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Two-year follow-up of outcomes related to scarring and distress in children with severe burns

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Abstract

Purpose—We assessed the perception of scarring and distress by pediatric burn survivors with burns covering more than one-third of total body surface area (TBSA) for up to 2 years post-burn.

Methods—Children with severe burns were admitted to our hospital between 2004 and 2012, and consented to this IRB-approved-study. Subjects completed at least one Scars Problems and/or Distress questionnaire between discharge and 24 months post burn. Outcomes were modeled with generalized estimating equations or using mixed linear models. Significance was accepted at $p < 0.01$.

Results—Responses of 167 children with a mean age of 7 ± 5 years and burns covering an average $54 \pm 14\%$ of TBSA were analyzed. Significant improvements over the 2-year period were seen in reduction of pain, itching, sleeping disturbance, tightness, range of motion, and strength ($p < 0.01$). There was a significantly increased persistent desire to hide the scarred body areas over time ($p < 0.01$). The perception of mouth scarring, inability to portray accurate facial expressions, and skin coloration did not improve over the follow-up period.

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Declaration of Interest statement

All authors made substantial contributions to the conception or design of the work (AAF, CCF, CRA, GH, KME, OES, PW, WJM) or to the acquisition, analysis, or interpretation of data for the work (AAF, CCF, DNH, GH, LKB, LPK, OES) and the drafting of the work or revising the intellectual content (all authors).

The authors report no conflicts of interest.

Conclusions—According to self-assessment questionnaires, severely burned children exhibit significant improvements in their overall perception of scarring and distress. However, these patients remain self-conscious with respect to their body image even 2 years after burn injury.

Keywords

itch; pain; children; burns; self-perception

1. Introduction

Over the past several decades, profound medical and technological advances in burn care have made it possible for children with burns covering up to 100% of the total body surface area (TBSA) to survive [1]. Although burn injury mortality rates have decreased [2], improving the quality of life after a burn injury remains challenging [3]. Redirecting the focus beyond patient survival, towards maximizing rehabilitation and the quality of life after injury is of increasing importance [4].

Post burn scarring often causes disfigurement, contractures, and thermoregulatory and sensory disruptions [5], negatively impacting quality of life. The negative psychological effects of scarring are often overlooked during recovery when compared to the treatment of physical disabilities [6]. However, emotional well-being is important for the recovery of physical function [7]. Lastly, Meyer et al. [8], demonstrated reported a significantly higher prevalence of major psychiatric issues in a cohort of burn survivors compared to a control group who had not experienced comparable trauma during childhood. Hence, the multifactorial challenges caused by burn scars require improvement of both physical and psychological treatment strategies.

To date, no comprehensive evaluation of long-term perception of scarring and distress among severely burned children exists. By identifying the subjective impact of scars and patterns of distress in children with more than 30% of TBSA burned, our study aims to determine the gaps in medical and emotional rehabilitation approaches that if addressed, could ameliorate quality of life deficits among pediatric burn survivors. Thus, we studied the perception of severely burned children, who filled out the questionnaires together with their parents, regarding their scarring and distress for up to 2 years post burn.

2. Methods

2.1. Design and Patients

This study has been approved by the local Institutional Review Board of The University of Texas Medical Branch (IRB #00-435). In this long-term follow-up study we prospectively enrolled patients between the ages of 0.2 and 19 years, who suffered from a burn covering more than 30% of TBSA and received the standard of care at our institution between 2004 and 2015. The studied cohort was part of a larger cohort enrolled into a multi-institutional study sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). As part of the NIDILRR project, participants together with their parents or legal guardians filled out various questionnaires focusing on

psychological and physiological outcomes. The Questionnaires assess the perception of the children and their parents/guardians regarding scarring and distress. To be included in the study, at least one questionnaire at either discharge (DC), 12 months (12mo), or 24 months (24mo) post burn had to be completed. This study focused on the Scars Problems Questionnaire and the Distress Questionnaire. We hypothesized that the perception of both, scarring and distress by pediatric burn survivors, would significantly improve over time.

2.2 Questionnaires

The Scars Problems Questionnaire (SQ) was developed as part of the Burn Model System (BMS) Child Interview Forms for the NIDILRR project. A total of 21 questions assess the perception of scar-related issues including problems with open wounds, fragility of the skin, dryness of the skin as well as tightness, loss of sensation, and problems with sensitivity.

Pain, amount of itch, and difficulty sleeping are assessed using a scale from 0 (no impairment) to 10 (maximal impairment). The remaining questions are binary measures ("Yes" or "No"). Participants were given the option to not answer any particular question.

The Distress Questionnaire (DQ), uses 12 questions to assess distress of the patient. Each question can be answered using a scale from 0 (no distress) to 10 (a lot of distress), or 99 (unknown, no answer). Besides pain, itching, and sleeping disturbances, the DQ can be used to assess decreased range of motion and strength, problems with skin coloration, and further scarring-related discomforts.

2.3 Statistical methods

Demographic variables were summarized by means and standard deviations for continuous data or counts and percentages for discrete data. Binary outcomes (yes/no) were modeled by generalized estimating equation (GEE) models, which are a variant of logistic regression models accounting for age, burn size, sex, and repeated measures by blocking on subjects. Continuous outcomes such as itch, pain, and sleep were modeled by mixed linear models and blocking on subject. The discharge time-point was defined as date within the period between the discharge minus two weeks. The 12-month time point was defined as the 1-year post-burn time point $\pm$ 4 months, and 24 months was defined as the 2-year post-burn time point $\pm$ 4 months.

Statistical analyses were performed using R statistical software version 3.2.1 (R Core Team, 2015, Vienna, Austria). Significance was accepted at $p < 0.01$.

3. Results

3.1 Patient demographics

One hundred sixty-seven children, treated between 2004 and 2013, with a mean age of 7 ± 5 years and burns covering an average of $54 \pm 14\%$ of TBSA were included in this analysis (table 1). The majority of burns were flame (64%), followed by scald (25%), electrical (10%) and chemical injuries (1%, (table 1)).

3.2 Scars Problems Questionnaire

Binary outcomes of the SQ are shown in table 2. When comparing discharge to the 12- and 24-month time points, patients developed a significantly increasing desire to hide their scars and were significantly more likely to avoid situations in which their scars can be seen when comparing the responses from discharge up to 24 months post burn ($p<0.01$). Fragility of the skin and hand function significantly improved ($p<0.01$). Perceived scar thickness significantly worsened when comparing responses from discharge to 12 months post burn ($p<0.01$). However, responses regarding scar thickness at 24 months were comparable to discharge responses. Problems with hypersensitivity, tightness and dryness of skin, and chronic open wounds significantly decreased from discharge up to 24 months post burn ($p<0.01$). Range of motion significantly improved ($p<0.01$); level of pain, amount of itch, and difficulty sleeping decreased significantly from discharge up to 12 and 24 months post burn ($p<0.01$, Table 3). In general, female patients reported significantly higher levels of pain than males ($p=0.002$). Females also indicated a desire to use clothing, cosmetics, and wigs to hide scars significantly more often than males ($p=0.001$). A greater burn size was significantly associated with chronic open wounds ($p=0.008$), mouth scarring ($p=0.002$), and problems with tight skin ($p=0.002$). In addition, a larger burn size had a higher tendency for problems related to temperature changes; however, this finding was not significant ($p=0.015$). For all other items addressed by the SQ, burn size, sex, and age had no effect on the scored values.

3.3 Distress Questionnaire

All outcomes from the DQ questionnaire are shown in table 3. Patients reported distress pain and sleep disturbances decreased significantly and strength increased significantly from discharge up to 12 and 24 months post burn ($p<0.01$). Distress related to decreased range of motion, itching, temperature changes and long recovery time from burn decreased significantly between discharge and 12 and 24 months post burn ($p<0.01$). Sleep disturbances were rated significantly higher in female patients than in male patients ($p=0.007$). The perception of pain was comparable in both sexes ($p=0.052$). For all remaining items addressed in the DQ, burn size, sex, and age had no effect on the scores.

4. Discussion

Van Baar et al. [3] showed that general quality of life, assessed using the burn outcome questionnaire, improved significantly for up to 2 years post burn. Our analysis of the questionnaires, which assessed the perception of scarring and distress of children with massive burns, showed that pain, itching, and sleeping disturbances decreased significantly during the first 2 years post burn. Perception of functional outcomes such as strength, range of motion, and hand function also significantly improved with time. However, problems with mouth scarring, skin coloration, foot function, and inability to portray accurate facial expressions persisted throughout the 2-year period. Overall, female pediatric burn patients had significantly more frequent use of cosmetic wigs to hide scars and described significantly more problems with sleep disturbances than males. In addition, a larger burn was significantly more prone to develop problems with chronic open wounds, mouth

scarring, or tight skin. Age at the time of burn showed no significant correlation with any of the studied endpoints.

Adequate high quality sleep is required in order to improve wound healing, to reduce susceptibility to infections, and to decrease post burn pain and anxiety during acute hospitalization [9]. Sleeping difficulties in burn patients present as substantial disruption and aberrations of sleep stages [10]. Our analysis showed that sleep disturbances were present at discharge and that female patients reported significantly more problems regarding sleep. We do not know whether male patients did not report their sleep disturbances or if female patients experience more or worse sleep disturbances following trauma. When compared to quality of life reported in the literature, the perceived health-related quality of life of pediatric burn survivors, with a mean age of 7 years and median follow-up time of 6.3 years post trauma, was better in terms of sleeping, learning, breathing, and appearance than that of the studied control population [11]. However, sex-specificity was not taken into account in this study. Although we are also able to show that sleeping disturbances were significantly reduced at 2 years post burn, we unfortunately were not able to compare our findings to a healthy control group. Determining whether our findings at the 2-year follow-up represent age predicted values is important as further reduction may not be possible. Furthermore, it is necessary to point out that the populations studied by Laitakari et al. [11] as well as van Baar et al. [3] included children with small burn sizes, with the majority of burns covering under 10% of TBSA, whereas our current research focused on burns covering an average of more than 50% of TBSA. Larger burns are associated with multiple surgeries during both the acute hospitalization and rehabilitation period; thus further psychological stress may contribute toward sleep disturbances. However, after 2 years, these burn-related sleeping difficulties diminish toward baseline.

An important contributing factor to the sleep disturbances experienced by pediatric burn survivors is burn scar-related intense itching. Skin damage, neuropathic, and psychogenic mechanisms have been proposed to cause the pruritus experienced after burns [12]. Our questionnaires showed that scar-related itching was rated worst at the time of discharge and diminished significantly over time. The majority of symptoms of itching are believed to arise during the skin re-epithelialization process, which likely explains the decreased distress levels from itch we observed 2 years after discharge. There are many risk factors for post burn pruritus, including total burned surface area, number of surgeries, and anatomical location of the burn [13]. However, our analysis of the perception regarding itch did not reflect an effect of the burn size on itching. One reason for that could be that itching is usually a clinical problem that occurs during the acute healing phase for up to 9 months post burn and our analysis compared itching between discharge and 12 months, a period during which itch has already considerably decreased. According to prior studies the majority of complaints about itching stem from burns on the legs and trunk, with facial burns being the least likely to cause significant pruritus [14]. Since our questionnaires did not ask the patient to specify which body part caused the itching and our studied cohort suffered from burns covering greater than 50% TBSA on average, it would be interesting to validate the type and location of the wound responsible for most of their pruritic distress in further studies. Additionally, a recent study by Carrougier et al. [13] demonstrated a higher likelihood of burn patients with dry skin and hypertrophic scarring to report itching. Supplementary

analysis of our data may show similar patterns to support this conclusion, thus suggesting prioritizing the topical prevention of itching in patients with dry skin and significant hypertrophic scarring. Of note, the study by Carrougher et al. [13] only included adult burn survivors, so the predictors of post-burn itch could be different within our pediatric study population. Fortunately, there was an overall reduction in scar related itching among our pediatric burn patients that may be even further improving as the time after burn increases.

While the acute burn injury and initial recovery is severely painful for the patient, the persisting pain a burn survivor experiences during and after scarring must be not be underrated. It has been shown that adequate pain management is crucial to the patient's outcome, reducing the risks of developing a psychiatric illness and the physical demands of stress on the body [15]. Our study is the first study showing that female pediatric burn patients score their pain significantly higher than males for up to 2 years post burn (Scars Problems Questionnaire); however, we could not confirm this finding in the same population by using the Distress Questionnaire. Interestingly, both questionnaires showed a significant decrease in scar-related pain at 2 years follow-up, and neither burn size nor age had a significant effect on the perception of pain. Taking into account the drastic emotional and psychological strain on severely burned children, the questionnaires used in this study make it difficult to distinguish a purely physical scar pain from a psychogenic source of pain.

While we observed substantial improvements in scar-related distress, patients' concerns about facial expressions and mouth scarring showed no significant changes by the 2-year follow-up. These areas of distress affected approximately one-third of the patients throughout the study population. The resulting scarring after facial burns at a young age can inflict substantial limitations on further development of the facial structures [16]. From our results, it can be concluded that the distress from mouth related scarring and unsatisfactory facial expression does not improve in a time-dependent manner, despite making use of all currently acceptable interventions. It would be worthwhile to further study the surgical or noninvasive approaches each patient received to determine which method was the most efficacious to alleviate these specific distresses concerning the face.

Foot function did not show any significant change over the study's 2-year period in 43 percent of our patients. Similar to the scarring mechanisms towards facial growth restriction, the lower extremity is also exuberantly growing while scar tissue remains rigid. The contractures that develop in the lower extremities can limit mobility, affect gait, and predispose the patient to sprains and other ankle or foot injuries [17]. Regardless, the persistent distress caused by impaired foot functionality was seen in almost half of our patient population. This observation emphasizes the need for more timely and efficient interventions to improve foot function in pediatric burn survivors.

Severe burns are associated with a vast loss of lean body mass and muscle strength caused by the burn related hypermetabolism and prolonged physical inactivity [18]. Our studied cohort reported at the time of discharge, decreased strength and range of motion due to trauma. However, both perception of muscle strength and range of motion significantly improved by 2 years post burn ($p < 0.01$). These increases in strength over time have also been described by Disseldorp et al. [19]; however, they studied children with smaller burns

ranging from 10 to 41% TBSA; our analyzed cohort suffered more extensive burns. Furthermore, we assessed the perception of muscle strength and range of motion with questionnaires whereas Disseldrop et al. [19] used objective tools. A future direction for studies will be the validation and comparison between perception and objective measurements. Nevertheless in our opinion, perception and patient's subjective well-being are crucial markers for satisfaction with burn care and post-burn recovery.

A limitation of our study is that, in young children, the questionnaires and assessment may more likely reflect the parents' perception rather than the child's perception as previously reported by Pan et al. [20]. Nevertheless despite this limitation, it is important to point out that, in cases where parental help was needed to answer the questionnaires, we made every attempt to ensure that the questionnaires were filled out with consideration of the child's own perception. Another limitation of our current study could be that we did not perform a separate analysis of the subgroup of the patients (10%) who suffered from massive burns covering more than 70% of the TBSA. Reports from our institution have shown that burn size is directly correlated with a worse physiological outcome [21]; however, we have not yet looked at the psychological and physiological long-term outcomes of these burns. Thus, further studies are warranted to determine the long-term effects of a massive burn during childhood.

5. Conclusions

According to self-assessment questionnaires filled out by severely burned children together with their parents, significant improvements were seen in their overall well-being, especially scarring and distress, up to 2 years post burn. Scar related pain, itch, and skin fragility were significantly reduced within 1 year post burn. However, severely burned children remain self-conscious with respect to body image throughout the observed study period. To improve mouth scarring and skin coloration are future directions that need to be addressed by improving current burn care.

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Table 1

Demographics (N=167, male:female = 110:57)

Characteristic	30–49% TBSA burn N=74	50–70% TBSA burn N=76	>70% TBSA burn N=17
<i>Sex, N (%) male</i>	45 (61)	52 (72)	13 (76)
<i>Length of hospital stay, days</i>	22 ± 13	41 ± 38	53 ± 39
<i>LOS/TBSA burn, days/%</i>	0.5 ± 0.3	0.7 ± 0.6	0.7 ± 0.5
<i>Age at burn, years</i>	7 ± 5	7 ± 5	9 ± 6
<i>Infant (<1year), N (%)</i>	0 (0)	2 (3)	0 (0)
<i>Toddler (1–2 years), N (%)</i>	11 (15)	16 (21)	2 (12)
<i>Child (3–13 years), N (%)</i>	49 (66)	44 (58)	10 (59)
<i>Teenager (14–18 years), N (%)</i>	13 (18)	14 (18)	5 (29)
<i>Adult (≥ 18 years), N (%)</i>	1 (1)	0 (0)	0 (0)
<i>TBSA burn, %</i>	41 ± 5	60 ± 6	80 ± 7
<i>TBSA 3rd burn, %</i>	41 ± 5	47 ± 17	71 ± 19
<i>Flame, N (%)</i>	44 (59)	50 (66)	13 (76)
<i>Scald, N (%)</i>	20 (27)	17 (22)	4 (24)
<i>Electrical, N (%)</i>	8 (11)	9 (12)	0 (0)
<i>Chemical, N (%)</i>	2 (3)	0 (0)	0 (0)

Data is presented as mean ± standard deviation or N (%); TBSA: Total Body Surface Area.

Table 2

Binary outcomes.

	Description	Discharge		12 months		12mo/DC		24 months		24mo/DC	
		N#	% Yes	N#	% Yes	N#	p-value	N#	% Yes	N#	p-value
SQ 1	Scars as a result of burn injury	113	100%	94	98%	0.442		112	96%	0.125	
SQ 2	Avoid situations	108	25%	90	37%	0.110		111	40%	0.006	
SQ 3	Dress as usual before burn	114	89%	92	82%	0.033		113	82%	0.067	
SQ 4	Dress to hide scars	110	21%	91	43%	0.001		113	37%	0.003	
SQ 5	Clothing, cosmetics, wigs to hide scars	112	5%	94	1%	0.114		114	5%	0.874	
SQ 6	Chronic open wounds	107	30%	92	13%	0.001		112	9%	0.000	
SQ 7	Fragile skin	110	73%	92	39%	0.000		114	33%	0.000	
SQ 8	Dry skin	114	83%	93	71%	0.009		114	62%	0.001	
SQ 9	Tight skin	103	61%	85	40%	0.002		109	43%	0.004	
SQ 10	Loss of sensation	95	36%	86	23%	0.022		102	24%	0.051	
SQ 11	Hypersensitivity	102	68%	82	44%	0.001		104	38%	0.000	
SQ 15	Scar thickness	107	66%	93	83%	0.003		114	78%	0.058	
SQ 16	Scar coloration	111	90%	91	91%	0.760		111	78%	0.023	
SQ 17	Range of motion	102	64%	89	44%	0.008		111	36%	0.000	
SQ 18	Facial expressions	104	42%	88	32%	0.141		105	31%	0.079	
SQ 19	Mouth scarring	108	29%	82	35%	0.164		113	34%	0.132	
SQ 20	Hand functioning	110	72%	93	58%	0.001		108	58%	0.001	
SQ 21	Foot functioning	109	49%	90	40%	0.190		108	42%	0.296	

Table 3

Continuous outcomes.

Description	Discharge			12 months			12mo/DC			24 months			24mo/DC		
	N#	Mean±SD	N#	Mean±SD	N#	Mean±SD	p-value	N#	Mean±SD	p-value	N#	Mean±SD	p-value	N#	Mean±SD
SQ 12 Level of pain	113	3.7±2.4	93	1.4±2.0	0.000	116	1.2±2.3	0.000	116	1.2±2.3	0.000	116	1.2±2.3	0.000	116
SQ 13 Amount of itch	115	5.4±3.1	93	3.3±2.9	0.000	116	2.1±2.5	0.000	116	2.1±2.5	0.000	116	2.1±2.5	0.000	116
SQ 14 Difficulty sleeping	115	3.2±3.1	93	1.1±2.0	0.000	115	1.0±2.1	0.000	115	1.0±2.1	0.000	115	1.0±2.1	0.000	115
DQ 1 Pain	115	3.7±2.7	103	1.9±2.3	0.000	114	1.4±2.2	0.000	114	1.4±2.2	0.000	114	1.4±2.2	0.000	114
DQ 2 Decreased range of motion	113	3.4±2.8	91	1.8±2.1	0.000	115	1.3±2.0	0.000	115	1.3±2.0	0.000	115	1.3±2.0	0.000	115
DQ 3 Itching	115	5.1±3.0	93	3.8±3.0	0.000	113	2.5±2.7	0.000	113	2.5±2.7	0.000	113	2.5±2.7	0.000	113
DQ 4 Sleep disturbance	114	2.8±3.1	104	1.5±2.4	0.000	115	1.1±2.2	0.000	115	1.1±2.2	0.000	115	1.1±2.2	0.000	115
DQ 5 Temperature changes	112	2.5±3.0	93	1.7±2.5	0.006	116	1.2±2.3	0.000	116	1.2±2.3	0.000	116	1.2±2.3	0.000	116
DQ 6 Decreased strength	111	3.4±3.2	93	1.5±2.3	0.000	116	1.3±2.4	0.000	116	1.3±2.4	0.000	116	1.3±2.4	0.000	116
DQ 7 Dislike appearance	107	2.3±2.8	93	1.6±2.6	0.074	114	2.0±2.9	0.592	114	2.0±2.9	0.592	114	2.0±2.9	0.592	114
DQ 8 Uncomfortable scars	109	3.5±2.8	94	3.1±3.0	0.351	114	2.9±3.3	0.125	114	2.9±3.3	0.125	114	2.9±3.3	0.125	114
DQ 9 Changes in skin color	110	3.2±3.1	94	2.5±2.8	0.031	116	2.6±2.9	0.073	116	2.6±2.9	0.073	116	2.6±2.9	0.073	116
DQ 10 Financial concerns	103	5.3±16.5	89	8.7±24.3	0.192	113	8.0±23.4	0.096	113	8.0±23.4	0.096	113	8.0±23.4	0.096	113
DQ 11 Long recovery time	109	3.5±3.6	90	2.5±2.9	0.007	114	2.5±2.9	0.004	114	2.5±2.9	0.004	114	2.5±2.9	0.004	114
DQ 12 Pressure garments	110	3.2±3.5	93	2.4±3.1	0.102	114	2.1±3.0	0.019	114	2.1±3.0	0.019	114	2.1±3.0	0.019	114