Related Quality of Life after burn

Fig. 1 presents the differences on the BOQ-scales between adolescents, mothers and fathers at 6 and 18 months after the

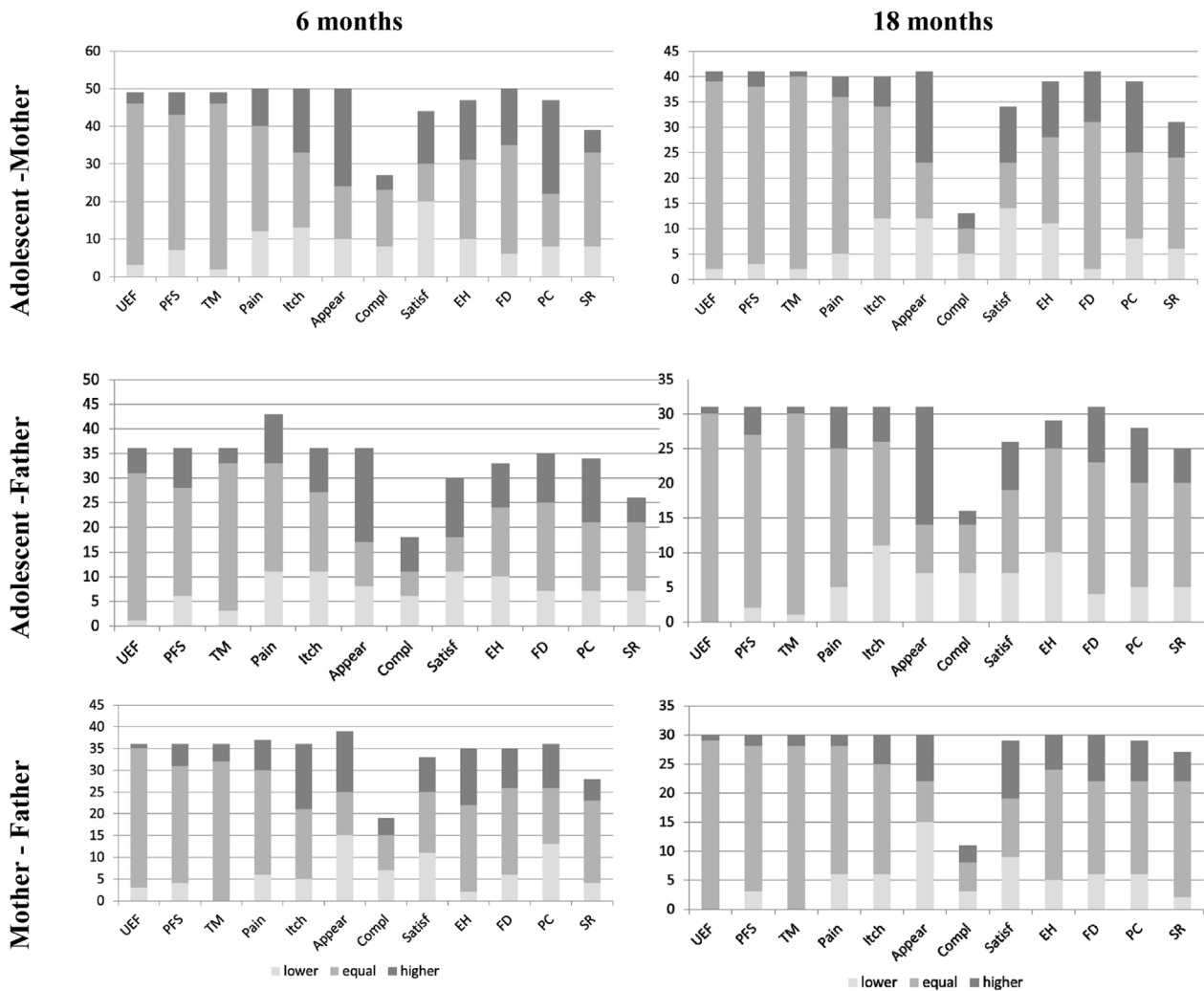


Fig. 1 – Differences between informants on the BOQ scales. Note. UEF = upper extremity function; PFS = physical function, sports; TM = transfers and mobility; Appear = appearance; Compl = compliance; Satisf = satisfaction; EH = emotional health; FD = family disruption; PC = parental concern; SR = school reentry. A lower score (white) indicates that the adolescent scores less favorable compared to the parents or that the father scores less favorable compared to the mother; equal (gray) indicates the difference between adolescent and parent, or between both parents, is zero; higher (black) indicates the parent scores less favorable compared to the adolescent or that the mother scores less favorable compared to the father.

burn. The means of the scales across the informants were subtracted and presented as “similar” when the difference was zero. An imperfect match could be either negative (parent scores higher than the adolescent; father scores higher than mother) or positive (adolescent scores higher than the parent; mother scores higher than father). As can be seen in Fig. 1, the three physical functioning scales showed a large proportion of perfect match (i.e., similar scores), indicating high agreement between parents and the adolescent. The proportion of perfect match was lower for the other scales. The appearance scale showed the largest proportion of imperfect match, with a high proportion of parents reporting less favorable scores compared to the adolescent.

Table 1 shows the means, standard deviations, medians, and the proportion of the adolescents, mothers, and fathers who had an optimal score (0 or 100) on all scales at 6 and 18

months after the burn. In general, a large proportion of the responders reported optimal scores across the scales, indicating good quality of life. The physical functioning scores showed to be optimal in almost all participants and across the three informants, varying between 82% and 97%. For the other scales the proportion of optimal scores was lower. For the adolescent-mother dyads, paired t-tests showed a statistically significant difference for appearance ($M_{ad} = 86, SD = 20, M_{mo} = 78, SD = 25; t(49) = 2.266, p = .028$), family disruption ($M_{ad} = 5, SD = 13, M_{mo} = 9, SD = 16; t(49) = -2.32, p = .024$) and parental concern ($M_{ad} = 11, SD = 17, M_{mo} = 20, SD = 20; t(46) = 2.721, p = .009$) at the 6-month measurement. As can be seen, mothers reported a higher level of problems.

As shown in Table 2, the correlations between the adolescent and parental reports varied between .03 and .86. For most of the scales the correlations were medium

Table 1 – BOQ scale scores at 6 and 18 months after the burn.

Subscale	Time (months)	Adolescent			Mother			Father		
		Mean (SD)	Mdn	Optimal N (%)	Mean (SD)	Mdn	Optimal N (%)	Mean (SD)	Mdn	Optimal N (%)
Upper extremity functioning	6	99 (3)	100	51 (94)	99 (3)	100	50 (93)	99 (3)	99	34 (85)
	18	100 (2)	100	45 (96)	99 (4)	100	44 (96)	100 (1)	100	33 (97)
Physical function and sport	6	97 (8)	98	40 (74)	96 (12)	99	45 (83)	97 (7)	98	29 (72)
	18	99 (6)	100	43 (92)	98 (9)	100	42 (91)	98 (7)	99	28 (82)
Transfer and mobility	6	99 (3)	99	48 (89)	98 (6)	99	49 (91)	99 (5)	100	37 (93)
	18	99 (5)	99	45 (96)	99 (5)	100	43 (94)	99 (5)	99	33 (97)
Pain	6	9 (17)	2	37 (69)	10 (14)	3	35 (64)	6 (12)	2	30 (73)
	18	4 (10)	1	38 (81)	3 (8)	3	38 (84)	5 (10)	2	26 (77)
Itch	6	20 (22)	19	20 (37)	22 (23)	21	21 (38)	19 (22)	20	17 (43)
	18	17 (22)	10	23 (49)	16 (21)	14	23 (51)	12 (16)	7	19 (56)
Appearance	6	86 (20)	93	24 (44)	77 (26)	86	17 (31)	81 (23)	89	12 (30)
	18	84 (25)	95	24 (51)	81 (26)	93	20 (44)	79 (22)	85	10 (29)
Compliance	6	88 (16)	93	16 (44)	91 (12)	96	21 (51)	91 (12)	94	13 (50)
	18	84 (25)	95	13 (45)	93 (10)	96	14 (58)	90 (23)	97	17 (74)
Satisfaction with current state	6	85 (25)	96	20 (41)	86 (20)	94	23 (44)	88 (17)	96	19 (49)
	18	87 (22)	97	21 (49)	89 (19)	96	19 (44)	89 (21)	97	17 (52)
Emotional health	6	92 (10)	96	25 (50)	92 (9)	94	22 (41)	94 (9)	96	19 (48)
	18	95 (8)	97	26 (58)	94 (8)	96	25 (56)	97 (6)	98	24 (71)
Family disruption	6	5 (13)	2	40 (74)	9 (18)	3	35 (64)	9 (18)	2	26 (67)
	18	6 (17)	1	39 (83)	6 (15)	1	35 (76)	6 (10)	2	22 (65)
Parental concern	6	12 (17)	6	27 (54)	21 (20)	18	13 (24)	16 (17)	10	14 (34)
	18	8 (15)	3	32 (71)	15 (20)	8	21 (47)	8 (12)	5	19 (58)
School reentry	6	55 (14)	52	2 (5)	54 (13)	52	2 (4)	54 (14)	52	1 (3)
	18	55 (13)	52	2 (5)	53 (10)	51	3 (8)	57 (16)	52	2 (7)

Note: Optimal score is a 0% score for the scales pain, itch, family disruption, and parental concern. Optimal score for school reentry is a score >50. For all other scales optimal is a 100% score.

(.30 < r < .50) or high (r > .50). In general, the correlations were slightly higher for adolescent–mother dyads and for the 6-month measurement. The correlations between the mother and the father were on average higher than the adolescent–parent dyads.

To examine a possible association with parental traumatic stress symptoms and their BOQ-reports, correlations were obtained for parental IES scores 3 months after burn and parental BOQ scale scores at 6 and 18 months after burn. The mean IES score for the 49 mothers who reported their stress

Table 2 – Pearson correlations between the BOQ scales of adolescents, mothers and fathers at 6 and 18 months after the burn.

Subscale	Adolescent–mother		Adolescent–father		Mother–father	
	6 m	18 m	6 m	18 m	6 m	18 m
Upper extremity functioning	.86**	-.04	.66**	. ^a	.81**	1.0**
Physical function and sports	.79**	.44*	.67**	.37	.70**	.97**
Transfer and mobility	.65**	.12	.35*	-.04	.54**	.98**
Pain	.50**	.29	.64**	.18	.71**	.09
Itch	.82**	.74**	.72**	.77**	.60**	.66**
Appearance	.43**	.37*	.28	.29	.76**	.64**
Compliance	.68**	-.25	.67**	.08	.69**	.22
Satisfaction with current state	.26	.24	-.07	-.18	.50**	.74**
Emotional health	.50**	.58**	.55**	.17	.58**	.27
Family disruption	.69**	.26	.66**	.37	.88**	.72**
Parental concern	.27	.23	.32	.26	.43*	.41*
School reentry	.15	.49**	-.00	.13	.17	.46*

* p ≤ 0.05.

** p ≤ 0.01.

^a All the fathers reported the optimal score.

symptoms was 18.4 (SD = 14.1) with 31% scoring in the clinical range. The mean IES score for the 39 fathers was 10.5 (SD = 11.9) with 13% scoring in the clinical range. Statistically significant ($p < .01$) Pearson correlations were found between the mother's traumatic stress symptoms and lower satisfaction with their own observation of the adolescent's current state ($r = -.42$), lower emotional health ($r = -.49$) and higher parental concern ($r = .53$) at 6 months and higher parental concern ($r = .47$) at 18 months. Fathers' traumatic stress symptoms were significantly ($p < .01$) related to their observation of the adolescent's higher itch ($r = .60$), lower appearance ($r = -.67$), less satisfaction with current state ($r = -.47$), lower emotional health ($r = -.48$), more family disruption ($r = .62$) and more parental concern ($r = .46$) at 6 months and to higher itch ($r = .56$) and lower appearance ($r = -.50$) at 18 months.

4. Discussion

This is the first study that compared self-reports on burn outcomes of adolescents with both parents' estimation of the adolescent's functioning and examined whether post-traumatic stress symptoms in parents were a determinant of discrepancies between adolescent and parent reports.

On average, the correlations between adolescent and parents reports were within the same range compared to previous studies [10,15]. Correlations between the adolescent and the parent estimates were generally medium to high; exceptions were satisfaction with current state, parental concern, and school reentry, on which there was low agreement in this study. Regardless of the noticeable differences in sample size and burn severity between the current study and previous studies, the adolescent-parent agreement in our study concurs with previous studies, illustrating the robustness of the findings.

In accordance with a prior review [14] and prior burn studies [10,15,23], cross-informant congruency was high for the observable physical functioning domains. Most adolescents and their parents in this study gave the highest possible scores on the scales upper extremity functioning, physical function and sports, similar to a previous study [23]. This suggests that, for these domains, it is appropriate to use the score of only the adolescent or a single parent.

Assessing both self and proxy reports in the psychosocial domain appears more relevant than in the physical domains, because psychosocial scores were less often optimal and larger variation in adolescent-parents dyads was found. On average, adolescents reported better functioning, compared to the reports of their fathers and mothers. In a previous study [15], the agreement between the adolescent and the parent on the appearance scale particularly was relatively low. In our study, mothers gave less favorable appearance scores as compared to the adolescent's score but mothers' lower scores were not related to maternal traumatic stress symptoms. Fathers' scores of appearance were related to their post-traumatic stress levels, suggesting that their own stress levels influenced the observation of their child's appearance score or that post-traumatic stress was higher when physical appearance of the child was more severely affected. Possibly, the

scars act as a reminder of the trauma and magnify the negative consequences of the burn event. Fathers may have negative appraisals of the trauma and related scars, which can be part of a post-traumatic stress disorder (PTSD). This would be in line with a cognitive theory on PTSD as proposed by Ehlers and Clark [20]. Our findings suggest that successful treatment of post-traumatic stress in parents may lead to a more positive appraisal of appearance in their children.

In both mothers and fathers, emotional health and parental concern reports showed to be significantly interrelated with traumatic stress levels, and concur with previous results revealing an association between parental concern and stress symptoms [21]. The suggestion that the psychological state of the parents may color the judgment of their child negatively emphasizes the relevance of including adolescent self-reports in clinical practice, where possible. It is not recommended that treatment decisions are mainly based on parental decisions. Possible discrepancies between adolescents and parents should be evaluated and discussed if they occur and both parents and adolescents should have a role in the treatment decision. With issues related to a negative appreciation of appearance, treatment options such as cosmetic camouflage can be discussed [28].

This study has some limitations that merit note. The small sample size and the high number of dropouts may affect the generalization of findings. Replication in larger study samples is warranted. The small sample size prevented performing subgroup analyses, like comparing burn severity groups or boys and girls or to examine other moderators and covariates. Although both parents were invited to participate in this study, more mothers than fathers filled out the questionnaires. Similar to other studies [15], adolescents and parents were instructed to separately fill out the questionnaires, but there is no guarantee that they did. Finally, parental post-traumatic stress scores were measured at 3 months after burn, while burn outcomes were assessed 6 and 18 months after burn. As it is expected that parental post-traumatic stress symptoms will decline with time in a subgroup of parents [29], the correlations between parental BOQ scales and their stress symptoms may have been more accurate if stress symptoms had been measured within the same period. The 18 months measurement in particular may be affected by the relatively large time interval. Research has shown that the prevalence of parental clinically significant stress symptoms stabilize only between 12 and 18 months after burn [29].

In conclusion, the reported scores of the three informants were quite similar on average, illustrated by a large proportion of perfect match. However, also meaningful discrepancies across informants were observed which were found to be associated with parental traumatic stress symptoms. Our findings suggest that the proxy estimation can be used when the adolescents cannot provide the assessment themselves but attention should be paid to the finding that parental traumatic stress symptoms are associated with a more frequent appraisal of poor quality of life in their child.

Conflict of interest

There is no conflict of interest to report by any of the authors.

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