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# Adolescents with and without head and neck burns: comparison of long-term outcomes in the burn model system national database



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### ABSTRACT

Introduction: Facial burns account for persistent differences in psychosocial functioning in adult burn survivors. Although adolescent burn survivors experience myriad chronic sequelae, little is known about the effect of facial injuries. This study examines differences in long-term outcomes with and without head and neck involvement.

Methods: Data collected for 392 burn survivors between 14–17.9 years of age from the Burn Model System National Database (2006–2015) were analyzed. Comparisons were made between two groups based on presence of a head and neck burn (H&N) using the following patient reported outcome measures: Satisfaction with Appearance Scale, Satisfaction with Life Scale, Community Integration Questionnaire, and Short Form-12 Health Survey at 6, 12, and 24 months after injury. Regression analyses were used to assess association between outcome measures and H&N group at 12-months.

Results: The H&N group had more extensive burns, had longer hospital stays, were more likely to be burned by fire/flame and were more likely to be Hispanic compared to the non-H&N group. Regression analysis found that H&N burn status was associated with worse SWAP scores. No significant associations were found between H&N burn status and other outcome measures.

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Conclusions: Adolescents with H&N burn status showed significantly worse satisfaction with appearance at 12-months after injury. Future research should examine interventions to help improve body image and coping for adolescent burn survivors with head and neck burns.

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### 1. Introduction

Modern burn care is resource intensive and requires a better understanding of the persistent symptoms and challenges that burn survivors face to optimize their long-term outcomes [1]. Burns can impact multiple domains related to quality of life in the long-term [2,3]. In adolescents, these chronic sequalae can potentially alter the trajectory of their life [4]. Hypertrophic scarring, for example, has a high prevalence in individuals with severe burn injuries, ranging from 32% to 67%, [5-8], is common in adolescents [9], and is often associated with symptoms of pain, itch and tightness. Contractures after burn affect 38% to 54% of burn survivors [10]. When contractures after burns occur in the H&N, these can cause deformities of the maxillofacial structures such as microstomia, eversion of the lower lip, ectropion of the lower eyelid [11], and altered teeth positioning. These deformities result in problems with speech and oral hygiene [12,13], nutrition [14,15], skin and graft healing, verbal expression, [16,17], as well as interfere with performance of activities of daily living. Scarring in the head and neck (H&N) region can affect respiratory function [18], vision [11], and oral continence [19]. Psychological complications from burn injury can include depression, posttraumatic stress, anxiety, poor sleep, body image dissatisfaction, and other adjustment issues [11,20-23].

Burns, the mechanical effects of their scars, and their resulting visible differences in the H&N region can significantly impact physical, cognitive, social, and emotional development for children and adolescents. During adolescence individuals often gain a sense of identity, are pre-occupied with appearance and are influenced by their peers [24]. Child burn survivors with facial burns report significantly greater psychosocial concerns related to appearance, emotional health, and parental concern four years after injury compared to child burn survivors without facial burns [25]. A longitudinal study in survivors 6 years or older with severe burn injuries reported increased body image dissatisfaction at 12-months after discharge compared to survivors with smaller burns [26]. Burns to critical areas such as the head/face, neck, chest, hands and genitals are associated with worse body image satisfaction in adolescent burn survivors at least 2 years after burn injury compared to a normative group [27]. Dissatisfaction with body image is a risk factor for depression, emotional distress, and low self-esteem [28]. In young-adult survivors with facial burns, Ryan and colleagues reported more perceived anger and sadness compared to burn survivors without facial involvement at 24-months after injury [29]. Pediatric and adolescent burn populations also exhibit transient difficulties with community integration [30], but over time, fare at least as well as adult burn survivors [31]. Evidence for health related quality of life (HRQOL) is mixed in the adolescent burn population, but most studies suggest a decreased HRQOL after injury [32,33]. Lastly, research on life satisfaction after burn injury in the adolescent population is scarce.

Overall, prior work examining the long-term impact of burn injuries is limited [18,34,35] with studies often comparing the overall health of burn survivors to the general, non-burned population [36,37] or conducted in adult [29,38-43] or pediatric burn populations [23,36,44]. Few studies compared the long-term outcomes of those with burns to sensitive areas such as the head, neck, or face to those with burns to other body areas [38,39,45] and even fewer focused on the adolescent burn survivor population [36,46]. Previous studies also singularly explore a construct such as body image dissatisfaction [40,47], utilize different outcome measures [23,36,40], study designs [44], or conducted outside the United States (U.S.) [36]. Addressing these shortcomings, this study utilizes self-reported data from the Burn Model System (BMS) National Database in a multicentered population of adolescent burn survivors from the U. S. to comprehensively assess the association between head and neck (H&N) burn status and long-term outcomes for life satisfaction, body image satisfaction, community integration, and HRQOL. Similar to previous findings on pediatric and young-adult burn survivors, adolescents with H&N burn status were hypothesized to have worse functional and psychosocial outcomes compared to adolescents without head and neck (non-H&N) burn status.

### 2. Methods

### 2.1. Database

Data were obtained from the BMS National Database funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The BMS Database was established in 1993 to examine functional and psychosocial outcomes of burn survivors and includes both adults and children [48]. Inclusion criteria for the BMS database have been modified over time. Details of the inclusion criteria, data collection process, and data collection sites have been previously published [48] and can be found at <a href="http://burndata.washington.edu">http://burndata.washington.edu</a>. Each burn center that provided data maintains independent IRB approval.

### 2.2. Enrollment criteria

Data included in this study were collected from 2006 to 2015. While the BMS database includes pediatric data for individuals aged 0–17.9 years, in order to utilize a consistent research methodology for the study population, this study used self-reported data which begins being collected at 14 years. Data for

pediatric survivors younger than 14 years old is collected by parent report. Hence, participants eligible for this study were burn survivors between the ages of 14 and 17.9 years who underwent autografting surgery for wound closure and met any of the following database inclusion criteria: ≥20% total body surface area (TBSA) burn or high voltage electrical burn injury or any burn injury to a critical area defined as the face/neck, hands, or feet.

### 2.3. Data variables and outcome measures

Demographic and clinical data were collected using medical record abstraction and patient-report. Demographic and clinical variables included age, gender, race/ethnicity, burn size, length of hospital stay, burn etiology (fire/flame, scald, electricity, grease, or other), and presence of burns to the head, neck, or face (coded as a single variable in the database).

The following patient reported outcome measures (PROMs) were assessed at three time points (6-, 12-, and 24-months) after burn injury. The constructs measured are relevant to older children (14–18 years) and have been used in this age group in other conditions [49–53].

### 2.4. Satisfaction with Life Scale (SWLS)

The SWLS scale is a 5-question instrument that measures life satisfaction as a whole, allowing the respondent to weight each item based on their personal value system. Subscales include satisfaction with social relationships, work/school and home, as well as personal life such as leisure, religious/spiritual life, and learning/growth. An example includes, "In most ways my life is close to my ideal." Items are scored on a 7-point Likert scale ranging from 1 strongly disagree to 7 strongly agree, with a maximum score of 35. Higher scores denote greater life satisfaction. The SWLS shows moderate temporal stability and strong internal consistency reliability with a coefficient alpha of 0.87 [54,55]. The SWLS has been used in adolescents 11–18 years old in non-burn populations [56–58] and in adult burn survivors [37,59].

### 2.5. Satisfaction with Appearance Scale (SWAP)

The SWAP scale is a 14-question instrument, developed for use with burn survivors with physical disfigurement [60]. Subscales include social distress, facial features, non-facial features, and perceived social impact. An example item includes, "Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my family." Items are scored on a 7-point Likert scale ranging from 1 strongly disagree to 7 strongly agree with total score ranging from 0 to 84 where higher scores indicate greater dissatisfaction with appearance and body image following injury. The SWAP demonstrated test-retest reliability of 0.59 with a credible level of internal consistency reliability, Cronbach's alpha of 0.87. There is also evidence of convergent and discriminant validity with other psychometric measures in adolescents with craniofacial anomalies and children 8-18 with cleft palate [50]. The instrument has also been examined in children older than 10 years with burn injuries [26,61].

### 2.6. Community Integration Questionnaire (CIQ)

The CIQ is a 15-question instrument that assesses home integration, social integration, and productive activity [62]. In the current study, only the social integration subscale is examined. An example item includes, "Can you tell me approximately how many times a month you now usually participate in the following activities outside your home?" Items are scored on a 3-point Likert scale (0–2) with higher scores indicating greater social integration. The CIQ has been used in pediatric populations with substance abuse and violence-related injuries (14+ years) [51], spinal cord injury (16+ years) [51], and traumatic brain injury (16+ years) [53]. This subscale has been validated in the adult burn population with a credible internal consistency reliability, Cronbach's alpha of 0.77 [63].

### 2.7. Short Form 12 Health Survey Version 2 (SF-12)

The SF-12 is a survey instrument used to assess mental and physical functioning defined as HRQOL [64]. Subscales include the physical and mental component summary (PCS and MCS). PCS assesses and weights factors such as physical function, role limitations due to physical problems, bodily pain, and general health perceptions. MCS assesses by weighting factors that include vitality, social function, emotional role, and mental health. Example items for PCS and MCS include, "In general, would you say your health is?" and "how much of the time during the past 4 weeks have you felt calm & peaceful?" Scores are standardized with a t-score transformation with mean of 50 and standard deviation of 10, and higher scores denoting better health. Scores greater than 50 represent above average health status compared to the general population. PCS and MCS subscales have a test-retest reliability of 0.89 and 0.76 respectively [64]. The SF-12 has been used in a study with adult burn population [43] and validated in an adolescent population with obesity [52] and cancer [65].

### 2.8. Statistical analysis

Burn survivors were stratified into two groups to compare long-term consequences of appearance: individuals with burns to the head, neck, or face (H&N) and individuals with burns to other areas of the body (non-H&N). Participants without information on burn location could not be stratified into the two groups and were removed from overall population included in the study. Differences in overall samples' demographic and clinical data (age, burn size, length of stay, gender, burn etiology, ethnicity/race, enrollment criteria, and enrollment site) between the H&N and non-H&N populations were assessed with Wilcoxon-Mann Whitney (WMW) rank tests and chi-squared tests for continuous and categorical variables, respectively. Demographic and clinical variables for participants with outcome data at 12-month time point, hereafter termed model participants, were also assessed. The WMW was used because multiple variables were nonnormally distributed. Due to multiple comparisons, Bonferroni correction was used and a p-value of 0.008 or less was considered significant. Differences in outcome measures by H&N burn status for each time point were also examined using WMW tests. A p-value of 0.003 or less was considered

significant, adjusting for multiple comparisons using Bonferroni correction (Table 1).

Demographic and clinical variables of participants with and without outcome data were assessed to examine representativeness of the studies population. Different comparisons for each outcome measure were conducted as the number of subjects with data for each outcome measure varied. For example, participants with SWAP data were compared to participants without SWAP data (Table 2).

Due to incomplete PROM data and/or model covariates, cross-sectional multivariate linear regression analyses were used to assess the association between outcome measure scores in model participants, controlling for potential confounding factors (i.e., age, gender, burn size, length of hospital stay, and etiology of burn). For the purposes of this analysis, 12months was considered the primary outcome time point. The time point of 12-months was specifically chosen as this was the longest time point after injury that contained adequate data for regression analyses. A separate model was created for each outcome measure. All models included the following covariates regardless of significance: age, gender, burn size in one-unit (percent) increments, length of hospital stay, and etiology. Etiology was coded as dummy variables for fire/ flame (reference group), electrical, and other. All models were fit using robust variance estimators to account for heteroscedasticity, which also resulted in the calculation of unadjusted  $R^2$  (Table 3). Analyses were completed using STATA/SE 14.2.

### Results

### 3.1. Characteristics of the study population

A total of 392 burn survivors aged 14 to <18 years were included in the study (275 H&N; 117 non-H&N) from six BMS sites, with approximately one-half (49.4%) enrolled from a single site (Table 1). Of the overall sample enrolled prior to 2005, 55% of the participants had a H&N burn. For participants enrolled after 2005 with a H&N burn, 38% had TBSA > 20%, 1% had electrical injury, and 6% had a burn injury to critical areas. Of the model participants enrolled prior to 2005, 17% had a H&N burn. For participants enrolled after 2005 with a H&N burn, 69% had TBSA > 20%, 3% had electrical injury, and 10% had a burn injury to critical areas. The two groups were similar in age at time of burn injury (16.1  $\pm$  1.1 vs. 16.1  $\pm$  1.1 years, p = 0.81) and gender (79% vs 76% male, p = 0.48). The H&N group had significantly larger burn size, measured by percent TBSA burned (41.2  $\pm$ 23.1% vs 17.9  $\pm$  16.2%, p < 0.0001) and longer hospital stay (37.0  $\pm$  40.3 vs 22.9  $\pm$  22.4 days, p = 0.0001). The H&N group was also

	Overall sample			Model participants only		
	H&N burn (n = 275)	Non-H&N burn* (n = 117)	p-value	H&N burn (n = 98)	Non-H&N burn* (n = 35)	p-value
Age, mean years (SD)	16.1 (1.1)	16.1 (1.1)	0.81	16.3 (1.1)	16.6 (1.0)	0.1
Burn size, mean percent (SD)	41.2 (23.1)	17.9 (16.2)	< 0.001	40.6 (21.1)	17.9 (19.3)	< 0.001
Length of stay, mean days (SD)	37.0 (40.3)	22.9 (22.4)	< 0.001	35.6 (26.7)	22.3 (18.5)	0.001
Male Gender, percent (n)	79 (218)	76 (89)	0.48	77 (75)	69 (24)	0.35
Etiology, percent (n)					4- 4	
Fire/flame	74 (204)	61 (70)	0.006	70 (69)	60 (21)	0.31
Electricity	16 (43)	17 (20)		17 (17)	17 (6)	
Other	10 (28)	22 (25)		12 (12)	23 (8)	
Ethnicity/race, percent (n)						
White, non-Hispanic	36 (98)	52 (59)	< 0.001	26 (13)	79 (11)	0.001
Black, non-Hispanic	7 (18)	18 (20)		8 (4)	7 (1)	
Hispanic	56 (153)	29 (33)		66 (33)	14 (2)	
Other	1 (4)	1 (1)		0 (0)	0 (0)	
Enrollment Criteria, percent (n)						
20%+ TBSA & Surgery	38 (105)	12 (14)	< 0.001	69 (68)	26 (9)	< 0.001
Electrical & Surgery	1 (3)	2 (2)		3 (3)	0 (0)	
Hand/face/foot burn & Surgery	6 (17)	12 (14)		10 (10)	29 (10)	
Criteria prior to August 2005	55 (150)	74 (87)		17 (17)	46 (16)	
BMS Site, percent (n)			< 0.001			< 0.001
A	19 (53)	23 (27)		19 (19)	17 (6)	
В	0.4 (1)	2 (2)		1 (1)	3 (1)	
С	16 (43)	24 (28)		16 (16)	23 (8)	
D	4 (12)	27 (31)		3 (3)	40 (14)	
E	60 (166)	25 (29)		60 (59)	17 (6)	

H&N = Head and Neck.

<sup>\*</sup>Non-H&N burn includes burns to the torso, arms, hands, legs, and/or feet. Individuals may have burns to more than one area.

<sup>\*\*</sup>P-value of 0.008 or less were considered significant, adjusting for multiple comparisons using Bonferroni correction.

<sup>\*\*\*</sup>Other etiologies include: scald, contact with hot object, grease, tar, chemical, hydrofluoric acid, radiation, frostbite/cold, TENS/Steven Johnson Syndrome, abrasion, flash.

<sup>\*\*\*\*</sup>Other race/ethnicity includes: Asian, Native American, Pacific Islander, Multiracial.

Table 2 – Comparison of outcomes between head & neck and non-head & neck burn populations at 6, 12, and 24 months after injury.

	H&N burn		Non-H&N burn***		
	Mean (SD)	n	Mean (SD)	n	p-value
SWLS					
6 months	23.9 (7.2)	75	25.1 (7)	24	0.460
12 months	23.9 (7.3)	78	26.8 (7.8)	27	0.028
24 months**	23.1 (7.4)	74	28.9 (5.6)	26	< 0.001
SWAP					
6 months	32.2 (16)	62	24.2 (12.2)	18	0.046
12 months**	31.2 (16)	57	14.6 (12)	18	< 0.001
24 months	27.2 (16)	57	16 (13.6)	14	0.022
CIQ					
6 months	7.5 (2.3)	97	8.3 (2.3)	32	0.124
12 months	7.9 (2.1)	96	9.2 (2)	29	0.004
24 months	8.0 (2.3)	89	9.1 (1.6)	28	0.025
PCS					
6 months	48.9 (8.7)	72	53.3 (7.8)	22	0.042
12 months	50.6 (7.6)	76	53.1 (6.6)	29	0.086
24 months	51.9 (7.2)	74	54.6 (5.8)	23	0.050
MCS					
6 months	49.1 (8.7)	72	51.8 (10.8)	22	0.106
12 months	49.4 (10)	76	51.3 (9.9)	29	0.458
24 months	50.7 (10)	74	53.6 (8.5)	23	0.230

Differences in outcome measures by H&N burn status for each time point were examined using WMW tests. A p-value <0.003 was considered statistically significant, adjusting for multiple comparisons using Bonferroni correction.

H&N = Head and Neck.

SWLS = Satisfaction with Life Scale.

SWAP = Satisfaction with Appearance Scale.

CIQ = Community Integration Questionnaire.

PCS = Physical Component Summary of the SF-12.

MCS = Mental Component Summary of the SF-12.

 $^{**}$  p < 0.003 using Bonferroni test.

more likely to have fire/flame injuries (74% vs. 61%, p < 0.006), more likely to be Hispanic and less likely to be white (56% vs. 29% and 36% vs. 52% respectively, p < 0.001). Model participants (n = 133) included in the regression modeling had similar differences in demographic and clinical characteristics between those with and without H&N burn status as reported above for the entire population except for etiology, which was not significantly different between the two groups. Complete demographic and clinical characteristics can be found in Table 1 along with a flowchart for the study population in Fig. 1.

Participants with and without outcome data (n = 397) were similar across all characteristics for each outcome except for age (SWLS, p < 0.000; SWAP, p = 0.036; PCS/MCS, p < 0.0001), gender (PCS/MCS, p = 0.012), length of stay (SWLS, p = 0.012; SWAP, 0.038; CIQ, p = 0.008), and burn size (SWAP, p = 0.008) compared to participants without outcome data (p = 0.041 and 0.005).

### 3.2. Comparison of outcome measures between groups

## 3.2.1. Wilcoxon-Mann-Whitney and chi-square tests Comparison of outcomes between H&N and non-H&N burn populations at all three time points are summarized in Table 2. H&N group exhibited worse SWLS at 12- and 24-months after injury (p < 0.05). At all three time points, the H&N group

displayed worse SWAP scores (p < 0.05). Compared to the non-H&N group, H&N group also exhibited worse CIQ scores at 12- and 24-months after burn (p < 0.05) and worse PCS scores at 6-months (p < 0.05). There were no statistically significant differences in MCS scores between the two groups at any time points. After adjusting for multiple comparisons using Bonferroni correction, only SWLS at 24-months and SWAP at 12-months remains significant at p < 0.003.

### 3.2.2. Linear regression analyses

Linear regression analyses examined the association between H&N burn status and each outcome at 12-months after injury (Table 3). H&N burn status was associated with worse SWAP scores (p = 0.003), scoring on average 12 points higher (worse satisfaction) after adjusting for clinical and demographic factors. H&N burn status was not significantly associated with scores on the CIQ or PCS in linear regression models. The SWLS (F = 0.182, p = 0.20) and MCS (F = 0.170, p = 0.72) models were not significant and therefore are not presented in the table.

### 4. Discussion

The current study compared long-term outcomes of adolescent burn survivors with and without H&N burn status. This

<sup>&</sup>quot;Non-H&N burn status includes burns to the torso, arms, hands, legs, and/or feet. Individuals may have burns to more than one area.

Table 3 – Association between H&N burn status and patient reported outcome measures examined using multiple linear regression analyses at 12-months after burn injury.

	Coeff	Robust SE	95% CI	p-value
SWAP	12.09	3.98	4.15, 20.041	0.003
CIQ	-0.69	0.460	-1.60, 0.22	0.137
PCS	0.31	2.10	-3.87, 4.48	0.88

Cross-sectional multivariate linear regression analyses were used to assess the association between outcome measure scores at 12-months and H&N burn status adjusting for potential confounding factors. A separate model was created for each outcome measure: Satisfaction with Appearance scale (SWAP), Community Integration Questionnaire (CIQ), and Physical Component Summary (PCS) of the SF-12. The SWLS (F = 0.182, p = 0.20) and MCS (F = 0.170, p = 0.72) models were not significant and therefore are not presented in the table. All models were adjusted for the following demographic and clinical covariates: age, gender, burn size, length of hospital stay, etiology of burn (fire/flame, electrical, other).

study is unique in that it used data from a multi-center longitudinal database using PROMs to investigate life satisfaction, appearance satisfaction, community integration, and general health status in an adolescent burn population. Additionally, no prior research has compared adolescent community integration outcomes for those with and without H&N burn status. While significant differences in several outcomes were found between groups, after controlling for demographic and clinical characteristics, only body image satisfaction (SWAP) remained significantly worse for the H&N group compared to the non-H&N group at 12-months after injury during linear regression analyses.

Few research studies corroborate the body image satisfaction findings of this study. Previous research on adolescent burn survivors with burns to critical areas found significantly lower ratings of their physical appearance compared to a nonburned group at least two years after injury [27]. Participants placed importance on physical appearance and expressed that having a burn injury impacting their appearance was very stressful [27]. Adjustment to visible differences and social participation is also one of the strongest predictors of satisfaction with appearance [66,67]. Alternatively, body image in burn survivors 16 years or older was worst at 6-months after injury with improvements seen at 12-months [26]. In another recent study, body image worsened at 6-months and did not return to pre-burn level [67]. The authors postulated that adolescent burn survivors go through an initial adjustment period in which they struggle to accept the physical changes associated with their injury followed by an adaptive period where they develop the social skills necessary

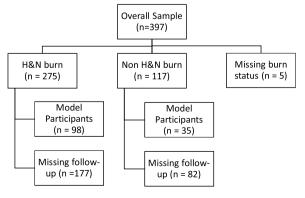


Fig. 1 – Breakdown of the study population. H&N = Head and Neck

to cope with the newly experienced social stigmatization [26]. Future research examining satisfaction with appearance outcomes beyond 12 months after injury will help address the inconsistencies in current and previous research.

Another finding of the study was that satisfaction with life and mental health outcomes at 12-month time point were not significant. While specific research focusing on life satisfaction in the adolescent burn population is scarce, prior research in the adult burn survivor population found that life satisfaction remained generally stable over 2 years [68]. On the other hand, the level of life satisfaction in adolescents and adults at discharge and 6-, 12-, and 24-months after burn was significantly worse than the general population [37,59]. In the adolescent burn population, worse HRQOL has been noted compared to the non-burned population [33]. Specifically, adolescents with facial burns self-reported lower psychosocial scores compared to adolescents with non-facial burns [25,32]. Thus, the current study's unadjusted findings that the H&N burned group experienced worse satisfaction with life are aligned with prior research while the similar mental health scores between populations was not the expected result.

Findings from the current study related to community integration in the adolescent burn population add to existing literature. A similar level of community integration between groups is aligned is aligned with findings from previous research studies. For example, a study using the Life Impact Burn Recovery Evaluation (LIBRE) Profile examined social participation differences and found that adult survivors burned as children scored at least as well or better compared to those burned as adults [31]. In addition, research showed that burn survivors (including children) may be well adjusted and reintegrated in their communities 1-6 years after injury based on performance on standardized self-reports measuring behavioral adjustment, activity competence, social functioning, school performance and self-concept [69-71]. Additionally, while adult participants burned as children fared better on social activities and work and employment scales, there were no statistical differences in education level [31]. On the other hand, long-term follow up of children and adults indicated diminished social function limited by appearance [72,73]. Adults noted an initial decrease in community integration scores followed by an increase between 6- and 12-months and a plateau between 12- and 24-months after injury [74]. Additionally, Hispanic burn survivors had significantly lower trajectory scores in community integration compared to white individuals [74]. These mixed findings necessitate further

examination of socio-economic status and community integration in adolescent burn population.

There is some evidence of interventions that may assist burn survivors with body image satisfaction and related issues. Social skills training, cognitive behavioral therapy (CBT), burn camps, and peer support groups [20,75-81] are a few interventions that may influence resiliency by effectively decreasing behavioral problems and optimizing psychosocial wellbeing [76,82]. These interventions are targeted at social integration and external interactions. For example, social skills training involves teaching the survivor to explain and guide conversations about their burn to help mitigate social avoidance and foster a healthy self-image [75]. CBT is the primary evidence-based treatment for other non-trauma populations with body image dissatisfaction using mindfulness and cognitive restructuring to accept the body even if it is not consistent with societal body ideals, respecting the body by attending to its needs and engaging in healthy behaviors [83].

Burn camps provide an opportunity for pediatric burn survivors to interact and socialize with other burn survivors and participate in recreational activities in a supportive environment. Increased years of attendance at burn camps is associated with reduced somatic symptoms, separation anxiety, and total anxiety symptoms [78]. In addition, camps help develop social and basic life skills, increase self-esteem, and build confidence [11,55]. Peer support groups such as those sponsored by the Phoenix Society for Burn Survivors significantly improve survivors' social comfort, life satisfaction, and interpersonal relationships by addressing aftercare and reintegration issues [80,84–86]. Survivors also found it helpful to have peer groups visit them during their hospital stay [57]. Changing Faces, based in the United Kingdom, is another support group working towards creating a culture of inclusion by challenging media to adopt more realistic portrayals of people with disfigurement and by supporting policy changes and anti-discrimination laws [87]. Facial reconstruction surgery is another option that may improve body image for survivors along with other surgical techniques that accommodate for facial growth in adolescents. Functional and cosmetic improvements are documented in adolescent patients with burn scar revision surgery [88]. Further research is needed to demonstrate the efficacy of these interventions using long-term PROMs [20,75,77,79,84,87,89,90].

A main limitation of the study is the eligibility criteria of the BMS database as it selects those with more severe burns and uses medical record abstraction to identify burn location. Further, the BMS database combines burns on the head, neck, and face into a single variable. Due to overlap between inclusion criteria, participants could not be directly compared for differences in outcomes between different types of critical areas (i.e., head/neck and hand/foot). As noted above, reconstructive surgery may improve body image. However, reconstructive surgery details are also not collected as part of the BMS database. This missing variable can potentially bias the current study's findings on body image and quality of life. The sample size additionally restricted the ability to draw inferences beyond the 12-month time point and fit data in a linear regression model for SWLS and MCS. Therefore, the analyses were only powered to detect moderate to large

effects. Additionally, the majority of the participants were from a single site, potentially impacting the ability to generalize the results of this study. A larger sample is required to detect additional significant differences between H&N and non-H&N adolescent burn population for each of the outcome measures explored in this study that may be clinically and socially important. Another possible bias of this study includes participant participation bias. Site specific practices and patient satisfaction with care may indirectly impact study participation. Previous studies examining attrition rates for adult participants in the BMS database [91,92] found that factors associated with increased loss to follow-up included younger age, shorter length of hospital stay, unemployment status, insurance status, and a history of drug abuse. These factors are likely to influence long term outcomes in adolescent participants as well.

Beyond finding statistically significant differences, it is also important to find differences that are clinically meaningful to patients [93]. The SWAP scale does not have an established minimal clinically important difference (MCID). There has been some research on MCID for SF-12 [94,95] and CIQ [96] in populations with other conditions. Elucidating MCID for SWAP would provide context to the statistical differences in scores found in this study. Future work should also include additional follow-up time points by building prognostic tools such as recovery curves to determine expected recovery at a given time point for this population [97]. Lastly, while the PROMs used in this study have previously been used in adolescents, they have not been formally validated in the adolescent burn population and may not accurately detect outcomes in this age group. A validated outcome metric assessing burn recovery in adolescent population, analogous to the LIBRE profile for use in adults [2] and the preschool LIBRE for use in children [98], should be the focus of future studies to standardize measurement of outcomes after injury.

### 5. Conclusion

This study compared long-term outcomes from a multicenter database between adolescent H&N and non-H&N burn survivors. Adolescents with H&N burn status had significantly worse SWAP scores 12-months after injury after controlling for clinical and demographic variables. No significant differences were found for satisfaction with life, community integration, physical and mental health between groups. Future studies should consider the use of recovery curves, MCIDs, and adolescent burn-specific standardized measurement tools. Psychosocial interventions such as social skills training, CBT, burn camps and peer support groups should also be evaluated for further efficacy in adolescent H&N burn survivors. This research helps to further identify the psychosocial rehabilitation needs of adolescent burn survivors with facial injuries.

### **Conflict of interest**

The authors have no conflicts of interest.

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