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Interpreting Life Impact Burn Recovery Evaluation Profile Scores for Use by Clinicians, Burn Survivors, and Researchers

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Abstract

The Life Impact Burn Recovery Evaluation (LIBRE) Profile is a patient-reported outcome measure developed to assess social participation in adult burn survivors. This study identified numeric score cut-points that define different levels of social participation ability and described each level. An expert panel identified numeric score cut-points that distinguish different levels of social participation for the six LIBRE Profile domains. Methods employed an iterative, modified-Delphi approach, and bookmarking to review calibrated item banks. Analyses (using calibration sample data and repeated in a validation sample) examined means, SDs, and sample distributions for each level. Analyses of variance examined score differences between levels. The panel developed descriptions for each established level. Initial cut-points resulted in four levels for five domains (Social Activities, Social Interactions, Romantic Relationships, Sexual Relationships, and Work & Employment) and five levels for the sixth domain (Relationships with Family & Friends). Comparisons demonstrated significant differences between level mean scores for all domains ($P < .05$) except Relationships with Family & Friends. Based on follow-up surveys, Relationships with Family & Friends score cut-points were adjusted to identify four levels with significant score differences between all levels. Panelists reached consensus for level descriptions. Score cut-points and descriptions identify different levels of social participation, providing a relevant context for

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interpreting LIBRE Profile numeric scores. LIBRE Profile Social Participation levels will help clinicians and persons with burn injury interpret LIBRE Profile numeric scores and promote use of this important new assessment.

Advances in treatment of acute burn injuries have greatly reduced mortality, resulting in a greater need to address social participation and community reintegration as an integral component of postburn injury rehabilitation.^{1,2} Burn injuries are associated with important physical, psychological, and social challenges and 30% of adult burn survivors consistently report moderate to severe psychological or social difficulties postburn injury.²⁻⁴ Furthermore, functional impairments associated with burn injury reduce burn survivors' ability to fulfill social roles, intensify social isolation, and introduce financial hardship.^{5,6} Burn injuries disrupt many aspects of social participation, including employment, engagement with family and friends, and intimate relationships^{7,8}; however, most measures used to document postburn injury outcomes focus on assessing physical impairments. A measure that provides the ability to assess and monitor the impact of burn injury on social participation will provide new insights to inform patient care, community-based programming, and advance burn injury research.⁹ The Life Impact Burn Recovery Evaluation (LIBRE) Profile is a patient-reported outcome measure (PROM) developed specifically to assess critical aspects of social participation for persons with burn injury. The LIBRE Profile has great potential to advance our understanding of burn survivors' psychological and social needs and support efforts to address those needs as an integral component of recovery postburn injury.¹⁰

The LIBRE Profile assesses the following six important social participation domains: Family & Friends, Social Interactions, Social Activities, Work & Employment, Romantic Relationships, and Sexual Relationships. Each domain is comprised of items that assess a wide range of social participation abilities relevant for persons with burn injury. LIBRE Profile item banks were developed and calibrated using item response theory (IRT) with graded response models. Traditional fixed-form assessments require that all respondents complete the same items, even though some items are irrelevant. A significant advantage of IRT-based measures is the ability to administer the assessment using a computer adaptive testing (CAT) approach where a small set of selected items from a large item bank are determined and unique for each respondent with the same common metric. PROMs administered as CATs offer an important advance in measurement, providing a precise and efficient method to estimate an individual's ability by administering a few carefully selected items. Previous research demonstrates that the LIBRE Profile CAT can estimate an individual's social participation ability in a given domain by administering a few items⁵⁻¹⁰ from the calibrated item bank.¹¹

IRT-based measures yield scores that are calculated based on logit values. IRT-based measures yield interval-level data, providing a significant advantage for quantitative analyses. While there is a great deal of interest in using IRT-based PROMs for outcomes assessment, there are concerns about interpretation of PROM scores to inform patient treatment and self-advocacy. Ideally, PROMs would be used for needs assessments, shared decision-making, and symptom management.¹² However, there is a growing recognition that

the difficulty of interpreting and communicating PROM scores presents a significant barrier to effective use of PROMs.¹³

Criteria for reviewing measures recommended by the Medical Outcomes Trust Scientific Advisory Board cites score interpretability as one of eight scientific criteria required to promote “high-quality, standardized health outcomes measurement instruments to national and international health communities.”¹⁴ The International Society for Quality of Life Research provides guidelines for implementing PROMs in clinical settings and recommends that PROM scores should include benchmarks for score interpretation.¹⁵ These recommendations highlight the importance of providing a context for interpreting IRT-based PROM scores. A strategy for interpreting and communicating PROM numeric scores involves determining score thresholds that identify different levels of severity. Several PROMs, including Patient Reported Outcome Measure Information Systems (PROMIS) assessments of physical function, cognitive function, and sleep disturbance,^{13,16–19} the Work Disability Functional Assessment Battery (WD-FAB),²⁰ and the Spinal Cord Injury Functional Index (SCI-FI)²¹ have established score thresholds associated with different ability levels to facilitate clinical interpretation of scores.

One method for interpreting IRT-based scores associated with different ability levels involves bookmarking methods. Commonly used in conjunction with scholastic performance assessments, bookmarking methods describe different levels of academic performance (eg, basic, proficient, and advanced). Bookmarking methods engage content experts to review IRT analyses and identify score cut-points that distinguish different ability levels.^{22,23} We report on a study that used bookmarking methods and engaged an expert panel to identify score cut-points to distinguish and describe different levels of social participation for all six LIBRE Profile domains. These findings will enable burn survivors, clinicians, and researchers to better understand, communicate, and use the LIBRE Profile scores to track recovery, set goals, and identify the need for resources. Including ability levels and descriptions as part of LIBRE Profile score reports will promote effective use of the LIBRE Profile in clinical settings.

METHODS

LIBRE Profile development, described in detail in previous publications,⁹ followed a standard protocol for developing PROMs.²⁴ As a first step, focus groups identified aspects of social participation important to burn survivors. Analyses of focus group transcripts were used to identify a conceptual framework and develop social participation items. Draft social participation items were winnowed and cognitively tested to yield an item pool. Next, a calibration study was conducted to administer the item pool to a large (N = 601) diverse sample of persons with burn injury. Factor analysis identified the following unidimensional social participation domains: Family & Friends, Social Interactions, Social Activities, Work & Employment, Romantic Relationships, and Sexual Relationships.²⁵ IRT analyses used a graded response model to yield calibrated unidimensional item banks for each of the six LIBRE Profile domains.¹⁰ Additional studies established the validity²⁶ and reliability¹¹ of the LIBRE Profile assessment.

A CAT algorithm was developed to administer the LIBRE Profile. CATs select and administer items from IRT-calibrated item banks. During a CAT assessment, the algorithm uses the individual's responses to select the next, most informative item from the calibrated item bank. In this manner, the CAT selects the items that are most appropriate for each individual, yielding a customized assessment. Since all items are calibrated on the same metric, CAT domain scores are comparable even though each respondent may complete different items. IRT-based measures yield scores based on logit values that are transformed to a standard metric (*T* score) where a score of 50 is the mean (based on the calibration sample scores) and a 10-point interval represents 1 *SD* from the mean. This study extends LIBRE Profile development and uses a mixed-methods approach to identify LIBRE Profile score cut-points that distinguish different levels of social participation ability along with descriptions of each level.

LIBRE Profile Item Maps and Bookmarking Process

The bookmarking process uses item maps to identify score ranges that define different ability levels. LIBRE Profile item maps for each domain were generated using study calibration data. Item maps (see Figure 1) provide a visual display of IRT-calibrated item banks and include the following components: 1) domain items hierarchically ordered based on difficulty (ie, logit scores) along the *y*-axis; 2) transformed scores (*T* scores) along the *x*-axis; and 3) horizontal bars representing the distribution of item responses in the calibration sample.²⁷ During the bookmarking process, these components are considered to identify score ranges deemed to distinguish different levels of social participation ability.

Expert Panel Consensus

We identified an Expert Panel comprised of 20 individuals with different areas of expertise: 7 burn survivors, 10 researchers, and 9 clinicians (6 panel members had dual areas of expertise). Several Expert Panel members were involved in long-term community-based support outside of clinical settings. A modified-Delphi approach^{28,29} engaged experts in an iterative process to review item maps. Panelists used item maps to identify LIBRE Profile score ranges that distinguish different levels of social participation and described abilities associated with each level. Prior to an in-person meeting, panelists participated in a webinar demonstrating the bookmarking process. At the conclusion of the webinar, panelists were instructed to: 1) complete an independent review of LIBRE Profile item maps for the two assigned domains; 2) identify initial score cut-points for different ability levels; 3) develop draft descriptions of each level. Panelists returned their individual responses and the research team summarized all responses prior to the in-person meeting. In preparation for the in-person meeting, Expert Panel members were organized into three groups balanced by areas of expertise. Each group was assigned two different LIBRE Profile domains to review. During the in-person meeting, each group met with a facilitator to review group members' suggestions for initial cut-points and level descriptions. Figure 1 presents an example of an item map demonstrating score cut-points that distinguish different ability levels. Discussion focused on considering the advantages and disadvantages of different cut-points and descriptions suggested by individual members to reach preliminary consensus within the group. At the end of the session, all panelists reviewed initial consensus documents completed by each group to synergize cut-point strategies and descriptions across all six

LIBRE Profile domains. Following the in-person meeting, expert panelists responded to web-based surveys and the research team implemented an iterative process to achieve final consensus regarding cut-points and descriptions for each level across all six LIBRE Profile domains.

Study Samples

This study was conducted using data collected in two different cross-sectional studies. The LIBRE Profile Calibration Sample engaged a rich heterogeneous national sample of 601 participants with a range of burn injuries.¹⁰ Calibration study data were used to develop domain item maps. Proposed cut-points for different social participation levels were examined by calculating mean scores and the participant distribution (% of sample) for each level. Analyses of variance (ANOVAs) routines were conducted to determine if suggested cut-points resulted in significant differences when comparing mean level scores. For validation purposes, these analyses were repeated using data from a pilot study (N = 259; henceforth referred to as the Validation Sample).¹¹ Participant inclusion criteria for both studies were as follows: 18 years of age or older, post initial discharge from the hospital, a TBSA of 5% or greater or a burn to a critical area (face, hands, feet, or genitals), able to read and understand English. The Validation Sample also required access to email and the Internet. Both studies used the following filter questions to select domains that were relevant for each individual: Are you currently working for pay? (Work & Employment); Are you currently involved in a romantic relationship? (Romantic Relationships); Are you currently sexually active? (Sexual Relationships). If a participant responded “no” to a filter question, the domain was not administered. Consequently, sample sizes are not equal across the six LIBRE Profile domains. Calibration sample items were administered via a web-based survey platform (Qualtrics, Provo, UT) or phone interview. Validation Study data were collected using an online data collection platform to administer LIBRE Profile Fixed Short Forms.³⁰ LIBRE Profile Short Forms are comprised of a fixed set of items (10 items per domains) selected from item banks to represent a range of ability and were demonstrated to have acceptable psychometric properties.³⁰ The Boston University Medical Center Institutional Review Board approved both studies.

Sample Demographic Characteristics

Table 1 summarizes demographic characteristics of participants included in the Calibration and Validation Study samples. The average age of the samples at the time of survey completion was similar (44.55 [15.98]; 45.5 [14.6], respectively). Slightly less than half of both samples were male (45.09%; 40.50%, respectively); primarily white (80.03%; 85.30%, respectively); and a small percentage of both samples identified as Hispanic (6.82%; 7.3%, respectively). The mean TBSA burned was fairly similar for the Calibration and Validation Samples (40.45 [23.65]; 44.50 [25.1], respectively). More than half of the participants indicated some education beyond high school (58.07%; 63.3%, respectively). The distribution of time since burn injury was similar for both samples (approximately 25% fewer than 3 years; 25% between 3 and 10 years; 50% more than 10 years). A comparison of demographic variables for the two samples revealed no significant group differences.

Data Analysis

For each LIBRE Profile domain, analyses included the following: 1) calculation of means and *SD* for each level; 2) distribution across levels (% of sample); 3) ANOVAs examined mean score differences. If ANOVA findings demonstrated overall significant differences, Tukey post hoc pairwise comparisons ($P > .05$) examined mean score differences between levels.³¹ All analyses were completed for Calibration and Validation Study data.

RESULTS

Establishing Score Cut-Points and Ability Levels

Initial score cut-points that emerged from the in-person consensus meeting identified four different ability levels for all LIBRE Profile domains, except Relationships with Family & Friends where five levels were identified. ANOVAs and post hoc analyses demonstrated significant differences ($P < .001$) between level mean values for all domains except Relationships with Family & Friends, where no significant difference was found between Levels 1 and 2. When Levels 1 and 2 were collapsed to yield four levels, significant mean score differences between levels were noted for all pairwise comparisons ($P < .05$). Across all domains, cut-point ranges by level were as follows: Level 1 upper boundary score cut-points ranged from 22 to 30 (approximately 2 to 3 SDs below the calibration sample mean); Level 2 upper boundary score cut-points ranged from 35 to 45 (1.5 to 0.5 SDs below the calibration sample mean); Level 3 upper boundary score cut-points ranged from 50 to 61 (approximately 0 to 1.1 SD above the mean).

Ability Level Analyses

Table 2 presents domain ability level score ranges, means, *SD*, and ANOVA results for the Calibration and Validation Samples. As expected, mean score values progressively increased across levels for all domains. Across both samples and six domains, level mean (*SD*) value ranges were: Level 1 = 17.00 (5.20) to 28.50 (1.85); Level 2 = 31.06 (2.99) to 40.11 (3.84); Level 3 = 45.36 (2.92) to 51.91 (3.61); Level 4 = 57.59 (4.97) to 68.31 (4.95). For all domains and levels, mean values were similar for the Calibration and Validation Samples; however, a comparison of *SD* values for the two samples reveals a tendency for greater score variability in the Calibration Sample compared with the Validation Sample. Score variability also differed by domain and level, with the largest variation noted for Romantic Relationships and Work & Employment scales in both samples. For all other scales, Level 4 had the largest score variance in the Calibration Sample, and Level 3 had the largest variation for the Validation Sample. For both samples, ANOVA results comparing level mean values revealed significant group differences ($P < .001$) and pairwise comparisons demonstrated significant differences levels ($P < .05$).

Participant Score Distribution

Table 2 displays participant score distributions across the four levels for each domain. Level 1 had the lowest representation across all domains for both samples (0 to 2.86%). Validation Sample participants were not represented at Level 1 for the Social Activities and Work & Employment domains. Level 2 had the next lowest representation of participants ranging

from 6.56% (Social Interactions—Validation Sample) to 30.06% (Sexual Relationships—Validation Sample). Level 3 had the highest percentage of participants, ranging from 44.09 (Social Activities-Calibration Sample) to 70.27% (Social Interactions—Validation Sample), except for the Work & Employment domain (Calibration Sample) where the highest percentage of participants was in Level 4. Across the six domains, participant score distribution was most variable for Level 4, ranging from a low of 9.27% (Relationships with Family & Friends—Validation Sample) to a high of 47.81% (Work & Employment—Calibration Sample).

Level Descriptions

Panelists developed level descriptions by examining domain item content, summarizing aspects of social participation assessed by each domain, and reviewing the distribution of response option endorsement to include a qualifying statement about the activity (eg, a lot, a little). Table 3 summarizes initial draft descriptions for each domain that emerged from the three Expert Panel groups. Initial descriptions used the following terms: difficulty, limitation, enjoyment, avoidance/acceptance, challenges, satisfaction, and comfort/discomfort. Panelists gathered to review initial level descriptions developed by each group with a goal of adopting common terminology across domains. Panelists agreed that the term “comfort” best characterized distinctions in ability levels across all six domains. Additional terms added to level descriptions varied by domain and included support (Relationships with Family & Friends), avoidance (Social Activities), satisfaction (Sexual Relationship, Work & Employment), and difficulty (Work & Employment). Panel members discussed strategies to introduce domains and agreed to include statements describing the types of activities assessed by domain items. Panelist continued to review level descriptions via surveys with modifications to achieve consensus. Table 4 presents the final LIBRE Profile cut-points and descriptions. For each domain, an introductory statement provides examples of domain activities. Across all domains, ability levels describe comfort with social participation activities, from very uncomfortable to very comfortable. The Relationships with Family & Friends domain includes level of support provided, from “little or no” to “a lot.” The Social Activities domain includes activity avoidance, from “almost always avoid” to “hardly ever avoid.” The Social Interactions domain includes comfort, avoidance, and reaction by others to appearance, from “very much troubled” to “not at all troubled.” The Sexual Relationships domain includes satisfaction, from “not satisfying” to “very satisfying.” The Work & Employment domain includes the comfort and satisfaction terms used in other domains and with an added description of difficulties doing work, from “many difficulties” to “hardly any difficulty.”

DISCUSSION

Lack of adequate guidelines for interpreting PROM scores is a significant barrier to using these assessments in clinical practice.³² Efforts to expand clinical use of PROMs requires research to provide a context for interpreting PROM scores.^{13,16–19} The bookmarking and consensus process implemented in this study identified score ranges and descriptions that distinguish different levels of social participation for all LIBRE Profile domains. An Expert Panel comprised of clinicians, persons with burn injury, and their family members agreed

that the established levels and descriptions represent qualitatively uniquely different social participation abilities. After collapsing five levels initially identified for the Relationships with Family & Friends domain into four levels, quantitative analyses confirmed that mean scores for all levels across the six LIBRE Profile domains were significantly different and were corroborated for both the Calibration and Validation Samples. For all LIBRE Profile domains, level score ranges are consistent with the distribution of IRT-based scores around the mean: Level 1 scores are approximately 2 to 3 *SD* below the mean; Level 2 scores are approximately 1 to 2 *SD* below the mean; Level 3 scores include the mean; and Level 4 scores are approximately 1 to 2 *SD* above the mean.

A review of the distribution of the sample across levels reveals that Level 1 had the lowest percentage for all domains and in both samples. Score ranges associated with Level 1 represent an extremely low level of social participation ability with mean scores that are 2 to 3 *SDs* below the calibration sample mean. The fact that Level 1 sample representation was low may suggest the need to increase the Level 1 upper boundary cut-point to increase sample representation. However, Level 1 score cut-points are associated with a very low level of social participation ability that will identify high-risk individuals. It is also important to consider the effect of time since injury on the sample distribution. For both study samples, approximately 50% of participants were 10 years or more since burn injury. A previous LIBRE Profile study on the impact of time since injury on Social Activities and Social Interaction scores demonstrated that each 10-year increase in the time since burn injury resulted in higher scores. It is likely that a sample comprised of individuals with more recent burn injuries would result in a higher percentage of persons with scores located in Level 1, providing further justification for retaining Level 1 cut-points.

For all domains, except Work & Employment (Calibration Sample), the percentage of scores located in Level 3 was the largest, which is consistent with the observation that Level 3 includes the mean score of 50. In contrast to the other domains, Work & Employment had the highest percentage of the sample at the highest ability level of Level 4 for both samples (47.81%, 35.98). The Work & Employment domain assesses participation at work and was not administered to participants currently not working. A previous LIBRE Profile study revealed that burn survivors identified as working had higher social participation scores than those not working,³³ which may help to explain the relatively higher Level 4 cut-point for this domain.

In addition to establishing level cut-points, the expert panel developed descriptions of social participation levels defined by the cut-points. The panel agreed that the terms “comfort” and “discomfort” were appropriate for describing different ability levels across all domains. Use of the term “comfort” to describe social participation is consistent with findings examining the social experience of disfigurement that classified patients into two groups: “occasionally comfortable” and “always comfortable.”³⁴ The term “comfort” is used to describe the ability of children with juvenile rheumatoid arthritis to engage in social participation.³⁵ Comfort also is related to social self-management among Persons with Parkinson’s Disease.³⁶ Additional terms included in descriptions reflect key aspects of domain item content. For example, descriptions of different levels of social participation in the Work & Employment

domain include descriptions of satisfaction and difficulty, while different levels of social participation in the Family & Friends domain are described in terms of support provided.

Study limitations are primarily due to differences in administering LIBRE Profile items. Calibration Sample participants responded to the entire LIBRE Profile item bank while the Validation Sample responded to fixed-short forms, which are comprised of 10 items from each domain selected from the large item banks. While research has demonstrated the validity of short forms,³⁰ the range of scores derived from short forms is more limited compared with scores based on calibration data. This difference may explain in part the greater variation noted for Calibration Sample scores.

This study developed a tool to interpret LIBRE Profile numeric scores by identifying and describing different levels of social participation ability. The ability to understand and communicate the clinical meaning of LIBRE Profile scores is essential to promoting widespread use of the LIBRE Profile assessment by persons with burn injury, clinicians, and researchers. Future work will conduct a study to determine if persons with burn injury who complete the LIBRE Profile assessment agree with the level and description associated with their numeric scores. Next steps involve integrating LIBRE Profile Levels and descriptions into score reports to provide a context for interpreting LIBRE Profile numeric scores. We also plan to identify and vet resources appropriate for different LIBRE Profile domains and ability levels. Linking these resources to the score report will help burn survivors understand their social participation abilities and provide access to resources that can promote recovery.

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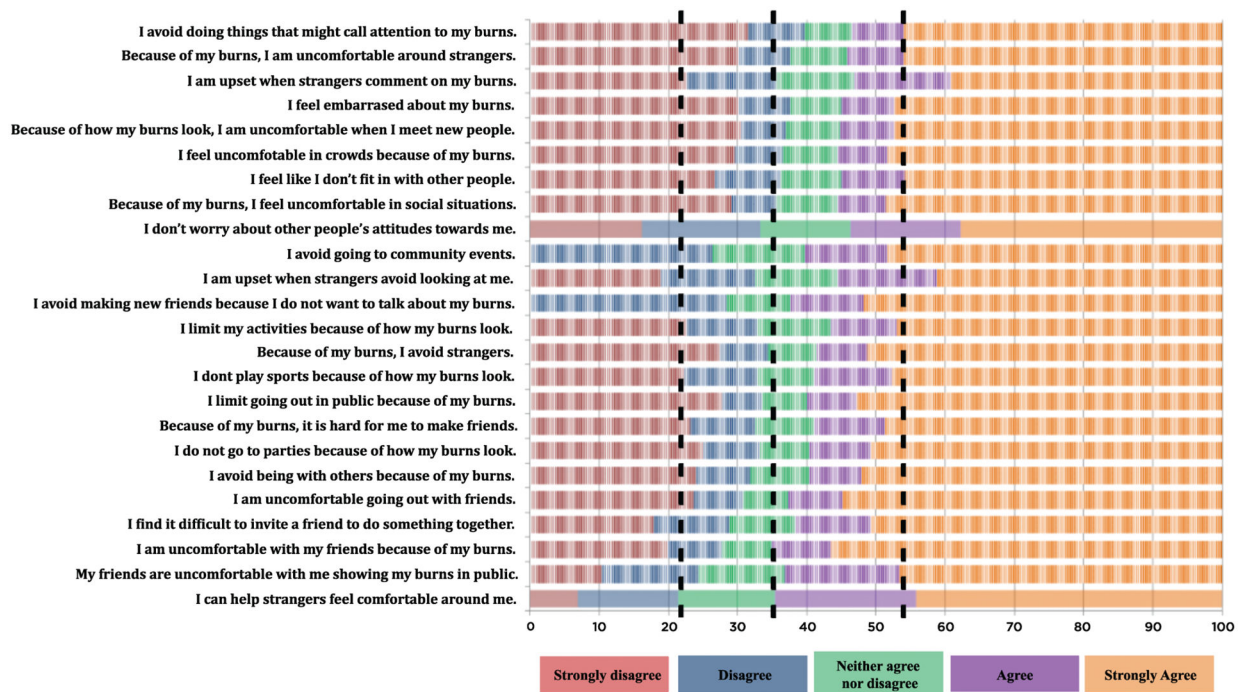


Figure 1. Life Impact Burn Recovery Evaluation (LIBRE) Profile item map with level cut-points: Social Interactions domain. LIBRE, Life Impact Burn Recovery Evaluation.

Table 1.
LIBRE Profile sample demographics: Calibration and Validation Study Samples

	Calibration Sample	Validation Sample
Participants	601	259
Age at time of survey mean years (SD)	44.55 (15.98)	45.5 (14.6)
Sex—male, N (%)	271 (45.09)	105 (40.5)
Missing, N (%)	1 (0.17)	2 (0.8)
Race, N (%)		
White	481 (80.03)	221 (85.3)
Black or African-American	57 (9.48)	16 (6.3)
Other	54 (8.99)	21 (8.1)
Missing	9 (1.50)	1 (0.4)
Hispanic Ethnicity, N (%)	41 (6.82)	19 (7.3)
Missing	8 (1.33)	0
TBSA mean (SD)	40.45 (23.65)	44.5 (25.1)
<10%, N(%)	197 (32.78)	15 (5.79)
10–29%, N (%)	82 (13.64)	41 (15.83)
30–49%, N (%)	158 (26.29)	69 (26.64)
50%, N(%)	165 (27.29)	74 (28.57)
Missing	0	60 (23.17)
Education, N (%)		
Less than high school	4 (0.67)	5 (1.9)
High school/General Education Diploma	244 (40.60)	90 (34.8)
Greater than high school	349 (58.07)	164 (63.3)
Missing	4 (0.67)	0
Time since burn injury		
<3 years	155 (25.79)	61 (23.6)
3–10 years	165 (27.45)	70 (27.0)
>10 years	281 (46.76)	128 (49.4)

LIBRE, Life Impact Burn Recovery Evaluation.

Table 2.

LIBRE Profile scores compared by levels: Calibration and Validation Samples

Domain	Sample	Level 1	Level 2	Level 3	Level 4	F value
Relationships with Family & Friends	\bar{X} (SD)	25.94 (3.47)	39.30 (3.48)	51.22 (4.00)	66.25 (5.84)	F3,596 = 978.28
	Range	19–30	31–44	45–60	61–84	$P < .0001$
	N (%)	17 (2.83)	125 (20.83)	344 (57.33)	114 (19.00)	
	\bar{X} (SD)	27.71 (1.89)	39.58 (3.43)	51.06 (4.06)	63.38 (2.68)	F3,255 = 359.70
Social Activities	Range*	24–30	33–44	45–59	61–68	$P < .0001$
	N (%)*	7 (2.70)	71 (27.41)	157 (60.62)	24 (9.27)	
	\bar{X} (SD)	24.83 (4.58)	39.66 (4.01)	51.91 (3.61)	64.31 (4.72)	F3,597 = 1091.81
	Range	16–28	29–45	46–58	59–72	$P < .0001$
Social Interactions	N (%)	6 (1.00)	150 (24.96)	265 (44.09)	180 (29.95)	
	\bar{X} (SD)	40.11 (3.84)	51.88 (3.89)	63.94 (3.41)	65.94 (3.41)	F2,256 = 591.90
	Range*	29–45	46–58	60–69	60–69	$P < .0001$
	N (%)*	66 (25.48)	139 (53.67)	54 (20.85)	54 (20.85)	
Sexual Relationships [†]	\bar{X} (SD)	17.00 (5.20)	31.51 (3.45)	45.83 (5.16)	60.38 (5.30)	F3,597 = 574.31
	Range	11–20	23–35	36–54	55–72	$P < .0001$
	N (%)	3 (0.50)	68 (11.31)	395 (65.72)	135 (22.46)	
	\bar{X} (SD)	22	31.06 (2.99)	45.53 (4.80)	60.02 (4.02)	F3,255 = 254.88
Romantic Relationships [‡]	Range*	24–35	36–53	55–67	55–67	$P < .0001$
	N (%)*	2 (0.77)	17 (6.56)	182 (70.27)	58 (22.39)	
	\bar{X} (SD)	17.44 (4.85)	38.35 (4.32)	51.49 (4.72)	68.31 (4.95)	F3,415 = 691.73
	Range	15–26	28–44	45–61	62–77	$P < .001$
Social Interactions	N (%)	9 (2.15)	114 (27.21)	238 (56.80)	58 (13.84)	
	\bar{X} (SD)	27	39.18 (3.62)	50.58 (4.63)	66.35 (2.03)	F3,159 = 204.25
	Range*	29–44	45–61	64–68	64–68	$P < .001$
	N (%)*	1 (0.61)	49 (30.06)	96 (58.90)	17 (10.43)	
Romantic Relationships [‡]	\bar{X} (SD)	28.50 (1.85)	37.94 (3.42)	48.38 (3.52)	61.38 (5.71)	F3,376 = 587.19
	Range	25–30	31–42	43–54	55–78	$P < .0001$

Domain	Sample	Level 1	Level 2	Level 3	Level 4	F value
	N (%)	8 (2.11)	93 (24.47)	170 (44.74)	109 (28.68)	
	\bar{x} (SD)	28.2 (2.49)	38.40 (3.32)	48.01 (3.38)	61.06 (3.68)	F3,171 = 397.84
	Range*	24–30	31–42	43–54	56–65	<i>P</i> < .0001
	N (%)	5 (2.86)	42 (24.00)	79 (45.14)	49 (28.00)	
Work & Employment [†]	\bar{x} (SD)	27.71 (2.43)	36.51 (2.92)	45.36 (2.92)	57.59 (4.97)	F3,316 = 481.84
	Range	24–30	31–40	41–50	51–65	<i>P</i> < .0001
	N (%)	7 (2.19)	47 (14.69)	113 (35.31)	153 (47.81)	
	\bar{x} (SD)		36.63 (2.59)	45.53 (3.41)	57.76 (4.79)	F2,161 = 320.56
	Range*		32–40	41–50	52–65	<i>P</i> < .0001
	N (%)		27 (16.46)	78 (47.56)	59 (35.98)	

\bar{x} = mean score; N = number; LIBRE, Life Impact Burn Recovery Evaluation.

* Validation Sample.

[†] Domains completed only by participants engaged in activities.

Table 3.

Initial LIBRE Profile level narrative descriptions

Domain	Initial Narrative Terminology	Severity
Relationships with Family & Friends	Difficulties, support, comfort, and enjoyment	1 Many difficulties, little support, and comfort
		2 Some difficulties, inconsistent support, and comfort
		3 Some enjoyment, comfort, and support
		4 A lot of enjoyment, comfort, and support
Social Activities	Limitation	1 Severely limited
		2 Moderately limited
		3 Mildly limited
		4 Few limitations
Social Interactions	Discomfort, avoidance, and acceptance	1 Severe discomfort and avoidance
		2 Moderate avoidance and uncomfortable
		3 Mild avoidance, uncomfortable, and some acceptance
		4 Does not avoid, easily interacts, and acceptance
Romantic Relationships	Uncomfortable	1 Uncomfortable
		2 Somewhat uncomfortable
		3 Somewhat comfortable
		4 Very comfortable
Sexual Relationships	Enjoyment	1 Do not enjoy
		2 Somewhat enjoy
		3 Enjoy
		4 Very much enjoy
Work & Employment	Difficulties, challenges, satisfaction, and comfort	1 Many difficulties, challenges with performance, satisfaction, and comfort
		2 Some difficulties, challenges, and satisfaction
		3 Generally satisfied at work and with performance and comfort
		4 Highly satisfied, high satisfaction with performance, and comfort

LIBRE, Life Impact Burn Recovery Evaluation.

Table 4.

Final consensus: LIBRE Profile levels and descriptions

Domain Levels	Score Interval	Description
Relationships with Family & Friends may involve: spending time together, close relationships, getting along.		
1	30	I am very uncomfortable in my relationships with family and friends. I get very little or no support.
2	31–44	I am somewhat uncomfortable in my relationships with family and friends. I get some support.
3	45–60	I am somewhat comfortable in my relationships with family and friends. I get quite a bit of support.
4	61	I am very comfortable in my relationships with family and friends. I get a lot of support.
Social Activities may involve: outdoor activities, going to community events, doing things with family and friends.		
1	28	I am very uncomfortable and almost always avoid participating in social activities.
2	29–45	I am moderately uncomfortable and often avoid participating in social activities.
3	46–58	I am mildly uncomfortable and sometimes avoid participating in social activities.
4	59	I am comfortable and hardly ever avoid participating in social activities.
Social Interactions may involve: meeting strangers, going out with friends, being in public		
1	22	I am very uncomfortable and almost always avoid social interactions. I am very much troubled by my appearance and how others react to me.
2	23–35	I am moderately uncomfortable and often avoid social interactions. I am quite a bit troubled by my appearance and how others react to me.
3	36–54	I am mildly uncomfortable and sometimes avoid social interactions. I am somewhat troubled by my appearance and how others react to me.
4	55	I am comfortable and hardly ever avoid social interactions. I am a little bit or not at all troubled by my appearance and how others react to me.
Romantic Relationships may involve: talking openly with my partner, doing things with my partner, trusting my partner and feeling secure in my relationship, loving and being loved		
1	30	I am very uncomfortable in my romantic relationship(s).
2	31–42	I am somewhat uncomfortable in my romantic relationship(s).
3	43–54	I am somewhat comfortable in my romantic relationship(s).
4	55	I am very comfortable in my romantic relationship(s).
Sexual Relationships may involve: interest in sex, ability to have an orgasm, emotional closeness, being able to do sexual activities		
1	27	I am very uncomfortable in my sexual relationship(s). My sexual relationship(s) is (are) not satisfying.
2	28–44	I am somewhat uncomfortable in my sexual relationship(s). My sexual relationship(s) is (are) somewhat satisfying.
3	45–61	I am somewhat comfortable in my sexual relationship(s). My sexual relationship(s) is (are) satisfying.
4	62	I am very comfortable in my sexual relationship(s). My sexual relationship(s) is (are) very satisfying.
Work & Employment may involve: going to my job, keeping up with my work responsibilities, learning new things, relationships with people at work		
1	30	I am very unsatisfied and uncomfortable at my job. I have many difficulties doing my work.
2	31–40	I am somewhat unsatisfied and uncomfortable at my job. I have some difficulty doing my work.

Domain Levels	Score Interval	Description
3	41–50	I am somewhat satisfied and comfortable at my job. I have few difficulties doing my work.
4	51	I am very satisfied and comfortable at my job. I have hardly any difficulty doing my work.

LJBRE, Life Impact Burn Recovery Evaluation.