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Development of the Preschool Life Impact Burn Recovery Evaluation (PS-LIBRE$_{1–5}$) Profile

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Abstract

Physical, social, and psychological outcomes have been identified as relevant to the rehabilitation process of children with burn injuries. Existing legacy measures are limited in item content and only cover a few constructs. Condition-specific outcomes are highly relevant to gauge early growth and development. Computerized adaptive tests (CATs) leveraging advanced psychometric technologies minimize respondent burden. This project developed PS-LIBRE$_{1–5}$ Profile CAT (Preschool Life Impact Burn Recovery Evaluation) to measure relevant postburn outcomes in

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Author Contribution Authors KFP and PN contributed to conceptualization, data curation, visualization, and writing of original draft. Additionally, KFP was responsible for investigation, project administration, and supervision. Author PN was additionally responsible for formal analysis, methodology, and software creation. Authors LEK and CMR made significant contribution to methodology as well. Authors PW, KSR, TP, JCS, LEF, and CMR also contributed to conceptualization and supervision. Funding was secured by PW, TP, JCS, LEK, and CMR. KES, CAR, SLR, and MBM also contributed to investigation. All authors read, reviewed, and approved the final manuscript.

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children aged one to five. Responses to the field-tested PS-LIBRE$_{1–5}$ Profile (188 items) were measured on a scale of frequency or ability. Scores were coded from 0 to 4 where higher scores reflected better functioning. Factor analysis identified the items retained in the final item bank of each scale. CAT simulations were conducted to estimate the mean score of each scale. The simulated CAT score and full item bank scores were compared based upon the score range, ceiling and floor effects, and marginal reliabilities. The child mean age was 3.0 ± 1.5 years (n = 500). Average burn size and time since burn injury were 4.2% TBSA and 1.1 years, respectively. Psychometric analysis resulted in eight scales: *Physical*, *Communication and Language*, *Emotional Wellbeing*, *Mood*, *Anxiety*, *Peer Acceptance*, *Play*, and *Peer Relations*. Ceiling effects were acceptable at <13% for all scales. Marginal reliabilities of the CATs were credible. The PS-LIBRE$_{1–5}$ Profile CAT contains 111 items, and is a comprehensive measure that captures physical, communication and language, psychological, and social functioning of preschool burn survivors.

Keywords

burn injury; children; computerized adaptive test; life impact burn recovery evaluation; patient-reported outcome measure

INTRODUCTION

The optimization of treatments aimed toward improving post-burn function requires precise measurement across biological, personal, and social aspects for individuals who have survived a burn injury and are living with its consequences.[1–3] Researchers face a challenge in developing measures of health-related quality of life in children younger than 5 years of age. During this age span, there is a rapid change in the rate of development. Overall, <30% of the problems with emotional disturbance, learning physical and health disabilities are identified before the age of five.[4] Factors such as the complexity of the problem and the association with other health-related developmental concerns are predictors of the age at which the issue is identified.[4] Previous knowledge of the normal developmental stages is needed as the evaluation of items depend on the abilities acquired through time.

There are many tools that assess the developmental status of children at different stages. In addition, previous burn literature has utilized widely used generic measurement tools when reporting outcomes; however, these instruments lack the nuances associated with experiences following a burn injury. The Burn Outcome Questionnaire (BOQ$_{0–4}$) is the only condition-specific instrument for this age group of children under five. However, the use of fixed-length measurements in clinical practice increases respondent burden due to the need to answer all items within the scale to obtain a score. This increases the length of time taken to complete the questionnaire. Instrument developers also face difficult choices between comprehensiveness, breadth, precision, and dimensionality. As a result, the limited item content of the BOQ$_{0–4}$ does not adequately address the wide range of formative development.

A comprehensive instrument that measures functioning across multiple domains is critical to the understanding of burn survivors' functioning. In addition, these instruments must

cover important developmental milestones taking into account the added complexities of burn injuries. Previously, LIBRE (Life Impact Burn Recovery Evaluation) Profile was developed and validated for use in adult burn survivors with a focus on measuring social participation.[5–7] The overall goal of the LIBRE project is to replicate its computerized adaptive test (CAT) methodologies across different age cohorts of 1–5, 5–12, 12–19, and over 18. The use of a CAT can provide important opportunities for tracking recovery at the individual level with reasonable precision in this population.[8,9] CATs allow for brief but accurate patient (or proxy) reported outcome measurements (PROM).[10–14]

This work applies item response theory (IRT) methods and CAT methodology to precisely functioning affected in children with burn injuries with a specific focus on including age-appropriate items. This work contributes towards the LIBRE project by reporting on the psychometric evaluation of a new measure: Preschool$_{1–5}$ LIBRE (PS-LIBRE$_{1–5}$) Profile CAT. This measure provides clinicians, patients, and their caregivers (such as parents and families) a means to profile the burn survivor's current recovery and henceforth guide future interventions as necessary.

METHODS

Conceptual model and item development

The previously developed conceptual model and item pool of the PS-LIBRE$_{1–5}$ instruments'[15,16] has items with recall period of "In the past 7 days" and item stem of "My child." Response categories for item pool are measured on the difficulty (unable to do, with much difficulty, with some difficulty, with little difficulty, with no difficulty) or the frequency (never, rarely, sometimes, often, always) scale. Negatively phrased items are recoded such that higher score reflected better functioning.

Sampling methods and data collection

The PS-LIBRE$_{1–5}$ instrument (188 items) was field-tested among parents (legal guardians and caregivers, hereinafter referred to as parents) of children: 1) between the ages of 1 and 5 years (inclusive) at time of assessment, 2) with a burn injury (of any size and at any location), and 3) discharged from inpatient care. Parents (≥18 years) additionally needed to speak and understand English. Parents were recruited from Shriners Children's in Boston, Northern California, and Ohio, and indirect recruitment in the larger burn community. Demographic and clinical characteristics of the burn injury were also collected.

The study was approved by the Western Institutional Review Board-Copernicus Group (#20183471) and all participants provided verbal informed consent.

Data analysis

The methods described below are guided by methods described in a previous manuscript[7] for the adult burn survivors. Those steps are replicated (as applicable) in the current work for preschool-aged burn survivors. Additional details are described in online supplemental information (Supplement 1).

Unidimensionality—We explored the unidimensionality within each domain to determine if the ratio of the first and second eigenvalues were >4 and the Confirmatory Factor Analysis (CFA) model was with acceptable model fit. If the domain(s) did not fit the unidimensional model, we determined the number of unidimensional factors within each domain using parallel analysis (PA). We applied exploratory factor analysis to extract number of factors determined from PA based on the unweighted least squares method, followed by Promax rotation. We removed the items with percent responses for one category >90% and items highly correlated (>0.9) with other items. We determined the final model when the model fit criteria met the CFA acceptable criteria and there was no residual correlation value >0.2.[17–21]

Item fit and response category function—We calibrated the emerged items from each factor using the partial credit model. We collapsed categories of items with disordered threshold parameters and the number of participants within category <10. To examine the monotonicity, we also examined whether the mean scores were increasing as the category score increased (e.g., the mean score in the first category should be less than that in the second category).

Differential item functioning—Differential item functioning (DIF) is a method of analysis to determine if subgroups of burn survivors at the same ability level demonstrate different probabilities of responses to a given item.[22] DIF was examined for age (≤3 vs >3), burn size (≤1 vs >1), sex (male vs female), parent education level (bachelor and above vs lower education), hand burn (yes vs no), face burn (yes vs no), and foot burn (yes vs no) by calculating the DIF contrast and corresponding standard error.

Psychometric evaluation—Standard scores for the PS-LIBRE$_{1–5}$ Profile CAT were transformed to a *T*-score distribution where the mean = 50, SD = 10, with the lower scores corresponding to poorer performance on the scale. The value of marginal reliability ranges from 0 to 1, where higher value means higher reliability.[23] The percentage of participants whose score was located in the reliability ≥0.9, 0.8 and 0.7 score range was calculated.

Computerized adaptive test—CAT simulations were conducted using the calibration sample. The CAT program selected the first item with the highest information function value around the mean score of a specific scale. A minimum of five items and a maximum of ten items with reliability ≥0.90 was used as the stopping rule in the algorithm. The simulated CAT score and the full item bank score were compared based upon the score range, ceiling and floor effects, and marginal reliability. The ratio between the average number of administered CAT items and the number of items in the full item bank were also calculated. The time saved in the CAT simulations compared to the full item bank was estimated, assuming a completion rate of three items per minute.[24]

We converted the logit score from 50 CAT simulation studies to the *T* score and calculated the average standard error at each fixed score point. A plot was generated to compare the actual person score distribution with the mean score standard error.

The factor analyses were conducted in Mplus,[25] the IRT and DIF analyses in WINSTEPS,[26] and the CAT simulations in SAS.

RESULTS

The sample included 500 parents of burn survivors. The child mean age was 3.03 (SD 1.40) years and 55.20% were male. The mean TBSA was 4.17% and the average time since burn injury was 1.10 years (Table 1).

Unidimenstionality

Eight factor solution emerged, which we titled for *Physical* (31 items), *Communication and Language* (21 items), *Emotional Wellbeing* (17 items), *Mood* (11 items), *Anxiety* (13 items), *Peer Acceptance* (7 items), *Play* (8 items), and *Peer Relations* (10 items). Unidimensional factor analysis was used for *Physical* and *Communication and Language* scales whereas PA was used for the remaining scales. A total of 69 items failed to load onto a factor in a conceptually interpretable way and were removed from further analyses. The resulting statistics for factor analysis are listed in Table 2.

Item fit and response category functioning

In the IRT analyses, seven misfitting items were removed from the item banks. All other items achieved an acceptable fit. Final item content of all eight factor loadings is listed in SI 2, along with the final number of items in each scale listed in Figure 1.

For the 111 fitted items, we identified 107 items that showed a response category that was not dominant for any range of scores or the sample size within category was <10 (SI 3). The reasons for nondominance in the middle or lower category may be because the item content is clear and therefore, few participants selected the neutral option. SI 4 describes the collapsed pattern for each scale. These items were retained in the item bank for three reasons: 1) we had initially collapsed several of the responses categories at the beginning of the analysis, 2) all items showed acceptable fit, and 3) the poorer performing response categories were at lower score ranges, and we did not want to decrease the ability of the measure to detect the respondents at the lower end of the scale—the population which would be in most need of further clinical support or interventions.

There was no item with Infit NMSQ >1.4, and percent of variance explained by the Rasch measurement model ranged from 50% (*Anxiety*) to 96% (*Communication and Language*). The 1st contrast for all scales is <2 for expected *Physical* and *Communication and Language* scales, but because Rasch measurement model explained over 90% of the variance for those two scales, we concluded those are unidimensional scales. Percent of ceiling effects ranged from 0.8% to 12.3% (<15% criteria); percent of floor effect is trivial (<1%).

For two items, the mean score reversing happened in lower score categories. Those categories had a smaller sample size of 14 and 18, which may have contributed to the mean score reversal. However, the statistical tests supported the interpretation that there was no violation of monotonicity. In further work, one might expand the sample to individuals

with hypothesized lower scores (for example, those with a recent burn) to have sufficient sample size at the lower end of the scales.

Differential item functioning

Thirteen items showed severe DIF (SI 2). One item showed DIF by "age at survey completion" and "face burn," and as there were only 72 participants with "face burn," sample size would be even smaller if we split this item by both variables. Therefore, we only split this item for DIF by "age at survey completion." All items were retained in the item bank and were given different item parameter values for different age subgroups (as new items for each of the age groups). An example item (SI 5) demonstrates the difference in prediction score based on adjusted and nonadjusted models. We examined the sample size for each category for new created DIF items and collapsed the categories if necessary.

Psychometric evaluation

Figure 2 presents the plots of the item threshold parameter and sample scores for each scale (the vertical lines are the 25%, 50% and 75% percentiles of the sample scores). In general, the item threshold distributed towards the lower end of the scale compared to the sample score distribution, and there was poorer item coverage in the relatively smaller item banks.

The marginal reliability of the full item bank and CAT are mentioned in Table 3. There were no participants with score reliability >0.9 in *Mood*, *Anxiety,* and *Peer Acceptance* and the percentages of participants with score reliability >0.9 for other scales ranged from 15% to 85%. Table 4 displays results from the IRT analysis comparing the full item bank and CAT simulations. For *Peer Acceptance*, *Play*, *Mood*, and *Anxiety* scales, the full item bank will be administered (ie, CAT will not be created for these scales due to the number of items in these scales and the percentage of participants who required the maximum administration of 10 items to generate a CAT score). This indicated that the CAT could save about 14 min with administering the CAT (10 min) compared to the full item bank (24 min) assuming it requires 1 minute for 3 items.[7]

Figure 3 illustrates the score distribution for each scale in the study sample and the average standard error from the simulated sample with the percent of the sample with reliability scores >0.9, 0.8 are shown in Table 3. The figures illustrate that the score ranges where the sample fell outside of 0.9 reliability were primarily focused on *higher* scores, revealing that burn survivors with lower scores (who would be the target of interventions and clinical work) achieved highly reliable scores. For individuals who were at an ability level of approximately one standard deviation *above* the mean, scores were somewhat less reliable.

DISCUSSION

The PS-LIBRE$_{1–5}$ Profile is a new PROM that assesses physical, communication and language, psychological, and social functioning of preschool burn survivors. Eight unidimensional scales were identified in this study with item content ranging from low to high functioning: *Physical*, *Communication and Language*, *Emotional Wellbeing*, *Mood*, *Anxiety*, *Peer Acceptance*, *Play*, and *Peer Relations*. Of the final 111 items from the eight scales of the PS-LIBRE$_{1–5}$ Profile, only 13 items displayed severe DIF, suggesting

that overall, the items function similarly across the different groups tested. The marginal reliability of the full item bank and CAT revealed credible reliability for a wide range of scores for each of the eight scales. The percentage of score reliabilities >0.90 also indicated highly acceptable levels.

The *Physical* scale measures observable gross motor (walking, climbing, and moving around) and fine motor (grasping and releasing objects, kicking, and turning) functioning.[27] Items ask parents about their child's ability to perform tasks and activities of daily living such as changing and maintaining body positions, moving objects with lower extremities, and getting dressed. Disseldorp et al. found that functional independence is impacted in children with burn injuries.[28] Mobility problems have been associated with less competency in carrying out activities.[29] This improves at 3 and 6 month follow-ups. Another study in preschool children has reported appropriate range of motion pertaining to self-care skills.[30] Given that burn injury can impact mobility during the acute phase, it is important to include the measurement of physical functioning. This becomes especially pertinent in this age group where children are just beginning to acquire skills required for activity and movement.

The *Communication and Language* scale measures the ability to receive and produce meaning in the years that children are first acquiring this skill. Items ask about children's ability to communicate literal and implied messages through speaking as well as nonverbal messages through gestures, symbols and drawing. Kazis et al. reported better communication skills compared to nonburned individuals, postulating this finding to increased interaction with adults and healthcare professionals compared to an age-matched population.[31] Alternatively, acquiring language skills was delayed longer than 1-year post-burn in pediatric burn survivors.[30] Developmental risk is additionally noted in young children with traumatic stress whereby acute stress during hospitalization was related to less vocalizations and smiles at 1 month postdischarge.[32] These findings indicate the need for appropriate measurement of communication as it develops in this age group.

The *Emotional Wellbeing* scale measures instances during which children regulate their behavior. Items ask about negative emotionality, sleeping problems, aggression, and defiance. The *Mood* scale measures frequency of eating behaviors, depression, and withdrawal. Items also ask about positive emotionality such as empathy, optimism, and resilience. The *Anxiety* scale measures the frequency of the child displaying anxious and trauma related behaviors. Items ask about separation distress, fear, avoidance, and reenactment. Previous research reports prevalence of anxiety, separation distress, trauma reactions, behavioral problems, and depression in months following burn injury.[24,33–43] At 1-year post burn, significant traumatic stress reactions range between 25% and 30% and lifetime rates of depression are comparatively higher than the general population.[44–46] Alternatively, few other studies report less anxiety and withdrawal behaviors in the long-term compared to younger children.[47–49] These scales are henceforth important as psychological functioning is associated with age and indicative of later functioning.[33,34]

The *Peer Acceptance* scale measures the frequency of children getting along with peers. Items ask about observable connections with peers, including making friends or experiencing bullying. The *Play* scale measures frequency of the child engaging in play

activities. Items ask about child imitating play behaviors as well as pretend-play. The *Peer Relations* scale measures frequency of the child participating in play activities alongside peers. Items ask about observable connections and getting along with peers during play activities. Previous research report positive functioning overtime with children being more active and social[47,49] whereas other studies report less competence with social interactions[48] in children up to 13-year post-burn.[50,51] High levels of bullying was also reported.[52] With previous research for this domain being limited in this age group, the inclusion of these scales will allow providers and caregivers to better understand social competence and peer relations in young burn survivors.

Strengths and limitations

This work describes the development of a set of CATs that provide framework for capturing the post-injury functioning of preschool burn survivors in their community. Prior work focused on generic measures that are better suited to measure functioning in individual constructs (ie, measures only aim to assess one outcome at a time). A CAT developed for purposes of monitoring recovery in preschool burn survivors can provide clinically nuanced assessments. Addressing multidimensional development in young children is important in burn care to introduce effective interventions in a timely manner. However, only two studies have previously considered development in children with burns.[30,53] This instrument is therefore unique such that we have considered the growth and development during these formative years with adjustments made to this metric that consider the condition-specific limitations and constraints posed by those with acute burn injuries. Furthermore, item content is clinically focused to allow monitoring trajectories of recovery from 1 to 5 years of age and each of the scales are age relevant. Previous research has generally reported on findings for larger age cohorts such as 0–18, 5–18, etc., making it difficult to attribute findings specific to preschool children younger than six. Burn-specific assessments like the PS-LIBRE$_{1–5}$ will provide more detail for functioning and developmental delays across multiple domains that are specific to burn survivors in this age group. This instrument will additionally take into consideration the challenges and resiliency among pediatric burn survivors that generic instruments which are limited to assessing one construct may fail to capture.[37]

This study includes a number of important limitations. First, the field-tested study employed a convenience sampling method where the participants were recruited from outpatient burn clinics. While not random, the sample is highly heterogeneous in terms of socio-demographic and clinical characteristics. The sample included clinics across the nation and allows for some generalizability. The results also demonstrated that the scores generated from the CAT and simulations were closely aligned suggesting that the scores were highly reliable. Second, a previous study compared similarities and differences in parent and child reports in older children.[54] Considering the young age group that the PS-LIBRE$_{1–5}$ is intended for, parents are the only available sources of information. However, it does limit reliability if a parent has not observed a specific behavior in their child.

Finally, the Classification Accuracy of *Peer Acceptance* showed a normal distribution measurement error around the center of each score point. If we pick one cut point score,

every score point with larger (or lower) value than cut point score will have higher probability to be classified as score above (or below) the cut point score.[55] For example, on average, the cut-point score of −2 will have 99% of accuracy of classify participants below or above −2 based on the observed scores from the sample score distribution (SI 6). Similarly, we have over 90% expected accuracy to classify participants below or above cut points if the cut-point score is <0 (which is about one SD below the mean score). *Peer Acceptance* scale will have higher accuracy of classifying participants at lower cut-point scores, but not at the higher-end of cut-point scores.

CONCLUSION

The PS-LIBRE$_{1–5}$ instrument measures functioning across eight scales: *Physical*, *Communication and Language*, *Emotional Wellbeing*, *Mood*, *Anxiety*, *Peer Acceptance*, *Play*, and *Peer Relations*. The CAT algorithm is adjusted for specific items that demonstrated significant differences in item functioning such that scores will account for the child's age. The development of a burn specific tool will provide clinicians with a better focus on areas of particular concern, and a better way to evaluate future interventions and treatment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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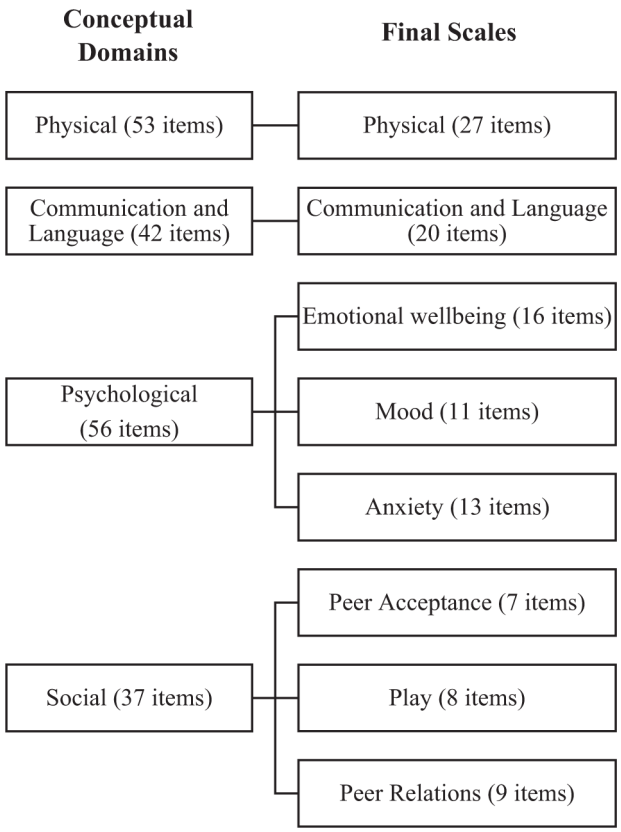

Figure 1.
Hypothesized Conceptual Domains and Final Scales of the Preschool$_{1–5}$ LIBRE Profile

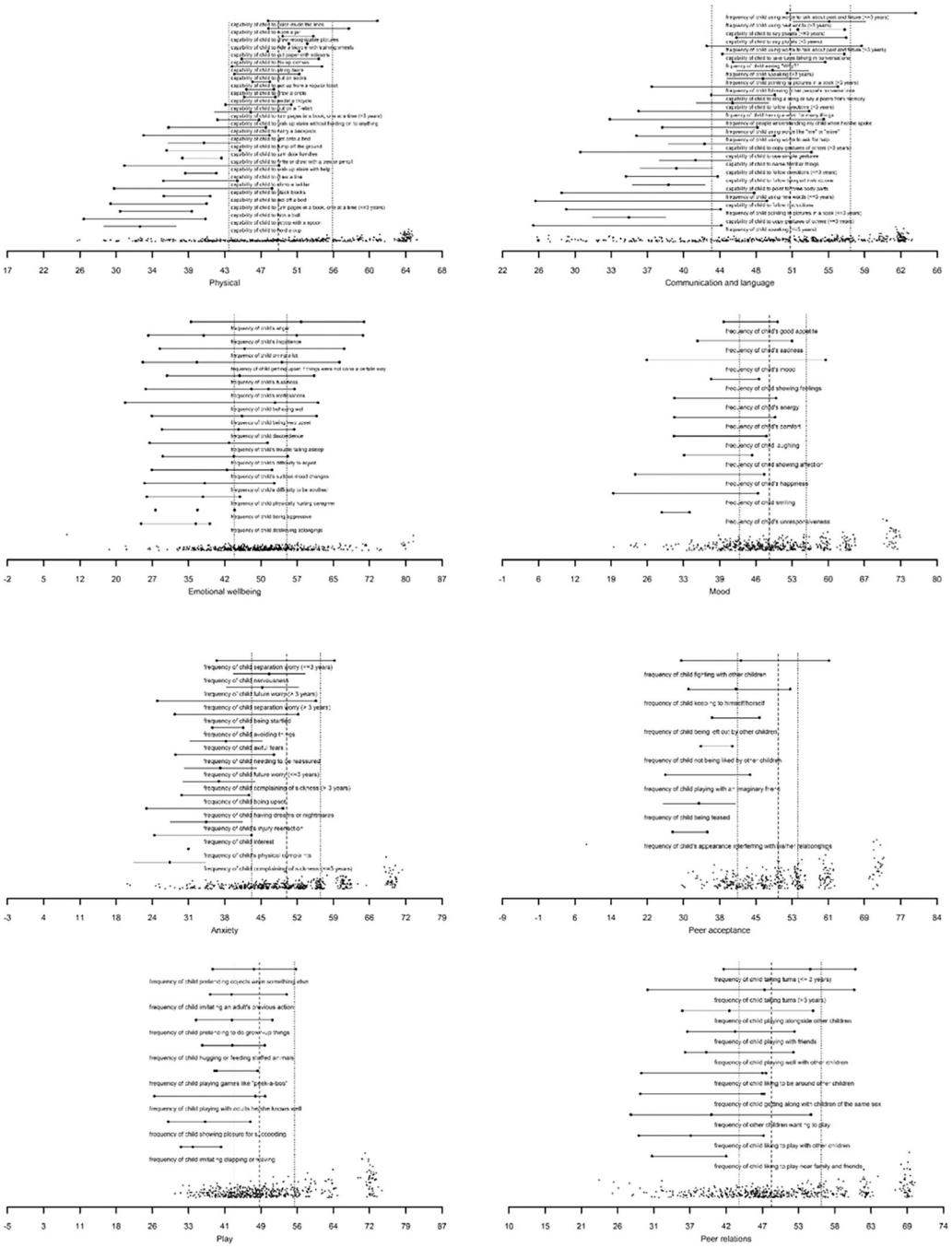

Figure 2.
Distributions of the Item Threshold Parameter and Sample Scores

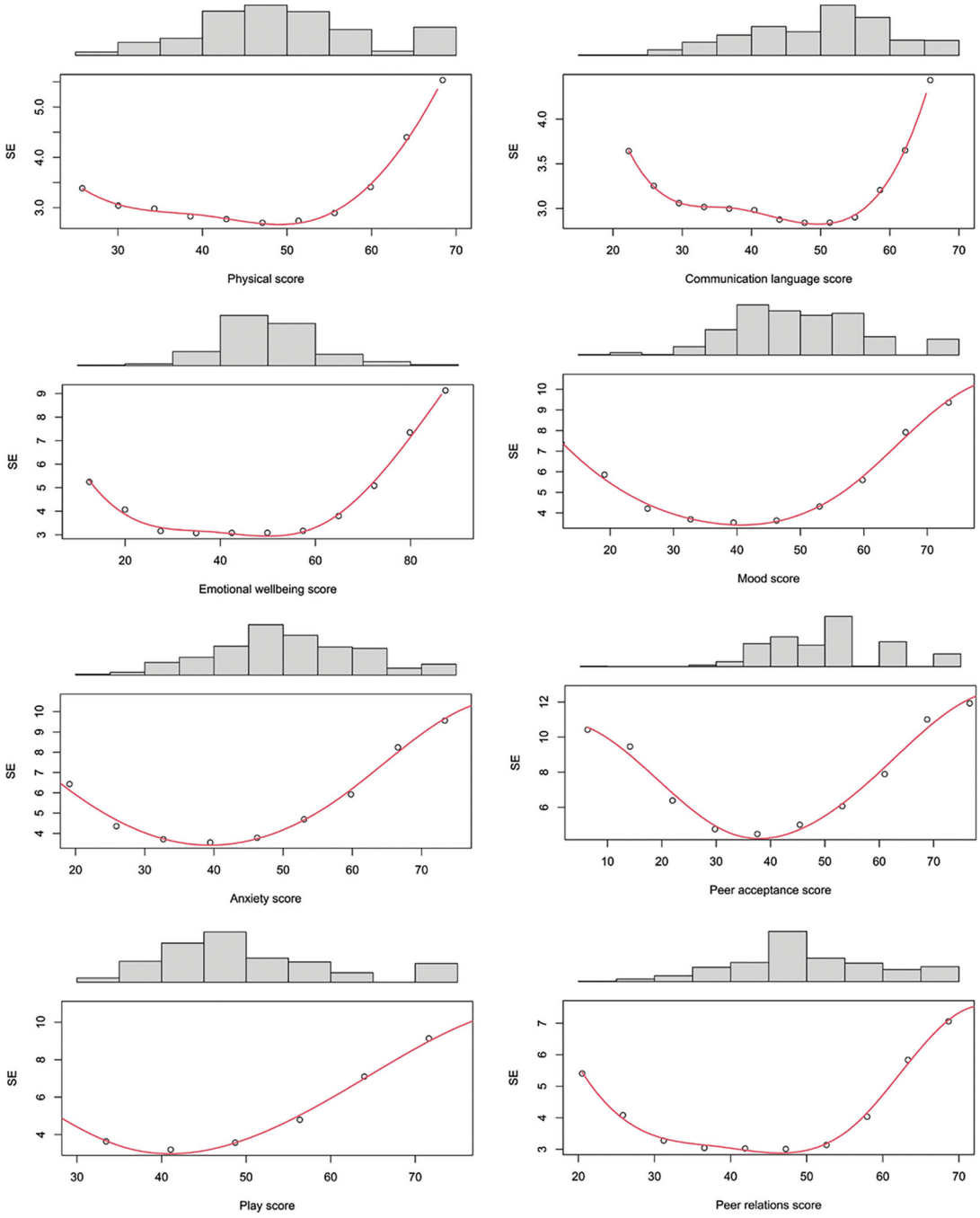

Figure 3.
Score Distribution and Mean of CAT Score Standard Error at Each Fixed Point

Table 1.

Sample Demographics

Characteristic	*N*	%
Age mean ± SD	3.03 ± 1.40	
Gender		
Male	276	55.20
Female	223	44.60
Missing	1	
Race		
White	337	67.40
Black/African American	43	8.60
Asian	32	6.45
Other*	88	17.60
Hispanic ethnicity		
Yes	91	18.20
No	406	81.20
Missing	3	0.60
Education		
Less than bachelor's	221	44.20
Bachelor's or higher	277	55.40
Missing	2	0.40
Time since burn injury mean ± SD	1.10 ± 1.32	
0 to <3 months	171	34.20
3 to <6 months	78	15.60
6 to <12 months	62	12.40
>12 months	189	37.80
Missing	1	0.20
TBSA mean ± SD	4.17 ± 7.80	
0 to ≤5	405	81.00
5 to ≤15	67	13.40
>15	27	5.40
Missing	1	0.20
Self-administration (internet)	488	97.60
Self-administration (paper)	5	1.00
Interview administration (telephone)	7	1.40

*Includes 1) American Indian or Alaskan Native, 2) Native Hawaiian or Other Pacific Islander, 3) Missing, or 4) Biracial (White, Asian, and/or Black or African American).

Table 2.

Internal Consistency, Ratio of the 1st and 2nd Eigenvalue and CFA Results for Each Domain

	Ratio between the first and second eigenvalues	CFI	TLI	RMSEA	Cronbach's Alpha
Physical	12.41	0.98	0.979	0.06	0.96
Communication and Language	13.17	0.99	0.985	0.07	0.96
Emotional Wellbeing	6.75	0.94	0.93	0.09	0.91
Mood	4.83	0.97	0.96	0.08	0.79
Anxiety	5.98	0.94	0.93	0.08	0.84
Peer Acceptance	3.79	0.98	0.97	0.05	0.55
Play	4.38	0.97	0.96	0.09	0.79
Peer Relations	8.85	0.98	0.98	0.10	0.90

Unidimensionality: the ratio between the first and second eigenvalue (>4 Comparative fit index (CFI), Tucker-Lewis Index (TLI), and Root mean square error of approximation (RMSEA). We determined acceptable model fit as CFI and TLI ≥ 0.9, and RMSEA ≤ 0.1.

Table 3.

Descriptive Statistics for Simulated CATs and Full Item Bank

Domain	Mode	N[a]	Marginal reliability	% Ceiling	% Floor	% sample score reliability >0.9	% sample score reliability >0.8	% sample score reliability >0.7
Physical	Item bank	498	0.92	11.65	0	-	-	-
	CAT	496	0.87	12.30	0	79.52	87.55	87.55
Communication and language	Item bank	498	0.94	6.22	0.20	-	-	-
	CAT	497	0.90	7.04	0.20	85.14	92.57	92.77
Emotional wellbeing	Item bank	498	0.91	0.80	0	-	-	-
	CAT	498	0.87	0.80	0	49.80	95.58	97.19
Mood	Item bank	498	0.77	6.43	0	0	68.07	86.14
Anxiety	Item bank	498	0.71	8.03	0	0	54.22	79.92
Peer acceptance	Item bank	347	0.56	7.49	0.20	0	14.70	46.40
Play	Item bank	498	0.74	10.40	0	15.26	73.90	84.74
Peer relations	Item bank	497	0.84	9.44	0	-	-	-
	CAT	484	0.82	9.30	0	50.50	82.90	90.54

[a]The sample size in this table is based on the subjects took at least 10 items in physical, communication and language, emotional wellbeing; and 9 items for peer relations. The stopping rule of the CAT is minimal number of items = 5, maximum number of items = 10 (9 for peer relations) and reliability of 0.9. To have fair comparison among subjects in CAT scores and full item bank scores, we required that the subjects being compared should have taken at least 10 items within each scale (or 9 items in peer relations).

Table 4.

Comparison of the Simulated CAT and Full Item Bank

Domain	Mean (SD) number items in simulated CAT	Mean (SD) score of simulated CAT	Correlation between simulated CAT and full item banks	Ratio of average CAT items and full item bank	Mean estimated time in minutes using simulated CAT[a]
Physical	6.36 (2.02)	49.51 (9.91)	0.97	0.24	2.12
Communication and language	6.26 (1.79)	49.54 (10.14)	0.98	0.31	2.09
Emotional wellbeing	9.59 (0.49)	50.13 (9.93)	0.98	0.60	3.20
Peer relations	7.16 (1.55)	50.24 (9.81)	0.99	0.80	2.39

[a]Assuming 1/3 min per item.