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Quality of Life of Young Adult Survivors of Pediatric Burns Using World Health Organization Disability Assessment Scale II (WHODAS) and Burn Specific Health Scale-Brief (BSHS-B): A Comparison

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Abstract

Objective—To determine long term psychological distress and quality of life (QOL) in young adult survivors of pediatric burns using the World Health Organization Disability Assessment Scale II (WHODAS) and the Burn Specific Health Scale- Brief (BSHS-B).

Methods—Fifty burn survivors 2.5–12.5 years post-burn (16–21.5 years old; 56% male, 82% Hispanic) completed the WHODAS and BSHS-B. The WHODAS measures health and disability and the BSHS-B measures psychosocial and physical difficulties. Scores were calculated for each instrument, and then grouped by years post-burn, TBSA, sex, burn age, and survey age to compare the effects of each. Next, the instruments were compared to each other.

Results—The WHODAS disability score mean was 14.4 ± 2.1. BSHS-B domain scores ranged from 3–3.7. In general, as Total Body Surface Area Burned (TBSA) increased, QOL decreased. Female burn survivors, survivors burned prior to school entry and adolescents who had yet to transition into adulthood reported better QOL than their counterparts. In all domains except Participation, the WHODAS consistently identified more individuals with lower QOL than the BSHS-B.

Conclusions—Young adult burn survivors' QOL features more disability than their non-burned counterparts, but score in the upper 25% for QOL on the BSHS-B. This analysis revealed the need for long term psychosocial intervention for survivors with larger TBSA, males, those burned after school entry, and those transitioning into adulthood. Both instruments are useful tools for assessing burn survivors' QOL and both should be given as they discern different individuals. However, the WHODAS is more sensitive than BSHS-B in identifying QOL issues.

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Keywords

World Health Organization Disability Assessment Scale II; Burn Specific Health Scale- Brief; quality of life; young adult; long term pediatric burn survivor

1. Introduction

As modern burn care has evolved over the last two decades, there has been an impressive increase in survival rate for large pediatric burns.[1] This increase has resulted in increasing numbers of children growing up with major burn scarring. With this amplification in rates of survival, burn care providers must aim to help survivors recuperate physically as well as psychosocially in the long term (after acute management). In order to do so, a better understanding of QOL of young adult survivors' of pediatric burns is needed.

After suffering a traumatic injury, survivors must cope with time on an acute care unit, potentially long hospitalization, painful procedures, and often multiple surgeries before they are discharged. Often, families believe discharge from the unit is the end of danger and can have little appreciation of long term psychosocial QOL.[2] The impact of the initial injury and the resultant scarring on the psychosocial outcomes can be significant. Also, pain and depression offer their own contributions to physical functioning and therefore play a huge role in the rehabilitation of burn survivors.[3] Pediatric burn survivors often have difficulties in the years post-burn, as seen through a high occurrence of PTSD paired with a low health-related quality of life (HRQOL).[4] Some sources state that while burn survivors depict normal QOL and psychological adjustment, they show fewer positive emotions.[5] The fact that there is a prevalent disregard of post-unit psychological distress emphasizes the need for long term follow-up for young adult survivors of pediatric burns.

Quality of Life is defined as the ability to return to normal life through "satisfactory performance of social roles in the context of family life and the social world."[6] Therefore, we must aim to help survivors psychosocially as well as physically as they reintegrate into society and implement this into their care. Doing so, however, means we first must define QOL in our patient populations, determine what long term QOL can be expected, and identify groups that need extra attention.

Russell et al. determined young adults, who were burned as children, rely on self-concept as they complete the transition into adulthood.[7] He defined self-concept as the "perception of all aspects of self." In another study, Brazilian burn survivors' QOL was directly associated with their independence and ability to work.[6] It has been shown that a variety of factors, such as childhood cancer, obesity, and complex heart disease, can be responsible for a lower QOL. [8,9] For example, in adult burn survivors, a better first year post-burn outcome results from less pain, less emotional distress, and better community reentry.[10] Yet another key factor that can influence long term QOL is personality, which is recognized in short term, long term, psychological, and even physical facets of QOL.[11]

There are two feasible ways to address QOL questions.[12] The first way is to use a generic instrument, like the World Health Organization Disability Assessment Scale II (WHODAS),

that is able to provide a more broad overview of QOL. The second way is to use a more specific instrument, like the Burn Specific Health Scale- Brief (BSHS-B), that is able to capture the subtleties of a specific state. Both options will be considered here as we investigate young adult burn survivors' QOL using the WHODAS and the BSHS-B.

Although research has been completed to better understand the QOL of burn survivors, little long term young adult research has been performed to date. This study aims to use the WHODAS and the BSHS-B to determine the quality of life of young adult burn survivors. We hypothesize that young adult burn survivors will report high disability and low health. We expect the survivors >7.5–12.5 years post-injury will report a higher QOL and lower psychological distress than survivors 2.5–7.5 years post-injury. In addition, we expect that the group of children who were burned before they attended school, which has an impact on socialization, will report better outcomes than those who were burned after school entry. We also expect much more difficult outcomes for young adults transitioning into adulthood than their adolescent counterparts, who are still part of the nuclear family. A further analysis will compare the generic instrument (WHODAS) and the more specific instrument (BSHS-B). Due to its broad nature, we expect the WHODAS to capture more individuals with lower QOL than the BSHS-B.

2. Methods

Study population

This site-specific study focused on 50 burn patients between 16 and 21.5 years old (56% male, 82% Hispanic, burn age= 8.3, SD=3, TBSA 49.6%, SD= 21.5). Subjects were eligible for this study if they were ≥16 years old and between 2.5 and 12.5 years post-burn. Those who returned for follow up between February 2011 and June 2012 were given the instruments. Tables 1 and 2 show the study population details. When analyzing the demographic variables, each subject entered the database only once. Therefore, each group had unique subjects. Initially, this population was surveyed at the same time as a cohort for a National Institute on Disability and Rehabilitation Research (NIDRR) collaborative project with baseline and follow-up data. However, this study's patients did not have baseline questionnaires completed at discharge and therefore, did not qualify for the collaborative project as part of the NIDRR cohort. Questionnaires were self-administered. However, if the survivor had trouble understanding or reading the questionnaire, a translator would read it to them clearly.

World Health Organization Disability Assessment Scale II (WHODAS) Instrument

The WHODAS measures health and disability by providing levels of function. The WHODAS was created by the World Health Organization and shows excellent internal validity (Cronbach's α is 0.98).[13] One of the reasons to use the WHODAS is its direct relationship to the Internal Classification of Functioning, Disability, and Health (ICF). The ICF provides definition, but not measurement, which the WHODAS is capable of. Furthermore, the WHODAS is used by the DSM-5 for routine clinical use, as it was deemed the best measure of disability.[14] The WHODAS is a 36-item questionnaire with a 5-point scale of severity.[13] It measures difficulty by asking "how difficult is it to…" where the

participant answers 1 for “no difficulty” or up to 5 for “extreme/cannot do.” There are six WHODAS domains: Cognition, Mobility, Self-Care, Getting Along, Life Activities, and Participation. The Life Activities domain is further divided into Household and Work components (see Table 3). In order to compare the two instruments and due to the nature of the WHODAS’ scoring, we considered the two components of the Life Activities domain to be separate. We scored the WHODAS using the complex scoring method, which allows for a more precise analysis. Complex scoring is derived from item-response theory (IRT), including and excluding work outside the home. Therefore, scoring the WHODAS requires 4 steps: (1) recode item scores per domain (2) sum recoded scores (3) sum all domain scores (4) convert summary score to metric score. This WHODAS metric score is the final score, and will range from 0–100, where 0 is no disability and 100 is full disability. The final score is determined as a total score including and excluding work in order to account for cases where the participant is unemployed. A higher WHODAS disability score indicates a higher level of disability. Consequently, a higher WHODAS disability score indicates lower QOL.

Burn Specific Health Scale- Brief (BSHS-B) Instrument

The BSHS-B instrument was created by Kildal et al. in 2001 and has become the most widely used instrument for assessment of burn survivors’ quality of life.[15,16] The original Burn Specific Health Scale was created by Blades et al. in 1982 and was subsequently shortened to the Burn Specific Health Scale Abbreviated (BSHS-A) and the Burn Specific Health Scale Revised (BSHS-R).[17,18,19] The original BSHS had 114 items, the BSHS-A 80 items (4 domains and 8 subscales), and the BSHS-R 31 items (2 domains and 7 subdomains). While the BSHS-A’s domains focused on the physical, mental, social, and general aspects of a burn, the BSHS-R’s domains honed in on the physical and psychological consequences.[20] Blades et al showed the dynamic nature of burn recovery through increasing BSHS scores until about two years. Here, we attempt to look at the recovery from 2.5–12.5 years post-burn. Due to deficiencies in the way the previous versions addressed burn-specific health questions as well as the inter-correlation of domains and sub-domains, the BSHS-B was created.[21] The BSHS-B is valid, relatively short, and keener to capture post-burn distress than the BSHS-R.[16] The 40-item questionnaire, aimed to assess QOL specific to post-burn topics, requires about 15 minutes to complete. The instrument measures psychosocial difficulties and physical difficulties using nine domains: Affective, Body Image, Interpersonal Relationships, Sexuality, Heat Sensitivity, Simple Abilities, Treatment Regimens, Hand Function, and Work. A description of the domains can be found in Table 4. The participant is asked to choose from a 5-point scale of severity, where “0” is extreme and “4” is none at all. Each domain receives a mean score. Like the WHODAS, the BSHS-B shows excellent internal consistency as Cronbach’s α is 0.75–0.93.[16] Opposite the WHODAS score, however, a greater BSHS-B score indicates fewer problems and accordingly, a higher QOL.

Analysis

Scores were calculated using the Statistical Analysis System (SAS) for each instrument. Then, Student’s t-test was used to compare groups using years post-burn, TBSA, sex, burn age, and survey age. Initially, each of the two instruments was examined individually for similarity between the results of 2.5–7.5 and >7.5–12.5 years post-burn groups. Then, the

impact of TBSA on QOL was analyzed. Before analyzing sex, it was important to prove sex had no influence of its own on TBSA. Following the Sex and TBSA analysis, the analyses of Sex, Burn Age, and Survey Age could be addressed. To capture the effects of school entry, the burn age group division was 7 years old, which separated the group who had already entered school from those who had yet to begin school. The separation for survey age groups was 18, to better analyze the transition into adulthood. Results include scores ± standard error of the mean, and $p<.05$ was deemed significant unless otherwise noted.

After the analysis of each individual QOL instrument, the two instruments were compared. We established which corresponding domains asked similar questions and addressed overlapping topics before looking for statistically significant correlations. We were unable to use norms from literature because the BSHS-B has no set norms for the burn population, and 50% of the norm population attained disability scores <2 on the WHODAS. Therefore, we attempted to determine a relevant break in the QOL scores. By considering the natural separations in the score distribution curves, we arbitrarily determined acceptable higher QOL scores and unacceptable lower QOL score outliers. These cutoffs would help make the data more clinically significant. Then, we noted exactly how many individuals would be classified as those needing further care due to lower QOL in each domain of both instruments. We were able to determine the overlap in the number of survivors flagged for additional attention in specific domains through each instrument. However, this analysis did not tell us if each instrument was flagging the same individuals. Therefore, we further ascertained the number of specific individuals with a relatively high QOL using both instruments, lower QOL using only one instrument, or lower QOL using both instruments. This presented a scoring problem because while the WHODAS has a total score (including or excluding work), the BSHS-B is scored by its domains. So, using the domain scores of each scale allowed us to determine the number of individuals who would have been classified as having a higher or lower QOL in each scale and missed by the other. Lastly, we determined the overall number of individuals who would have been found to have a lower QOL in any single domain of each instrument. This attribute was likely what would be used clinically in the future and therefore, decide which instrument was more sensitive to those individuals in need of psychological follow-up. In order to examine multivariate influences on the scale scores we ran ordinary least squares (OLS) regression models using PROC REG in The Statistical Analysis System (SAS). These included the likely demographic and medical variables: burn age, survey age, sex, TBSA, and TBSA 3rd degree). A multiple regression simultaneously controls for multiple explanatory variables and therefore, looks at their combined effect on the outcome. The analysis was done in a parametric way as has been done in the literature with this type of data. Beyond that approach, another type of analysis was attempted. Given the small sample size and the severity of the burn experience, the distribution of the outcome variables are not smooth. In order for a clinician to understand the importance of these measures, a dichotomization of the scores around their level of clinical importance and significance has been done. This helped to have identify the ranges of the scores that are considered abnormal and illustrated their significance in a clearer way. Other types of non-parametric analysis such as rank order are not feasible with this data. A measure of skew in the data would be possible, but it seems apparent that the manuals for the WHODAS and the previous literature for the BSHS-B report scale scores as

metric and using multi-variate analysis such as factor analysis or confirmatory factor analysis rather than non-parametric analysis. Nearly every psychological measure starts off with a skewed distribution of symptoms and yet is now analyzed as means even if the transformation to t scores is used. The t test is highly robust for comparing two groups even when the skew is present. Therefore, there should not be a problem.

3. Results

WHODAS Results

The WHODAS disability score mean was 14.4 ± 2.1 (μ±stdev) with domain scores ranging from 9.6 (Self-Care) to 17.1 (Getting Along). (Table 5) The total scores including work ranged from 0–59.4. As seen in Table 5, the WHODAS years post-burn analysis revealed the difference in QOL between 2.5–7.5 and >7.5–12.5 years post-burn groups was not significant. The total score of the 2.5–7.5 year post-burn group was 13.6±5.2, while the total score of the >7.5–12.5 year post-burn group was 17.2±3.6. The two groups did not significantly differ in their survey age, TBSA, TBSA 3rd degree, Sex, or ethnicity, but their burn ages were 11.8±1.8 and 7.5±2.5 for the 2.5–7.5 and >7.5–12.5 years post-burn groups respectively. Survivors' disability scores increased with increasing TBSA in all domains except Cognition and Self-Care. Higher TBSA corresponded to higher total disability scores: 11.3±6 for TBSA<30%, 14.9±4.1 for 30% ≤TBSA< 70%, and 26.3±6.4 TBSA ≥70%. (Table 6) The analysis of TBSA and Sex revealed sex has no impact on TBSA (Males mean TBSA=50.5±23.1, Females' mean TBSA =48.4±19.8; see Table 7). So, there was no need for TBSA adjustment in the following sex analysis. The Sex analysis revealed although females scored lower in all disability domains, only the Life Activities- Household domain difference between males and females was significant (p=.04).(Table 8) The total score revealed males' disability score was 20.9±4.5 and females' was 9.9±3, but this difference was not significant. Through the burn age analysis, we determined survivors burned after school entry reported higher disability than those burned prior to school entry in all domains.(Table 9) This difference between school status at burn age was significant in the Getting Along domain (p=.05). The total score was 10.7±3.2 for those with burn age<7, and 19.9±4.3 for those with burn age ≥7. Lastly, the survivors who were surveyed as they transitioned into adulthood reported a higher level of disability (20.8±6.7) than those who had not begun the transition (14.6±3.3), yet this difference was not significant. (Table 10) Also, 17 survivors were not employed and therefore did not answer questions in the Work domain. The data were skewed towards more extreme scores for increased pathology. This skewed distribution is evident in the means and standard deviations which show higher disability scores as expected. The overall model was significant in the WHODAS only for Participation (p<.0089) and none of the variables (burn age, survey age, sex, TBSA, and TBSA 3rd degree) in the model reached significance. Without significant contributions of variables in the models we did not test for interactions. There was little relationship between the scales, the demographics, and burn age, survey age, sex, TBSA, or TBSA 3rd degree. To reemphasize this, the regression of the whole group did not add information to this analysis and shows no contribution from burn age, survey age, sex, TBSA, and TBSA 3rd degree.

BSHS-B Results

Although the BSHS-B does not have a total score, domain scores ranged from 3 to 3.7. (Table 5) As seen in Table 5, the BSHS-B years post-burn analysis revealed that the survivors 2.5–7.5 and >7.5–12.5 years post-burn showed no significant differences in their QOL. Quality of Life and TBSA showed an overall inverse relationship. (Table 6) All domains, except Hand Function and Simple Abilities, showed an overall inverse relationship between TBSA and QOL. The largest decrease in QOL was in Heat Sensitivity at TBSA≥70%. Females reported a better QOL than males in all domains; three were significant: Interpersonal Relationships (p=.02), Simple Abilities (p=.02), and Sexuality (p=.01). (Table 8) School status at burn age had no significant effect on QOL. However, individuals burned prior to school entry reported a higher or equal QOL in most domains, but lower QOL in Body Image. (Table 9) The survivors who were surveyed as they transitioned into adulthood reported a lower QOL in all domains, except Body Image. (Table 10) Furthermore, this difference was significant in the Simple Abilities domain (p=.01). The data were skewed towards more extreme scores for increased pathology. This skewed distribution is evident in the means and standard deviations which show lower BSHS-B scores as expected. For the BSHS, significance for the overall regression model was found for Heat Sensitivity (p<.0.300). For Sexuality, the regression model was significant at (p<.0198) along with the variable sex=.0473. For Simple Abilities, the model was not significant at .1110 but sex was significant at .0495. Without significant regression models we did not test for interactions. Overall, therefore, there was little relationship between the scales, the demographics and burn age, survey age, sex, TBSA, or TBSA 3rd degree. To reemphasize this, the regression of the whole group did not add information to this analysis and shows no contribution from burn age, survey age, sex, TBSA, and TBSA 3rd degree.

Comparison of the BSHS-B and the WHODAS

In order to determine which domains had similar topics, we combed through each domain looking for overlapping questions (see Table 11). Table 12 demonstrates the degree of similarity between the instruments. Statistically significant correlations were found between a number of WHODAS and BSHS-B domains at both the p<.05 and p<.0001 levels. Some significant correlations were not extremely surprising, e.g., the BSHS-B Hand Function and WHODAS Self-Care (r= −0.70, p<.0001) This analysis also allowed us to see which domains we didn't classify as similar that were correlated, e.g., BSHS-B Simple Abilities and WHODAS' Getting Along (r=−0.60, p<.0001) and BSHS-B Simple Abilities and WHODAS Work (r=−0.70 with p<.0001).

The natural breaks in the score distribution curves for the lower QOL limit and percent of lower QOL individuals flagged in each domain was also determined for both instruments (see Table 13). The BSHS-B survey resulted in 84 lower QOL flags for the 50 individuals across all nine domains. On the other hand, the WHODAS survey resulted in 100 lower QOL flags for the 50 survivors across its seven domains. The WHODAS was more sensitive than the BSHS-B in all domains except Participation. The WHODAS' participation domain was less sensitive than the BSHS-B when addressing Affective, Body Image, Interpersonal Relationships, Heat Sensitivity, and Treatment Regimens. However, a limitation of this

analysis was that it did not reveal whether or not the same individuals were flagged as having the lower QOL in more than one domain.

Further analyses determined the clinically significant number of individuals who had a relatively low QOL by the scales (Table 14). For example, the WHODAS Work domain and the BSHS-B Work domain both identified 17 burn survivors as having relatively high QOL. Together, the instruments' Work domains classified 3 individuals as having a lower QOL. Additionally, the WHODAS Work domain identified 11 individuals with a lower QOL that the BSHS-B Work domain would have missed entirely. This was supported by the domain scores' correlation coefficient (r= −0.52) seen in Table 12. Table 14 shows the overlap between the individuals recognized as either having a higher or lower QOL by each domain pair with similar subject matter. Only the domains which questioned similar information were compared.

Although this information was very useful, it was not clinically significant because we could not yet determine the number of individuals who clinically would have been flagged for further follow-up based on having a lower QOL in any domain of the WHODAS or BSHS-B. As evidenced in Table 14, there were 15 survivors (30%) who were classified with higher QOL, and 23 survivors (46%) classified with lower QOL on both scales. The WHODAS classified an additional 8 survivors as having lower QOL, while the BSHS-B determined another 4 as lower QOL. For treatment purposes, the authors are interested in identifying those with a low QOL. Therefore, in the "Overall" category, an individual had to score a higher QOL score in all the domains to be classified as having a higher QOL, and had to register a lower QOL score in any domain to be classified as having a lower QOL.

4. Discussion

WHODAS Disability Scores

According to the World Health Organization, 52% of the normal population reports ≤2 as their disability score on the WHODAS.[13] Our findings here show the total disability score for the WHODAS was 14.4 ± 2.1. These long-term young adult burn survivors' disability scores are much higher than the scores in the normal population. Previous research has determined that while pain and physical function gradually returned to normal, depression did not change in the first two years post injury in adults.[3] Similarly, 30% of adult burn survivors show moderate to severe difficulties psychologically as well as socially.[22,23,24,25] This study has allowed us to follow individuals for much more time and determine their health, disability, and specific psychosocial and physical difficulties long term. Importantly, QOL is directly linked to survivors' ability to return to their expected roles in families and society, which is addressed by including the Work domain.[6]

We further analyzed the data using a multiple regression analysis to see if independent explanatory variables are making an effect on our results and did not find much. The regression of the whole group did not add information to this analysis and shows no contribution from burn age, survey age, sex, TBSA, and TBSA 3rd degree. This analysis continues previous parametric literature analysis (Tables 7–10, 12) while adding a non-parametric analysis to clarify the clinical significance in Table 13.

BSHS-B Scores

The BSHS-B domain scores range from 3–3.7, with the highest domain scores being Interpersonal Relationships and Simple Abilities and the lowest being Heat Sensitivity. Contrary to what was expected, these young adult burn survivors scored in the upper 25% of the scale. This agrees with previous research that states “many burn survivors do achieve a satisfying quality of life and that most are judged to be well-adjusted individuals.”[31]

The BSHS-B has been assessed in a normal population by Kvannli et al.[26] Unfortunately, Kvannli et al. used a different scoring method than used here, so that direct comparison with our results is difficult. To determine the population norms, Kvannli et al. changed the terms “injury, burn, and scars” to “problem and body,” respectively and dropped the last 10 questions of the BSHS-B, deeming they were too burn specific. Results show that >73% of the normal population report a full QOL score in the physical questions, while a mere 7.6% report a full QOL score in the generic questions. Kvannli et al’s results show that even the control population does not attain 100% QOL scores, and this is especially noticeable in psychological and environmental domains.

It is difficult to compare this burn-specific instrument to a control population, as it addresses questions specific to scars, heat sensitivity, and treatment regimens. It also goes further to ask how the burn has affected the survivors’ lifestyle, as seen in the statement “My burn interferes with my work.” These tests can be used to better define a standard QOL for burn survivors and, in effect, show the burn team what they can expect.

The BSHS-B’s multiple regression analysis was similar to that of the WHODAS. The regression model showed no contribution from burn age, survey age, sex, TBSA, and TBSA 3rd degree. Therefore, we have shown a parametric analysis through our t tests (Tables 7–10, 12) as well as a non-parametric analysis (Table 13) in attempt to make the data more clinically significant.

Years Post-Burn

Contrary to what was expected, the >7.5–12.5 years post-burn cohort does not show significant improvement in QOL compared to the 2.5–7.5 years post-burn cohort. The 2.5–7.5 and >7.5–12.5 years post-burn groups are different, but these differences are not significant. In fact, there is no significant difference between the two groups overall or in any specific domain. The lack of significant QOL differences between both years post-burn groups is supported by both the WHODAS and the BSHS-B.

TBSA

As expected, both the WHODAS and the BSHS-B show that, in general, increasing TBSA contributes to decreased QOL. The WHODAS shows this through increasing disability contributing to decreased QOL, while the BSHS-B directly depicts QOL data. This inverse TBSA and QOL trend is not evident in the WHODAS Self-Care domain or the BSHS-B Hand Function and Simple Abilities domains. The 30≤TBSA<70 group reports less disability in the Self-Care domain than the two more extreme TBSA groups as well as

increased QOL in the Hand Function and Simple Abilities domains. The largest decrease in QOL was in the Heat Sensitivity domain at TBSA≥70%.

This study indicates that the total surface area burned affects QOL and disability, similarly to previous studies which show facial burns also decrease QOL.[27] Also in agreement with what we have seen, Kildal et al reported the Heat Sensitivity and Work domains had the most noteworthy health consequence.[28] Kildal also determined there is a significant connection between self-reported outcome and sociodemographic variables like work, partnership, and living.

Sex

The WHODAS and the BSHS-B agree in that females are faring better across all domains; they report less disability using the WHODAS and better QOL using the BSHS-B. This difference is significant in the WHODAS Life Activities-Household domain, and the BSHS-B Interpersonal Relationships, Simple Abilities, and Sexuality domains. This difference cannot be accounted for by TBSA because there is no significant difference between the mean TBSA of males and females.

This finding agrees with previous research that shows greater improvement of females in intensive care units (ICUs) compared to males.[29] Females have lower inflammatory and hypermetabolic responses compared to males, as well as less lean muscle loss and better muscle protein net balance. Together, these factors are associated with better ICU outcomes and shorter ICU stays. Another study states post-burn females engage in more sexual behavior than their male counterparts, while both sexes report similar sexual attitudes and behaviors with non-burned individuals.[30] However, other studies report females have lower sexual satisfaction, which is closely related to body image than burn size and location.[31,32] Kildal et al. adds “depth of injury, gender, marital status and living conditions” also influence the burn survivors’ outcome.[33] Lastly, the current study shows females report significantly less disability in the Life Activities- Household domain. Female individuals could potentially be classifying their activity in the household as their work. While work does not offer any improvement in mood for burn survivors, Dyster-Aas noted that those who do no work often report a lower QOL due to their health, more post-traumatic stress disorder (PTSD), and more avoidance.[34]

Burn Age and School Entry

The WHODAS measure illustrates that burn survivors burned ≥7 years old (after school entry) report a higher disability in all domains and therefore, lower QOL (Table 9). The BSHS-B agrees with the WHODAS as it shows burns survivors whose burn age is ≥7 report a lower QOL in 6 out of 9 domains (Table 9). This difference in burn age is significant in the WHODAS Getting Along domain. These results are expected, as Blakeney et al. states that burn survivors are afraid of social rejection due to their post-burn disfigurement, which directly affects socialization at school entry.[31] Being burned prior to school entry allows survivors to socialize with their scars present, instead of reintegrating back into their school community with new scars.

Burn survivors report that the reaction of others to their burn is the most difficult part of discharge.[31] If possible, it is better for the survivors to leave the hospital for brief periods for outings prior to discharge, in order to return to the burn team for positive reinforcement and encouragement. An even better option is to provide a video, a pamphlet, a letter, or a visit by a member of the burn team to the burn survivors' school prior to the survivors' school reentry. This allows for the community to ask questions in an open environment and therefore assist in the survivor's coping upon their return. A small percentage of burn survivors state they experience frustration with their appearance as well as social and occupational problems. After a burn injury, survivors experience a reduced social environment and decrease in vocational activities. [31] This study agrees with previous research that states higher-quality family relationships and lower burn ages are significant signs of a positive QOL.[5] In addition to school status at time of burn, studies show that pre-burn psychiatric disorders affect post-burn adjustment.[31]

Survey Age and Transition to Adulthood

The instruments' survey age analyses agree and complement each other well. The WHODAS measure reveals those surveyed as they transition to adulthood (age 19 and older) report higher disability in all domains and the BSHS-B measure shows the transitioning group reports lower QOL in all domains except Body Image. The difference is significant in the BSHS-B- Simple Abilities domain.

This concurs with Kildal et al's determination that Body Image, Heat Sensitivity, and Work are key aspects of a burn survivor's recovery.[33] Body image can be influenced by "scarring, disfigurement, deformity, and loss of function."[31] Previous research also shows that 30% of adult burn survivors exhibit "moderate to severe psychological and/or social difficulties."[31] Meyer et al report a high prevalence of serious psychiatric diagnosis in young adults who were burned as children.[35] Using a different instrument, Thomas et al report a much lower prevalence of psychiatric diagnosis in teenagers who were still being treated for their burn injuries.[36] This discrepancy leads us to investigate the time of survey in the current population.

Although some studies show burn size and severity are nominal in the post-burn recovery, many also state that regardless of age, the burn survivors must undergo similar psychosocial and therapeutic hurdles.[31] It has already been shown how family support can affect a burn survivors' post-burn QOL. However, an important aspect of the family support for an adolescent is the degree of autonomy encouraged by the family. Survivors with families that promote and prioritize autonomy for the burn survivor within the family unit often show better outcomes.[37]

Comparison of WHODAS and BSHS-B

WHODAS Cognition—The WHODAS Cognition domain covers information similar to as the BSHS-B Interpersonal Relationships domain. Together, they classify few individuals as individuals with lower QOL. However, they also both uniquely classify about an equal number of survivors. This shows that both domains are important to capture the difficulties in Cognition and Interpersonal Relationships of burn survivors.

WHODAS Mobility—The WHODAS Mobility domain overlaps with the BSHS-B's Heat Sensitivity, Simple Abilities, and Hand Function domains. In each comparison, the WHODAS Mobility domain results in more individuals with lower QOL than the BSHS-B's domains. This is important because this indicates that a large number of individuals would not be identified as lower QOL survivors if the cohort was only given the BSHS-B.

WHODAS Self-Care—The WHODAS Self-Care domain shares similar subject matter with BSHS-B Simple Abilities as well as Hand Function. Although together the instruments create a large number of individuals flagged for follow up, the WHODAS instrument identifies more individuals with lower QOL over and above what the two surveys identify mutually. While the WHODAS instrument gathers 5 or 9 survivors with lower QOL in each comparison, the BSHS-B flags a single survivor.

WHODAS Getting Along—The WHODAS Getting Along domain is able to cover a wide variety of topics which coincide with the topics of the BSHS-B Affective, Interpersonal Relationships, and Sexuality. It also consistently flags more individuals with lower QOL and therefore, for further psychological care in all three comparisons.

WHODAS Household—While the WHODAS Household domain overlaps with BSHS-B Hand Function and Work, it alone identifies seven times the number of individuals as having a lower QOL as the BSHS-B corresponding domains does. This is a prime example where the WHODAS is more sensitive at flagging individuals with lower QOL than the BSHS-B.

WHODAS Work—Although both the WHODAS and BSHS-B have specific domains to address work, only one is able to capture survivors with QOL issues where the other does not. The WHODAS is able to identify 11 additional survivors for follow-up, while the BSHS-B does not identify any.

WHODAS Participation—The WHODAS Participation domain coincides with many of the BSHS-B domains. It crosses with Affective, Body Image, Interpersonal Relationships, Heat Sensitivity, and even Treatment Regimens. However, WHODAS Participation is the only WHODAS domain that does not identify more individuals for follow-up than the corresponding BSHS-B domains. The WHODAS Participation domain identifies fewer individuals with lower QOL than the BSHS-B domains. It consistently flags between 3 and 10 individuals fewer than its BSHS-B counterparts.

Overall—This comparison does not coincide with previous studies that report 30% of adult burn survivors show psychological and/or social problems.[31] This study actually shows that only 30% of this population was classified as individuals with higher QOL on both instruments, while the remaining 70% had lower QOL in at least one domain of either instrument. The WHODAS identified a 62% of the population as lower QOL, while the BSHS-B identified 54% as lower QOL. Together, the instruments designate 46% of the population as lower QOL. However, the WHODAS identifies an additional 16% as lower QOL, where the BSHS-B uniquely identifies half that.

Further Research

Future research could study a larger population and aim to analyze how the location of burn and family/marital support affect long term QOL. Other studies have shown that family support and previous psychological issues have larger consequences in post-burn QOL than TBSA, location of burn, or even trips to the operating room.[31] In the future, questionnaires could also be given to the caretaker of the survivor. A survey of mothers, fathers, or domestic partners might yield different results. In other studies, family members attributed more QOL problems for the survivor than the survivors themselves did.[38] Furthermore, since our population was predominantly Hispanic, it would be useful to consider QOL in cohorts with varying ethnicities to determine what other groups use to determine QOL.

Limitations

One limitation of this study is the small sample size. Furthermore, the domain cut offs for "lower QOL" were based on natural separations in the score distributions. It is innately difficult to determine an acceptable value for QOL. Lastly, the concern exists as to whether the BSHS-B is more accurate and the WHODAS is simply emphasizing a poorer outcome. Since this study focuses on identifying survivors with low QOL for treatment purposes, the only solution would be the use of a clinical measure for calibration.

Conclusions

This study proved the importance of long term psychosocial intervention for burn survivors, especially those with larger TBSA, males, those burned after school entry, and survivors transitioning into adulthood. In addition to the individuals both instruments deem as having a higher or lower QOL, the WHODAS flags twice as many for follow up (lower QOL) as the BSHS-B does, while the BSHS-B still finds a small cohort that the WHODAS does not. Therefore, if possible, both instruments should be given to ensure every possible survivor with lower QOL and in need of follow-up is found. However, if forced to choose between instruments, the WHODAS is a more sensitive tool for identifying survivors with psychological distress and lower QOL."

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Table 1

Study Population

Category	All Age Groups	≥16 years old
Eligible	1380	780
Questionnaires Handed Out	150	51
Questionnaires Returned	149	50

Table 2

Study Population Demographics

	Total
N	50
Burn Age (μ±stdev)	8.3±3
Survey Age (μ±stdev)	17.9±1.7
TBSA (μ±stdev)	49.6±21.5
TBSA 3rd degree (μ±stdev)	40.6±26.8
Sex (n(%))	
Male	28(56)
Female	22(44)
Ethnicity (n(%))	
Non-Hispanic Caucasian	6(12)
Hispanic	41(82)
Non-Hispanic African American	3(6)

Total Body Surface Area Burned (TBSA).

Table 3

World Health Organization Disability Assessment Scale (WHODAS) Domain Summaries

Domain	Summary
Cognition (C)	Concentrating, remembering, problem-solving, learning, communicating
Mobility (M)	Standing, moving around inside home, getting out of home, walking long distances
Self-Care (SC)	Bathing, dressing, eating, staying alone
Getting Along (GA)	Getting along with other people, especially difficulties that might be encountered due to health condition
Life Activities-Household (LA-H)	Activities that people do on most days, including household activities
Life Activities-Work (LA-W)	Activities that people do on most days, including work and school activities
Participation (P)	How much do other people and the world around make it difficult to take part in society
Total Score	**Complex score including all domains, Representative score based on weighting each item equally irrespective of domain**
Score - Work	**Complex score excluding the work domain**

Table 4

Burn Specific Health Scale-Brief (BSHS-B) Domain Summaries

Domain	Description
Affective (A)	Feel lonely, feel sad, emotional problem, not interested, visit anyone, no one to talk to, trapped
Body Image (BI)	Appearance changed, unattractive, general appearance, appearance of scars
Interpersonal Relationships (IR)	Further from family, rather be alone, how family acts, family better off without subject
Sexuality (S)	Sexual arousal, not interested in sex, hug, hold, kiss
Heat Sensitivity (HS)	Being in sun, hot weather, cannot get out, cannot be in sun, sensitive skin
Simple Abilities (SA)	Bathe, dress, get in/out of chair
Treatment Regimens (TR)	Bothersome skin, dislike treatment, dislike taking care of burn, difficult burn care, difficult to do other things
Hand Function (HF)	Sign name, eat, tie shoe, turn door knob, pick up from floor
Work (W)	Work old job, perform old abilities, interferes with work, ability to work, problems with working

Table 5

Scores of Total Cohort, Survivors 2.5–7.5 Years Post-Burn, and Survivors >7.5–12.5 Years Post-Burn

Domain	All (n=50)	2.5–7.5 Years Post-Burn (n=10)	>7.5–12.5 Years Post-Burn (n=40)
WHODAS			
TOTAL SCORE	14.4 ± 2.1	13.6 ± 5.2	17.2 ± 3.6
Score-W	15.3 ± 2.2	17 ± 5.6	15.2 ± 2.6
C	16.9 ± 2.5	17.2 ± 6.2	16.9 ± 2.8
M	12.0 ± 2.7	11.3 ± 5.7	12.2 ± 3.1
SC	9.6 ± 2.7	2 ± 2	11.5 ± 3.3
GA	17.1 ± 3.3	20.4 ± 8.6	16.2 ± 3.6
LA	15.5 ± 3.1	20.1 ± 8.6	14.4 ± 3.3
LA-H	16.8 ± 3.4	21 ± 9.2	15.8 ± 3.6
LA-W	13.2 ± 3.3	10.2 ± 5.4	14 ± 4
P	15.4 ± 2.0	15.8 ± 5.7	15.2 ± 2.2
BSHS-B			
A	3.4 ± 0.1	3.5 ± 0.2	3.4 ± 0.1
BI	3.1 ± 0.1	3.4 ± 0.2	3.1 ± 0.2
HF	3.6 ± 0.1	3.9 ± 0.1	3.5 ± 0.1
HS	3.0 ± 0.2	2.8 ± 0.5	3.1 ± 0.2
IR	3.7 ± 0.1	3.9 ± 0.1	3.7 ± 0.1
SA	3.7 ± 0.1	4 ± 0	3.6 ± 0.1
S	3.6 ± 0.1	3.5 ± 0.3	3.7 ± 0.1
TR	3.6 ± 0.1	3.4 ± 0.3	3.7 ± 0.1
W	3.6 ± 0.1	3.5 ± 0.2	3.6 ± 0.1

Values are reported as mean ± standard error of the mean.

Table 6

Impact of TBSA on Quality of Life

Domain	TBSA<30% (n=10)	30% ≤TBSA< 70% (n=30)	TBSA ≥70% (n=10)
WHODAS			
TOTAL SCORE	11.3 ± 6	14.9 ± 4.1	26.3 ± 6.4
Score-W	10.2 ±4.6	15.4 ± 3.2	20.5 ± 5.1
C	17.2 ± 6.4	16.7 ± 3.1	17.5 ± 6.3
M	8.1 ± 3.8	11.9 ± 3.8	16.3 ± 6.3
SC	15 ± 7.3	6.3 ± 3.3	14 ± 5.2
GA	7.4 ± 5.5	18.3 ± 4.5	23.1 ± 8
LA	12.6 ± 7.5	13.8 ± 3.9	23.4 ± 7.5
LA-H	14 ± 7.8	14.7 ± 4	26 ± 9.1
LA-W	6.1 ± 5	10.9 ± 3.9	29.8 ± 9.7
P	9.7 ± 3.5	14.7 ± 2.7	22.5 ± 4.6
BSHS-B			
A	3.6 ± 0.1	3.5 ± 0.1	3.1 ± 0.3
BI	3.6 ± 0.2	3.2 ± 0.2	2.6 ± 0.4
HF	3.3 ± 0.4	3.8 ± 0.1	3.3 ± 0.3
HS	3.8 ± 0.1	3.1 ± 0.2	2.2 ± 0.4
IR	3.9 ± 0.1	3.8 ± 0.1	3.4 ± 0.3
SA	3.6 ± 0.3	3.8 ± 0.1	3.4 ± 0.3
S	3.9 ± 0.1	3.7 ± 0.1	3.3 ± 0.3
TR	4 ± 0	3.6 ± 0.1	3.2 ± 0.4
W	3.7 ± 0.1	3.7 ± 0.1	3.2 ± 0.2

* p≤.05,

** p≤.01

Values are reported as mean ± standard error of the mean.

Table 7

Sex and TBSA Analysis.

	Male	Female	Total	P-value
TBSA (%)	50.5±23.1	48.4±19.8	49.6±21.5	.90
TBSA 3rd degree (%)	42.1±29.2	38.6±24.1	40.6±26.8	.82

Total Body Surface Area Burned (TBSA).

Table 8

Comparison of Male and Female Burn Survivors' Quality of Life

Domain	Male (n=28)	Female (n=22)
WHODAS		
TOTAL SCORE	20.9 ± 4.5	9.9 ± 3
Score-W	19.2 ± 3.5	10.3 ± 2.3
C	20.9 ± 3.6	12 ± 3.2
M	16.5 ± 4.2	6.3 ± 2.5
SC	13.9 ± 4.3	4.1 ± 2.2
GA	22 ± 4.9	10.2 ± 3.7
LA	20.7 ± 4.9*	8.9 ± 3.1*
LA-H	22.9 ± 5.2	9.1 ± 3.5
LA-W	17.3 ± 5.2	8.1 ± 3.4
P	17.4 ± 3	12.7 ± 2.5
BSHS-B		
A	3.3 ± 0.2	3.6 ± 0.1
BI	3 ± 0.2	3.3 ± 0.1
HF	3.4 ± 0.2	3.8 ± 0.1
HS	3 ± 0.2	3.1 ± 0.2
IR	3.6 ± 0.1*	4 ± 0*
SA	3.5 ± 0.2*	4 ± 0*
S	3.4 ± 0.2**	3.9 ± 0**
TR	3.5 ± 0.2	3.8 ± 0.1
W	3.4 ± 0.1	3.8 ± 0.1

* $p \leq .05$,

** $p \leq .01$

Values are reported as mean ± standard error of the mean.

Table 9

Impact of Burn Age on Quality of Life

Domain	<7 years (n=15)	≥7 years (n=35)
WHODAS		
TOTAL SCORE	10.7 ± 3.2	19.9 ± 4.3
Score-W	10.6 ± 2.5	18.1 ± 3.3
C	14 ± 3.8	18.2 ± 3.2
M	7.9 ± 3.5	13.8 ± 3.5
SC	8.7 ± 3.6	10 ± 3.5
GA	8.3 ± 3.4*	21.7 ± 4.6*
LA	11.3 ± 4	17.3 ± 4.1
LA-H	13.3 ± 4.7	18.3 ± 4.4
LA-W	9.1 ± 4.3	15.2 ± 4.5
P	13.7 ± 3.2	16.1 ± 2.6
BSHS-B		
A	3.5 ± 0.1	3.4 ± 0.1
BI	3 ± 0.3	3.2 ± 0.2
HF	3.8 ± 0.2	3.6 ± 0.1
HS	3.3 ± 0.2	2.9 ± 0.2
IR	3.9 ± 0.1	3.7 ± 0.1
SA	3.9 ± 0.1	3.6 ± 0.1
S	3.9 ± 0.1	3.6 ± 0.1
TR	3.6 ± 0.2	3.6 ± 0.1
W	3.6 ± 0.2	3.6 ± 0.1

* $p \leq .05$,

** $p \leq .01$

Values are reported as mean ± standard error of the mean.

Table 10

Impact of Transition to Adulthood on Quality of Life

Domain	<19 years (n=35)	≥19 years (n=15)
WHODAS		
TOTAL SCORE	14.6 ± 3.3	20.8 ± 6.7
Score-W	13.2 ± 2.4	21.2 ± 5.5
C	15.9 ± 2.8	19.6 ± 5.3
M	9.3 ± 3	18.3 ± 5.6
SC	8.9 ± 3.3	11.3 ± 4.6
GA	15 ± 4	21.8 ± 6.1
LA	13.6 ± 3.2	20 ± 7.4
LA-H	14.9 ± 3.5	21.3 ± 7.9
LA-W	10.9 ± 3.6	18.2 ± 7.1
P	13.4 ±2	19.7 ± 4.8
BSHS-B		
A	3.5 ± 0.1	3.2 ± 0.2
BI	3.1 ± 0.1	3.2 ± 0.3
HF	3.7 ± 0.1	3.3 ± 0.3
HS	3.2 ± 0.2	2.8 ± 0.3
IR	3.8 ± 0.1	3.6 ± 0.2
SA	3.9 ± 0.1**	3.3 ± 0.3**
S	3.7 ± 0.1	3.4 ± 0.3
TR	3.7 ± 0.1	3.4 ± 0.3
W	3.7 ± 0.1	3.3 ± 0.2

* p≤.05,

** p≤.01

Values are reported as mean ± standard error of the mean.

Table 11

Domains with Overlapping Questions in the World Health Organization Disability Assessment Scale (WHODAS) and the Burn Specific Health Scale-Brief (BSHS-B)

	BSHS-B								
WHODAS Domains	**Affective**	**Body Image**	**Interpersonal Relationships**	**Sexuality**	**Heat Sensitivity**	**Simple Abilities**	**Treatment Regimens**	**Hand Function**	**Work**
Cognition	--	--	X	--	--	--	--	--	--
Mobility	--	--	--	--	X	X	--	X	--
Self-Care	--	--	--	--	--	X	--	X	--
Getting Along	X	--	X	X	--	--	--	--	--
Household	--	--	--	--	--	--	--	X	X
Work	--	--	--	--	--	--	--	--	X
Participation	X	X	X	--	X	--	X	--	--

Table 12

Correlation Coefficients Between World Health Organization Disability Assessment Scale (WHODAS) and the Burn Specific Health Scale- Brief (BSHS-B)

	BSHS-B								
WHODAS Domains	**Affective**	**Body Image**	**Interpersonal Relationships**	**Sexuality**	**Heat Sensitivity**	**Simple Abilities**	**Treatment Regimens**	**Hand Function**	**Work**
Cognition	−0.44*	−0.21	−0.40*	−0.26	−0.22	−0.47*	−0.34*	−0.39*	−0.31*
Mobility	−0.43*	−0.45*	−0.43*	−0.53*	−0.46*	−0.60**	−0.48*	−0.38*	−0.44*
Self-Care	−0.14	−0.09	−0.09	−0.11	−0.13	−0.69**	−0.18	−0.70**	−0.39*
Getting Along	−0.40*	−0.18	−0.23	−0.40*	−0.29	−0.60**	−0.29	−0.45*	−0.46*
Household	−0.45*	−0.32*	−0.28	−0.47*	−0.34*	−0.45*	−0.47*	−0.39*	−0.44*
Work	−0.39*	−0.30	−0.39*	−0.40*	−0.52*	−0.70**	−0.42*	−0.55*	−0.52*
Participation	−0.43*	−0.48*	−0.39*	−0.36*	−0.59**	−0.28	−0.49*	−0.21	−0.52*

* = p< .05,

** p< .0001

Table 13

Lower Quality of Life Classification and Percent of Population in Each Domain of the World Health Organization Disability Assessment Scale (WHODAS) and the Burn Specific Health Scale- Brief (BSHS-B)

Domain	Lower QOL Limit	% with Lower Quality of Life
WHODAS		
Cognition	35	22
Mobility	6.25	42
Self-Care	10	32
Getting Along	25	30
Household	10	40
Work	7.14	44
Participation	37.5	8
BSHS-B		
Affective	2.8	16
Body Image	2.75	27
Interpersonal Relationships	3.5	19
Sexuality	3.34	17
Heat Sensitivity	2.8	27
Simple Abilities	3.67	22
Treatment Regimens	3.4	17
Hand Function	3.2	16
Work	3	13

Table 14

Analysis of Higher and Lower Quality of Life Individuals by Either the World Health Organization Disability Assessment Scale (WHODAS) and the Burn Specific Health Scale Brief (BSHS-B)

WHODAS Overlapping Domain	BSHS-B Overlapping Domain	Higher QOL on Both Scales n(%)	Lower QOL only on WHODAS n(%)	Lower QOL only on BSHS-B n(%)	Lower QOL on Both Scales n(%)
Cognition	Interpersonal Relationships	32(64)	6(12)	5(10)	4(8)
Mobility	Heat Sensitivity	24(48)	11(22)	4(8)	8(16)
Mobility	Simple Abilities	27(54)	11(22)	1(2)	10(20)
Mobility	Hand Function	27(54)	14(28)	1(2)	7(14)
Self-Care	Simple Abilities	33(66)	5(10)	1(2)	10(20)
Self-Care	Hand Function	32(64)	9(18)	1(2)	7(14)
Getting Along	Affective	28(56)	8(16)	2(4)	5(10)
Getting Along	Interpersonal Relationships	24(48)	9(18)	5(10)	3(6)
Getting Along	Sexuality	27(54)	7(14)	2(4)	5(10)
Household	Hand Function	27(54)	14(28)	2(4)	6(12)
Household	Work	26(52)	14(28)	2(4)	4(8)
Work	Work	17(34)	11(22)	0(0)	3(6)
Participation	Affective	39(78)	2(4)	5(10)	2(4)
Participation	Body Image	33(66)	1(2)	11(22)	2(4)
Participation	Interpersonal Relationships	36(72)	2(4)	7(14)	1(2)
Participation	Heat Sensitivity	33(66)	2(4)	10(20)	1(2)
Participation	Treatment Regimens	38(76)	2(4)	5(10)	2(4)
Overall	**Overall**	**15(30)**	**8(16)**	**4(8)**	**23(46)**

Quality of Life (QOL).