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Social Interactions and Social Activities After Burn Injury: A Life Impact Burn Recovery Evaluation (LIBRE) Study

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Abstract

Social interactions and activities are key components of social recovery following burn injuries. The objective of this study is to determine the predictors of these areas of social recovery. This study provides a secondary analysis of a cross-sectional survey of adult burn survivors. The Life Impact Burn Recovery Evaluation-192 was administered to 601 burn survivors for the field-testing of the Life Impact Burn Recovery Evaluation Profile. Survivors aged 18 years and older with injuries 5% total BSA or burns to critical areas (hands, feet, face, or genitals) were eligible

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to participate. Multivariate linear regression analyses were used to determine predictors of the Social Activities and Social Interactions scale scores. A total of 599 people completed the Social Interactions and Social Activities scales. Of these, 77% identified as White Non-Hispanic, 55% were female, 55% were unmarried, and 80% had burns to critical areas. Participants had a mean age of 45 years, a mean time since burn injury of 15 years, and a mean burn size of 41% total BSA. Younger age ($P < .01$) and being married/living with a significant other ($P = .01$) were associated with higher Social Activities and Social Interactions scale scores. Individual item responses reveal that survivors had lower scores on items related to participating in outdoor activities (30.4%) or feeling uncomfortable with their appearance (32.4% report dressing to avoid stares). Social interactions and activities are long-term challenges for burn survivors. It is important for clinicians to identify patients who may struggle with social recovery in order to focus on future community-based interventions.

Advances in acute burn care have greatly decreased mortality and, as a result, increased the number of burn survivors. In light of these trends, there is a growing need to focus research on long-term recovery and address social recovery following burn injury.¹⁻⁵ The ability to participate in social interactions and activities is an important aspect of social recovery.¹ Several studies have shown that changes in appearance can significantly impact a burn survivor's ability to interact with others.^{6,7} Burn survivors with physical disfigurement often face stigmatization and invalidation, and many report cases of staring, avoiding, teasing, and manifestations of pity.⁶⁻⁹ Some survivors have characterized these experiences as "dehumanizing" and, have suggested it can lead to "social death."^{8,10,11} As many as 40% of burn survivors are dissatisfied with their appearance,¹² and some burn survivors avoid social interactions entirely.⁶ Avoidance of social interactions and activities due to disfigurement can lead to social isolation and severely impact burn survivors' psychological health.^{11,13,14} However, the effect of the burn injury on social interactions and activities of burn survivors remains underexplored in the literature.^{11,15,16}

Previous efforts to understand the effects of burn injury on social interactions and activities have been predominantly qualitative,^{11,17,18} though several quantitative studies,^{2,19-22} which employ general or burn-specific metrics, also exist. Burn-specific metrics are valuable in that they probe topics particular to, and of interest to burn survivors. However, the burn-specific legacy outcome measures such as the Burn Outcome Questionnaires (BOQs) and the Burn Specific Health Scale (BSHS) have limitations with respect to measurement of social recovery of adults. The BOQs are a suite of age-based multidimensional outcome metrics.¹⁹ All BOQ forms contain questions geared towards social function and social reintegration. However, most are tailored to specific age groups, namely the pediatric and young adult populations.^{19,22} The ABOQ is now published, addressing the whole age group. However, this adult form is a short form limited by single item domains. The BSHS includes questions about social reintegration that mainly address sexual and family/friend relationships.²⁰ Additionally, the BSHS has inadequate psychometric properties, with significant ceiling effects and poor discriminant validity.²³

The Life Impact Burn Recovery Evaluation (LIBRE) Profile measures the social impact of burn injury. Based on the World Health Organization International Classification

of Functioning, the LIBRE Profile is made up of six scales: Romantic Relationships, Sexual Relationships, Family & Friends, Work & Employment, Social Interactions, and Social Activities. These domains are reliable and psychometrically valid.^{16,21,22} There are important relationships previously demonstrated in the literature linking social activities and interactions with family and friends, employment, and romantic and sexual relationships.²⁴ Therefore, the purpose of the present study is to determine the predictors of social reintegration and recovery as measured by the Social Activities and Social Interaction scales of the LIBRE Profile.

METHODS

Study Design and Participants

The present study is a secondary analysis of the cross-sectional survey of adult burn survivors. The LIBRE-192 was administered to 601 burn survivors during the field-testing and calibration of the questions for the development of the LIBRE Profile. Between October 2014 and December 2015, burn survivors were recruited through burn peer support groups, social media, burn clinics, the Phoenix Society for Burn Survivors, and at the 2014 and 2015 Phoenix World Burn Congress. Burn survivors aged 18 years and over with injuries to 5% total BSA (TBSA) or burns to critical areas (hands, feet, face, or genitals) were eligible to participate.

Demographic and Clinical Characteristics

Demographic and clinical variables were collected through self-report. Demographic variables included age at time of survey, gender, race/ethnicity, education level, and marital status. Clinical variables included TBSA burned, presence of burns to critical areas, and time since burn injury. When a TBSA range was reported, the median value of the range was used for analysis given non-normal distributions.

Outcome Measures

Participants responded to the LIBRE-192 by phone interview, or online survey. Development of the 126-item LIBRE Profile from the LIBRE-192 has been described previously.²⁵ The LIBRE Profile measures six domains of social participation: Family & Friends, Social Interactions, Social Activities, Work & Employment, Romantic Relationships, and Sexual Relationships. Responses were coded on a 5-point Likert scale, with higher scores indicating better health outcomes. Specific items were reverse coded as necessary. Scale scores were standardized to a mean of 50 and SD of 10 based upon the mean of the overall sample of burn survivors. The primary outcomes for the present study were scores on the Social Interactions (25 items) and Social Activities (15 items) scales. Individual item scores were explored as secondary outcomes to provide greater granularity of the socially related scales.

Data Analysis

Descriptive statistics were generated for demographic and clinical data. Multivariate linear regression analyses were used to identify demographic and clinical predictors of the Social Activities and Social Interaction scale scores. Independent variables included age at the time of survey, time since burn injury, gender, education level, relationship status, burn

size, and presence of visible burn (hand and/or face). In addition to the significance of the independent variables, effect sizes are included defined as the magnitude of the beta coefficients divided by the SD relative to a comparator group, where a small effect is defined as 0.20 SD, a small to moderate effect is defined as between 0.21 and 0.50 , a moderate effect is defined as 0.50 to < 0.80 and a large effect size is 0.80 . This is based on Cohen's definitions of effect size to provide an understanding of the clinical and social relevance of the significant findings.^{26–28} The robustness of the parameter estimates was tested using bootstrap techniques.^{29,30} We assessed whether the point estimates and 95% confidence intervals of the regression coefficients remained stable across 200 bootstrap subsamples. The percentages of participants who reported low scores (defined as 1 or 2 on the 1–5 scale) for each item within the Social Activities scale and Social Interactions scale were calculated to provide proportional analysis of the data at the item level.

RESULTS

Demographic and Clinical Characteristics

Of the 601 burn survivors who completed the survey, two participants did not complete the Social Activities and Social Interactions scales and were excluded from the analyses. In the final sample of 599 participants, 77% ($n = 464$) identified as White Non-Hispanic, 55% ($n = 328$) were female, 45% ($n = 269$) were married or living with a significant other, and 81% ($n = 484$) had burns to critical areas. Participants had a mean age of 45 (± 16) years, a mean of 15 years (± 16) for time since burn injury, and an average burn size of 41% ($\pm 24\%$) TBSA. Data on TBSA burned were missing for 42 participants (7%). For all other variables, data were missing for fewer than 1% of participants. Complete demographic and clinical characteristics are presented in Table 1.

Regression Analysis

Results of linear regression analyses are presented in Tables 2 and 3. Each 10-year increase in age at the time of the survey was associated with approximately half a SD decrease in scale scores for the two scales ($B = -5.93$ for Social Activities, $B = -4.71$ for Social Interactions, $P < .01$ for both scales), a moderate effect size. Each 10-year increase in the time since burn injury was independently associated with *higher* scale scores ($B = 3.68$ for Social Activities, $B = 2.65$ for Social Interactions, $P < .01$) (a small to moderate effect size). Not being married or living with a significant other was associated with approximately a quarter of a SD decrease in scale scores ($B = -2.20$ for Social Activities, $B = -2.92$ for Social Interactions, $P < .01$), a small to moderate effect size. Scores for men on the Social Interactions scale were slightly less than half a SD higher than for women in adjusted analyses ($B = 4.13$, $P < .01$), a small effect to moderate effect size. Having a higher education level was associated with higher scores on both scales (B for each category increase = 1.55 for Social Activities, $B = 1.21$ for Social Interactions $P < .01$), a small effect and presence of visible burns ($P = 0.04$) was associated with higher scores on the Social Activities scale ($B = 1.99$, $P < .04$) also a small effect. The point estimates and 95% confidence intervals from bootstrap inference assessing the relationship between independent variables and scores on the Social Activities and Social Interactions scales remained stable (data not shown).

Item-Level Analysis

Of the 25 items in the Social Activities scale, items with the largest percentage of low scores included questions about avoidance of outdoor activities (30%), limitations on what survivors could do with their families (25%), and tiring easily when doing things that are fun (23%; Table 4). Within the Social Interactions scale, participants demonstrated low scores on items related to dressing to avoid stares (32%), avoidance of things that may call attention to their burns (26%), and worrying about other people's attitudes towards them (25%; Table 5).

DISCUSSION

Burn injuries can have a significant impact on social activities and social interactions. Understanding these aspects of social participation is important when assisting burn survivors in the recovery process. In the present study, younger age, being married/living with a significant other, and higher education levels were associated with higher, meaning better, Social Activities and Social Interactions scale scores. On the other hand, those with a 10-year increase in age at the time of the survey gave a moderate decremental effect size for social activities and interactions. Selected demographics, including gender, time since burn injury, and marital status, had small to moderate effect sizes, indicating that these variables were both significant with some clinical and social relevance.

Previous research within the general population has shown that younger age and being partnered can affect social participation. Several studies have found that social participation becomes more difficult with older age as it might lead to increased physical and mental health problems.³¹⁻³³ Others have found that older, less socially active people are more likely to become disabled later in life.^{31,34,35} In addition, social support, experienced by married individuals and those living with someone, has been shown to reduce distress and depressive symptoms.^{36,37} This study builds on past research showing a similar relationship in the burn population. A previous study found that older patients required up to two times the length of stay in a hospital.³⁸ Research has also shown that social support is a positive predictor of functional outcomes among the burn population.³⁹ This kind of support can facilitate coping and aid with motivation and, thus, lead to improved quality of life.⁴⁰ Esselman et al identified being married and not living alone as among the best predictors of home integration scores in the Community Integration Questionnaire.⁴¹ Though it may not be specific to the burn population, it is important to note that younger age and being partnered can affect social participation.

In this study, a substantial proportion of burn survivors reported low scores within the Social Activities scale on items relating to avoidance of outdoor activities, limitations on activities with family members, and tiring easily. Challenges such as chronic pain, fatigue, photosensitivity, and depression or anxiety may impact burn survivors' participation in these kinds of activities. Chronic pain and fatigue are two commonly reported factors that may limit social participation. One study found that those with burn injuries were more likely to report pain 28 to 56 months following a traumatic event than those without burns exposed to the same event.⁴² Burn survivors may experience pain up to 7 to 12 years after their initial injury.⁴² Additionally, fatigue has been described as an "almost universal complaint."^{43,44} A study conducted by Holavanahalli et al found that, in adult burn patients with a burn of

30% TBSA or greater, 54% continued to experience fatigue after burn injury.⁴⁵ Fatigue may be due to burn-induced hypermetabolism, muscle wasting, and transcriptome changes within energy production genes and mitochondria.^{44,46,47}

Social activities, especially those taking place outdoors, can also be affected by skin complications. Full thickness thermal burns often result in heat intolerance and, due to the sensitivity of the burn site, burn survivors are advised to avoid exposure of burn scars to the sun.⁴⁸ Psychological challenges, such as depression and anxiety, may also influence one's ability to participate in activities. One study found that, in a sample of 83 young adult survivors, more than 50% of the subjects qualified for a psychiatric disorder, with anxiety being the most prevalent.⁴⁹ Similarly, a study conducted by Meyer et al found that a childhood burn injury increased one's risk of developing a mental illness.⁵⁰ Studies show that these psychological challenges can have a significant interactive effect on physical functioning and daily life activities postinjury.^{51,52} Fatigue, pain, heat intolerance, photosensitivity, and psychological issues can limit the activities burn survivors participate in, and the extent to which they are able to engage in activities of their family and friends.

In addition to affecting social activities, psychological challenges can also impact social interactions following burn injury. In the Social Interactions scale, burn survivors frequently reported dressing to avoid stares, avoiding things that may call attention to their burns, and worrying about other people's attitudes. Burn survivors may dress to avoid stares or avoid things that may call attention to themselves due to their burn scarring. Both scarring and disfigurement have been shown to increase distress and dissatisfaction with body image and, in turn, decrease social interactions.^{7,53} Similar to the present study, those with facial deformities have reported problems with meeting new people, making friends, and developing intimate relationships.⁶ Stares, startled reactions, remarks, and personal questions have also been reported during interactions with the public.⁶ Often, these stigmatization behaviors push burn survivors to alter their daily habits (for example, dressing differently) in order to avoid criticism. Burn survivors may also turn to social isolation as a way to escape possible confrontations.⁵⁴ This becomes increasingly problematic, as social isolation can lead to further psychological distress.^{13,14}

Findings from the present study indicate that the presence of visible burns is associated with higher Social Activities scores. Currently, there is a debate as to whether hidden scarring, scarring that can be covered, or visible scarring, scarring to either the face or feet, results in greater difficulties with regards to social recovery.^{7,55} Some studies have found that those with visible burns encounter stigmatization behaviors more frequently and have a harder time with social connection.^{7,11,56} Other research suggests that the inability to hide one's scars may force survivors to develop coping mechanisms earlier in their recovery. Additionally, it is possible that those with visible burns receive more resources related to social participation.^{7,57} Recent literature has investigated the theory of resilience and post-traumatic growth to explain improvement post-injury. Resilience is defined as the return to a pre-trauma condition while, post-traumatic growth is the act of surpassing one's original health.⁵⁸ Though it is a relatively new area of study, some research suggests that the location of a burn may influence post-traumatic growth.^{58,59} However, due to limited research, it is unclear how or why the physical aspects of an injury impacts recovery.

Returning to daily life can be a difficult adjustment for burn survivors, and some may struggle to adapt. However, lack of social participation can also have severe and potentially dangerous effects. Past research shows that social isolation is associated with higher levels of depression and suicidal ideation.^{11,13,25} In a study of 113 patients, approximately 50% had severe depression at 60 days postinjury.¹⁴ Therefore, it is important that clinicians understand the importance of social participation, can identify patients who may need additional assistance, and are able to direct patients to community resources and interventions that may be available.

Many resources are available to burn survivors for support with social recovery. The Phoenix Society for Burn Survivors offers several services including peer support, group meetings, online learning, and the Phoenix World Burn Congress. Though limited, research shows that peer support has a positive impact on adult patients with burn injuries.⁶⁰ In a study by Sproul et al, 92% of the patients found it helpful to speak with another survivor.⁶¹ Similarly, a study conducted by Davis et al found that burn survivors experienced themes such as acceptance of self, perspective change, and value of community following burn peer support group meetings.⁶²

There are several limitations to this study to consider. The study used a convenience sample as participants were recruited from support groups and major burn centers. The participants in this study represent only a fraction of the burn survivor community and, therefore, these findings are limited in their generalizability. This study may also be subject to selection bias. However, as previously reported, this sample was national in scope and represented a range of clinical and social characteristics among those sampled.²⁵ Future investigations into social participation would benefit from a longitudinal follow-up study design.

This study also employed a cross-sectional design and thus only allows for a single snapshot of burn survivors' recovery. Social recovery is a dynamic process that may vary at different time-points for different individuals. Furthermore, the study did not explore sexual orientation, gender assignment, economic status, and cultural differences between survivors from different geographical areas, all of which may affect social recovery.

Further research into the challenges of social recovery will help clinicians pinpoint barriers, design interventions, and allocate appropriate resources. In turn, this may enable better communication between clinicians and patients, help to prevent social isolation, and assist with social recovery.

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Table 1.

Demographic and clinical characteristics of the study population

Variable	
Number of participants	599
Age at time of survey, mean (<i>SD</i>)	45 (16)
Female, % (<i>N</i>)	54.8 (328)
Race/ethnicity, % (<i>N</i>)	
White	77.5 (464)
Non-white	21.6 (130)
Education level, % (<i>N</i>)	
High school or less	41.2 (247)
Technical/trade training or associate's degree	16.5 (99)
Bachelor's degree or higher	41.5 (249)
Married/living with significant other, % (<i>N</i>)	44.9 (269)
Percent total BSA burned, mean (<i>SD</i>)	24 (41)
Has burn(s) to critical areas, % (<i>N</i>)	80.8 (484)
Years since burn injury, mean (<i>SD</i>)	16 (15)

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Table 2.

Linear regression analysis predicting Social Activities scale score

Variable	B	P-value	Effect Size
Age at the time of survey, per 10-y increase	-5.93	<.01	Moderate
Male gender	1.63	.06	Small
Highest education level completed	1.55	<.01	Small
Not married/living with significant other	-2.20	.01	Small to moderate
Time since burn injury, per 10-y increase	3.68	<.01	Small to moderate
Total BSA quintile	-1.60	<.01	Small
Visible burn	1.99	.04	Small

Terms for age at time of survey² and time since burn injury² were both statistically significant and are included in the adjusted model. Effect sizes are defined based on the magnitude of the beta coefficient divided by the SD of the outcome variable, where according to Cohen's definition, a small effect is defined as 0.20 SD, a small to moderate effect is defined as between 0.21 and 0.50, a moderate effect is defined as 0.50 to < 0.80 and a large effect size is 0.80. The LIBRE scales were standardized to a SD of 10. Thus, for example, a 10-y increase in age at the time of survey was associated with a lower Social Activities scale score, with a moderate effect size (0.593 SD), whereas male gender was associated with a higher Social Activities scale score with a small effect size (0.163 SD).

Linear regression analysis predicting Social Interactions scale score

Variable	B	P-value	Effect Size
Age at the time of survey, per 10-y increase	-4.71	<.01	Small to moderate
Male gender	4.13	<.01	Small to moderate
Highest education level completed	1.21	<.01	Small
Not married/living with significant other	-2.92	<.01	Small to moderate
Time since burn injury, per 10-y increase	2.65	<.01	Small to moderate
Total BSA quintile	-0.20	NS	
Visible burn	1.34	NS	

Terms for age at time of survey² and time since burn injury² were both statistically significant and are included in the adjusted model. Effect sizes are defined based on the magnitude of the beta coefficient divided by the SD of the outcome variable, where according to Cohen's definition, a small effect is defined as 0.20 SD, a small to moderate effect is defined as between 0.21 and 0.50, a moderate effect is defined as 0.50 to < 0.80 and a large effect size is 0.80. The LIBRE scales were standardized to an SD of 10. Thus, for example, a 10-y increase in age at the time of survey was associated with a lower Social Interactions scale score, with a small to moderate effect size (0.471 SD), whereas a one-category increase in education level completed was associated with a higher Social Interactions scale score with a small effect size (0.121 SD).

Table 4.

Percentage of participants with low scores on the Social Activities scale

Variable	Percentage of Participants Reporting Low Score (1 or 2 on the scale of 1–5)
Q520 I avoid outdoor activities because of my burns	30.4
Q913 I am limited in what I can do for my family	25.7
Q1012 I tire easily when I go out with friends	14.6
Q1010 I am upset that my burns limit what I can do with friends	15.4
Q57 My burns limit me being active	14.2
Q510 I am disappointed in my ability to do leisure activities	13.0
Q1016 I am satisfied with my ability to do things for my friends	12.3
Q58 How much do you enjoy your social life?	10.8
Q91 I am able to do all of my regular family activities	6.2
Q53 I am able to go to all the community events that are important to me	4.4
Q98 My family is upset that I can't do more things with them	3.9
Q92 My burns interrupt simple family activities	3.7
Q1013 My friends are disappointed in my ability to do things with them	3.3
Q101 I am able to socialize with my friends	3.0
Q93 My burns limit the time my family has for themselves	2.7

Table 5.

Percentage of participants with low scores on the Social Interactions scale

Variable	Percentage of Participants Reporting Low Score (1 or 2 on the scale of 1-5)
Q615 I dress to avoid stares	32.4
Q613 I avoid doing things that might call attention to my burns	26.6
Q621 I don't worry about other people's attitudes towards me	25.8
Q620 I am upset when strangers comment on my burns	21.1
Q69 I feel embarrassed about my burns	18.5
Q61 Because of my burns, I am uncomfortable around strangers	17.7
Q611 I feel like I don't fit in with other people	17.4
Q65 I am upset when strangers avoid looking at me	17.1
Q518 I don't play sports because of how my burns look	16.8
Q612 Because of how my burns look, I am uncomfortable when I meet new people	15.6
Q610 I feel uncomfortable in crowds because of my burns	15.0
Q1021 Because of my burns, it is hard for me to make friends	13.2
Q513 I do not go to parties because of how my burns look	12.6
Q63 Because of my burns, I feel uncomfortable in social situations	12.4
Q62 Because of my burns, I avoid strangers	11.1
Q51 I limit my activities because of how my burns look	10.8
Q103 I find it difficult to invite a friend to do something together	8.7
Q616 I limit going out in public because of my burns	8.4
Q1011 I am uncomfortable going out with friends	8.2
Q55 I avoid going to community events	7.9
Q102 I avoid being with others because of my burns	7.3
Q1029 My friends are uncomfortable with me showing my burns in public	7.1
Q618 I avoid making new friends because I don't want to talk about my burns	6.9
Q622 I can help strangers feel comfortable around me	5.1
Q1015 I am uncomfortable with friends because of my burns	4.9