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Comparison of long-term quality of life of pediatric burn survivors with and without inhalation injury*

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Abstract

Objective—To examine the long-term quality of life of pediatric burn survivors with and without inhalation injuries. We hypothesized that patients with inhalation injury would report more disability and lower quality of life.

Methods—We examined 51 patients with inhalation injury and 72 without inhalation injury who had burns of 10% total body surface area, were age 16 years at time of the interview, and were greater than 5 years from injury. Subjects completed the World Health Organization Disability Assessment Scale II (WHODAS II) and the Burn Specific Health Scale-Brief (BSHS-B). Multiple regression analyses were used to measure the effects of inhalation injury while controlling for age at burn and TBSA.

Results—The mean age of burn of participants with inhalation injury was 11.7 ± 3.6 years, mean TBSA $55\% \pm 18$, and mean ventilator days 8.4 ± 9 . The mean age of burn of participants without inhalation injury was 10.3 ± 34.1 years, mean TBSA $45\% \pm 20$, and mean ventilator days 1.3 ± 5.2 . Inhalation injury did not appear to significantly impact participants' scores on the majority of the domains. The WHODAS II domain of household activities showed a significant relation with TBSA ($p = 0.01$). Increased size of burn was associated with difficulty completing tasks for both groups. The BSHS-B domain of treatment regimen showed a relation with age at burn ($p = 0.02$). Increased age was associated difficulty in this area for both groups.

Conclusions—Overall the groups were comparable in their reports of disability and quality of life. Inhalation injury did not affect long-term quality of life.

Keywords

Inhalation injury; Long term; Quality of life; Psychosocial; Outcome adolescents

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1. Introduction

Extensive research has looked at the physiological impact of inhalation injury following burns [1,2]. Woodson and colleagues [1, p. 229] defined inhalation injury as damage to the respiratory tract or pulmonary parenchyma by heat or chemical irritants carried into the airways during respiration. The severity of the injury varies, depending on the chemical composition of the agents inhaled, the duration of the exposure, temperature reached during combustion and pre-existing co-morbidities [3–5]. The prevalence of inhalation injury differs across countries. According to Pruitt and colleagues [6], up to 30% of burn admissions in the US have inhalation injury. Shirani and colleagues [7] reported that inhalation injury is an important predictor of morbidity and mortality and may increase mortality by 20%. The sequelae of inhalation injury for survivors may include obstructive lung disease, restrictive lung disease, reduced diffusion capacity, signs of fibrotic lung disease, and ventilatory limitations during recovery [8,9]. Although the pathophysiology of acute inhalation injury has been extensively studied, limited work has been done evaluating the long-term outcomes of inhalation injury. Previous work by Mlcak and colleagues [8] has shown the development of obstructive and restrictive disease patterns on pulmonary function studies 8 years after burn. However, to the best of our knowledge, long-term quality of life and adjustment following inhalation injury have not been reported.

Quality of life studies of burn survivors reveal that most survivors achieve optimal psychosocial outcomes but many continue to have long-term difficulties with physical and psychosocial functioning [10–17]. However, not much is known about the long-term psychological impact of burn survivors with inhalation injury. We are not aware of any studies that have examined the long-term quality of life of pediatric burn survivors who initially sustained inhalation injuries. The purpose of this study was to evaluate the effect of inhalation injury on the long-term perceived quality of life of pediatric burn survivors. We hypothesized that patients with inhalation injury would report more disability and lower quality of life.

2. Methods

2.1. Design

The University of Texas Medical Branch Institution Review Board approved this study (IRB #00-435). This site specific study focused on patients who were treated acutely at this pediatric burn facility. This sample was part of a larger cohort for the National Institute on Disability and Rehabilitation Research (NIDRR). It was a prospective design that consisted of two groups (inhalation injury group and non-inhalation injury group). Participants and their parents/guardians consented to participate in the NIDRR long term follow up study at this pediatric burn hospital and this was documented. Participants completed various questionnaires at different time points at their follow-up hospital appointments, at outreach clinics, or by telephone interview. The questionnaires were administered by trained research personnel.

2.2. Participants

We initially identified 135 patients with and without inhalation injuries from electronic medical records of burn survivors who were treated acutely at this pediatric burn facility between 1998 and 2009. Only 123 of these 135 patients met the inclusion criteria and had completed the outcome quality of life measures, which included the World Health Organization Disability Assessment Scale II – (WHODAS II) [18] and the Burn Specific Health Scale-Brief (BSHS-B) [19]. Participants were age 16 at time of the interview, had burns of 10% of the total body surface area (TBSA), were greater than 5 years from injury, and underwent grafting of at least 10% of their body. Inhalation injury was defined by bronchoscopy and clinical findings and documented in the medical records. Participants completed the questionnaires at their follow-up hospital appointments, at outreach clinics, or by telephone interview. Excluded from the study were participants who could not complete the long term follow up questionnaires in person or by telephone, who were unable to provide informed consent, who were considered vulnerable patients at the time of follow up due to incarceration or institutionalization, and who were deceased.

2.3. Instruments

The World Health Organization Disability Assessment Scale II – (WHODAS II) by Ustun et al. [18], is a global measure of health and disability and provides levels of functioning. It is a 36-item questionnaire with 6 domains which include cognition, mobility, self-care, getting along, life activities (home, work, and/or school), and participation in social activities. It is scored on a 5-point scale. Respondents specify their level of agreement or disagreement to a series of statements, with 1 = no difficulty and 5 = extreme difficulty or not being able to do activity. A summary score is obtained which ranges from 0 to 100, with 0 = no disability and 100 = full disability. Higher scores are indicative of greater perceived disability [18]. English and Spanish forms were used and the questionnaire was given in the persons' primary language. For participants who had difficulty reading, the questions were read to them by a trained research assistant. The WHODAS II has demonstrated stable reliability and validity and accurately discriminates between groups with various medical and psychiatric conditions [18]. Internal consistency coefficients for individual items ranged from 0.47 to 0.94, for the domains from 0.87 to 0.99, and for the total score from 0.97 to 0.99 [18]. Concurrent validity correlations varied from 0.45 to 0.65 [18].

The Burn Specific Health Scale-Brief (BSHS-B) by Kildal et al. [19], is a measure of quality of life that was developed to identify areas in which burn survivors have difficulty. It provides clinically meaningful information. It is a 40-item questionnaire with 9 domains which include heat sensitivity, affect, hand function, treatment regimens, work, sexuality, interpersonal relationships, simple abilities, and body image. It is scored on a 5-point scale. Respondents specify their level of agreement or disagreement to a series of statements, with 0 = extremely difficult and 4 = no difficulty at all. Each domain receives a mean score [19]. Unlike the WHODAS II, a greater BSHS-B score indicates fewer problems and a higher quality of life. English and Spanish forms were used and the questionnaire was given in the persons' primary language. For participants who had difficulty reading, the questions were read to them by a trained research assistant. The BSHS-B appears to have good reliability

and validity when given to burn survivors. Internal consistency coefficients for the BSHS-B ranged from 0.75 to 0.93 [19,20].

2.4. Procedure

As mentioned previously, all patients in this study were treated acutely at this pediatric burn facility between 1998 and 2009. Patients and their parents/guardians consented to participate in the NIDRR long term follow-up study. In the NIDRR site specific database, participants are categorized into one of three groups: patients age 13, patients age 14–15 and patients age 16. Each group completes a specified set of questionnaires at set time points. Since we were interested in long term outcomes greater than 5 years after injury, we focused on the data subset of patients who were age 16 years at time of the interview.

2.5. Analysis

Demographic data was analyzed using t-tests for continuous variables such as age and chi-square tests for discrete variables such as gender. Multiple linear regression was used to model the effects of the WHODAS II and BSHS-B domain scores due to inhalation injury, while adjusting for the effects of age at burn and TBSA. Statistical analyses were performed using R statistical software (R Core Team, 2013, version 3.1.1) [21]. A 95% level of confidence was assumed.

3. Results

One hundred and twenty-three subjects met the criteria for the study ($n = 51$ with inhalation injury and $n = 72$ without inhalation injury) and had answered the two outcome questionnaires. Most of the subjects answered the questionnaires at 5 or 10 years after injury. However six patients completed questionnaires at both time points, so the most recent questionnaires were used for these patients in the analyses. Of the 123 study subjects, 84% of the patients with inhalation injury and 82% of the patients without inhalation injury were Hispanic/Latino. The inhalation injury group consisted of 30 males and 21 females whose mean total body surface area (TBSA) burned was $55\% \pm 18$, mean percent 3rd degree burn was $50\% \pm 20$, and mean ventilator days was 8.4 ± 9 . For this group, the mean age at time of burn was 11.7 ± 3.6 years, mean age at time of interview was 19.7 ± 3 years, and mean years after burn were 8.0 ± 3 . The non-inhalation injury group consisted of 49 boys and 23 girls whose mean total body surface area (TBSA) burned was $45\% \pm 20$, mean percent 3rd degree burn was $36\% \pm 22$, and mean ventilator days was 1.3 ± 5.2 . For this group, the mean age at time of burn was 10.3 ± 4.1 years, mean age at time of interview was 19.4 ± 3 years, and mean years after burn were 9 ± 3 . There were no significant differences between the groups in terms of age at time of burn and interview, years after burn, and admission P/F ratio. Statistically significant differences were found between the groups in terms of TBSA ($p = 0.006$), percent 3rd degree burn ($p = 0.001$), and ventilator days ($p = 0.001$) (Table 1).

Multiple linear regression was used to model the effects on the WHODAS II and BSHS-B domain scores due to inhalation injury, while adjusting for the effects of age at burn and TBSA. Inhalation injury did not significantly impact participants' scores on the majority of

the domains. On the WHODAS II household activities domain, there was a significant relation with TBSA ($p = 0.011$). Each percent increase in TBSA was associated with a 0.3 unit increase in score (on the 100 point scale), which indicated increases in difficulty completing these types of tasks. Table 2 summarizes the results of the WHODAS II. On the BSHS-B treatment regimens domain, there was a significant relation with age at burn ($p = 0.019$). Each additional year of age was associated with a 0.04 unit reduction in score (on the 5 point scale), which indicates increased difficulty adhering to treatment regimens as one gets older. Additionally, on the BSHS-B body image domain, a significant relation was found with the presence of inhalation injury ($p = 0.041$). The presence of inhalation injury was associated with a 0.4 unit increase in score (on the 5 point scale), which indicates less concerns about body image. However, this result may be spurious considering the total number of tests performed (Table 3).

4. Discussion

To the best of our knowledge this is the first attempt to compare the long-term psychological outcome of pediatric burn survivors with and without inhalation injury. In general, we know from outcome research that the majority of pediatric burn survivors achieve optimal long-term outcomes, but many continue to have long-term physical and psychological needs [10–17]. We also know that participation in a structured exercise and rehabilitation program can improve physical, respiratory, and emotional functioning for pediatric burn survivors [22–24]. Unfortunately, not much was previously known about the perceived long-term psychological outcome of pediatric burn survivors with inhalation injury. Did their initial health status affect their perceived long-term quality of life, or were they happy and well adjusted?

We hypothesized that patients with inhalation injury would report greater disability and lower quality of life. Overall the groups were comparable in their reports of disability and quality of life. Inhalation injury did not affect long-term outcome. The WHODAS II was used to measure perceived disability [18]. Inhalation injury did not have a relation with any of the domains of the WHODAS II when age at burn and size of burn were controlled for. A statistically significant relation was found between the groups on the household activities domain and size of burn. As burn size increased so did the participants score in this domain, which indicates difficulty participating in activities such as getting household work done and taking care of household responsibilities. The research on the effects of size of burn and quality of life differs. Leblebici and colleagues [25] examined the effects of joint contractures on quality of life. They did not find a correlation between burn size and physical functioning. However, they found that larger burn size was associated with poorer psychosocial functioning [25]. Anzarut and colleagues examined predictors of quality of life following massive burns and found that burn size and number of days receiving mechanical ventilation were not predictive of quality of life for survivors. They reported that the strongest predictor of physical functioning are total full thickness injury and hand function and the strongest predictors of emotional functioning are younger age at time of burn and level of social support [26].

The BSHS-B was used to measure quality of life given that the tool was specifically developed for burn survivors [19]. Inhalation injury did not have a relation with the majority of the domains on the BSHS-B. A statistically significant relation was found between the groups on the body image domain and inhalation injury. The presence of inhalation injury was associated with an increase in score in this domain, which indicated less difficulty with body image. However, this result is believed to be spurious given the marginal significance and multiple tests performed. The relation between inhalation injury and body image is unclear.

On the BSHS treatment regimen domain, there was a significant relation with age at burn. An increase in age was associated with difficulty adhering to treatment regimens. Sheridan and colleagues examined the long term outcome of children with massive burns. They found that early reintegration with activities before injury and participation in a burn aftercare programs for 2 years was related to better physical functioning [14]. It may be that adherence to burn treatment regimens is easier early on in the recovery phase and this may become more difficult with the passage of time.

In general both groups reported comparable quality of life. One can speculate that early psychological intervention received at this pediatric burn facility, psychological resilience of the patients, as well as family and community support may have contributed to the adjustment of these patients. We know from the existing literature that perceived social and family support is a key factor in successful psychosocial recovery and social re-integration after a burn [27–30]. Studies have found that psychological status before injury [27], younger age at time of injury [26], and perceived level of social support [27–30] were predictive of long-term psychosocial functioning. The mean age at time of interview for both groups was 19 years. According to Erikson, this is the stage of life in which adolescents form their identities and explore different social relationships and roles. Acceptance by others is a key aspect of this developmental stage and a normal part of transitioning into young adulthood [31]. For the present study, limited information was available about the individuals' current and past social experiences, their current social support networks, personality characteristics that may have influenced socialization, successes with past and new relationships, and coping styles. Qualitative psychological interviews might add valuable information to explain the current results.

One can speculate that the instruments used may not have picked up on subtle differences between the groups. A recent review compares these two instruments in greater detail and found that they measure different concepts [32]. Past research using general health measures to infer quality of life have found that overall burn survivors are doing well [14,16]. We chose to use the WHODAS II [18] and BSHS-B [19] because they provide specific information about physical and emotional well-being. However, the addition of qualitative data may have added valuable information about the subjects' long-term functioning in various physical and psychosocial domains.

This study has several limitations including the lack of a matched comparison group and the over-representation of burn survivors from Latin America, which limits the generalizability. However, the use of model adjustments for age at burn and TBSA should partially

compensate for the lack of matching between the two groups. Data were not available for comparison with normative samples, given that the WHODAS II measures health and disability across diverse cultural groups and populations with various disabilities [18] and the BSHS-B was developed specifically for use with burn survivors [19]. Additionally, a comparison with normative samples was not the focus of this study but an area that merits future investigation. It is unknown whether cultural factors may have influenced the perceptions of participants' ratings. A single center study may not be representative of other pediatric burn centers; however, some states have similar demographics that match our sample.

Future research needs to examine the long-term quality of life of pediatric burn survivors with and without inhalation injury from other pediatric burn centers to determine if the present results are substantiated. For the present study, pediatric burn survivors in both groups reported comparable quality of life 8–9 years after burn. It is possible that the instruments used did not pick up on subtle differences between the groups. Therefore, additions of qualitative data in future studies may help clarify factors that contribute to perceived long-term quality of life.

5. Conclusion

This was an initial attempt to identify the long-term quality of life of pediatric burn survivors with inhalation injury. The results of this study are clinically meaningful and give us insight about the long term physical and emotional well-being of pediatric burn survivors. We are hopeful that these results add information to the existing literature.

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Table 1
Demographics ($N = 123$)

	Inhalation injury ($n = 51$)	Non-inhalation injury ($n = 72$)	p value [*]
TBSA	55% $\pm$ 18	45% $\pm$ 20	0.006 [*]
3rd degree	50% $\pm$ 20	36% $\pm$ 22	0.001 [*]
Burn age	11.7 $\pm$ 3.6	10.3 $\pm$ 4.1	0.055
Age interview	19.7 $\pm$ 3.0	19.4 $\pm$ 3.0	0.560
Years after burn	8.0 $\pm$ 3.1	9.1 $\pm$ 3.0	0.057
Vent days	8.4 $\pm$ 9.0	1.3 $\pm$ 5.2	0.001 [*]
Admission P/F ratio	266.1 $\pm$ 102.7 ($n = 28$)	327.3 $\pm$ 73.3 ($n = 8$)	0.080

Admission P/F ratio (partial pressure arterial oxygen/fraction of inspired oxygen concentration); P/F ratio = $\text{PaO}_2/\text{FiO}_2$.

T -tests were used for continuous variables.

^{*} Significance ($p < 0.05$).

Table 2
WHODAS II – results of multiple linear regression analyses controlling for age and TBSA

Domains	Estimate	Std. error	<i>p</i> value*
Cognition			
Age at burn	0.38	0.41	0.36
TBSA	0.06	0.09	0.51
Inh (<i>n</i> = 50) – none (<i>n</i> = 70)	−0.82	3.33	0.81
Mobility			
Age at burn	0.40	0.49	0.41
TBSA	0.13	0.10	0.20
Inh (<i>n</i> = 50) – none (<i>n</i> = 71)	−4.16	3.98	0.30
Self-care			
Age at burn	−0.53	0.41	0.20
TBSA	−0.02	0.08	0.82
Inh (<i>n</i> = 50) – none (<i>n</i> = 71)	−1.38	3.32	0.68
Getting along			
Age at burn	0.60	0.50	0.23
TBSA	0.12	0.11	0.26
Inh (<i>n</i> = 45) – none (<i>n</i> = 66)	−1.40	4.18	0.74
Life activities – (household)			
Age at burn	−0.61	0.60	0.32
TBSA	0.32	0.13	0.01*
Inh (<i>n</i> = 37) – none (<i>n</i> = 49)	−3.26	4.75	0.50
Participation			
Age at burn	0.37	0.49	0.45
TBSA	0.06	0.10	0.52
Inh (<i>n</i> = 49) – none (<i>n</i> = 70)	−0.33	3.93	0.93

Inh = inhalation injury; none = no inhalation injury.

* Significance (*p* < 0.05).

Table 3
BSHS-B – results of multiple linear regression analyses controlling for age and TBSA

Domains	Estimate	Std. error	<i>p</i> value*
Affective			
Age at burn	−0.03	0.02	0.09
TBSA	0.00	0.00	0.60
Inh (<i>n</i> = 48) – none (<i>n</i> = 71)	0.09	0.16	0.55
Body image			
Age at burn	−0.04	0.03	0.14
TBSA	−0.00	0.01	0.68
Inh (<i>n</i> = 49) – none (<i>n</i> = 69)	0.43	0.21	0.04*
Interpersonal relationships			
Age at burn	−0.02	0.02	0.18
TBSA	0.00	0.00	0.92
Inh (<i>n</i> = 49) – none (<i>n</i> = 69)	0.16	0.13	0.21
Sexuality			
Age at burn	−0.01	0.02	0.46
TBSA	−0.00	0.00	0.47
Inh (<i>n</i> = 49) – none (<i>n</i> = 67)	0.07	0.12	0.59
Heat sensitivity			
Age at burn	−0.05	0.03	0.08
TBSA	−0.01	0.01	0.07
Inh (<i>n</i> = 49) – none (<i>n</i> = 70)	−0.19	0.20	0.36
Simple abilities			
Age at burn	0.02	0.03	0.40
TBSA	−0.00	0.01	0.49
Inh (<i>n</i> = 50) – none (<i>n</i> = 70)	−0.17	0.20	0.40
Treatment regimen			
Age at burn	−0.04	0.02	0.02*
TBSA	−0.00	0.00	0.73
Inh (<i>n</i> = 49) – none (<i>n</i> = 71)	0.00	0.14	0.98
Hand function			
Age at burn	0.03	0.03	0.26
TBSA	−0.00	0.01	0.63
Inh (<i>n</i> = 49) – none (<i>n</i> = 71)	−0.27	0.20	0.18
Work			
Age at burn	−0.03	0.02	0.17
TBSA	−0.00	0.00	0.25
Inh (<i>n</i> = 47) – none (<i>n</i> = 69)	−0.06	0.16	0.71

Inh = inhalation injury; none = no inhalation injury.

* Significance (*p* < 0.05).