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The Development and Validity of the Adult Burn Outcome Questionnaire Short Form

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Abstract

Patient Reported Outcome Measures (PROMs) are useful for understanding the health needs and outcomes of the general public. We aim to develop a burn-specific metric—Adult Burn Outcome Questionnaire (ABOQ)—that is brief and can be administered electronically to all burn survivors over the age of 18. The 14-item ABOQ was developed from the already validated Young Adult Burn Outcome Questionnaire (YABOQ) long form. The ABOQ questionnaire, along with Patient-Reported Outcomes Measurement System-10 (PROMIS-10), was administered to 120 outpatient burn survivors at three hospitals. Clinical validity of the ABOQ was measured by testing associations between ABOQ items and burn size, the PROMIS-10 generic items and composite scales using correlational analysis including multivariate canonical analysis. Nine out of 14 ABOQ items were significantly correlated with burn size (correlations ranging from −0.25 to −0.46, $P < .01$). The canonical correlation between ABOQ and burn size was 0.68 ($P = .0002$). The overall canonical correlation between two instruments was also significant ($P < .0001$). At the item level, at least 25% of the variation in each of the five ABOQ items could be explained by

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CONFLICT OF INTEREST STATEMENT

The results of this study were not contingent on sponsor approval and do not necessarily represent the views and opinions of the sponsoring organizations. The authors have no conflicts of interest to declare.

PROMIS-10 items and composite scores, while six other items could only be accounted for by less than 15% of the variation. ABOQ short form assessment can be used to efficiently measure burn outcomes across a range of relevant clinical domains with credible validity. A large proportion of the variation in ABOQ scores was not accounted for by PROMIS-10, suggesting that ABOQ provided additional health-related information specifically for the burn population beyond the generic instrument.

A structured approach to clinic visits of the burn survivor enables the clinician to perform a more efficient and thorough evaluation of the patient's situation. Patient Reported Outcome Measures (PROMs) are tools that provide structure to the clinical visit through assessments that are patient centric. PROMs have been used in clinical research and are useful to understand the health needs of a population, as metrics for quality improvement efforts, and to optimize treatment regimens. Recent work, however, demonstrates that PROMs also have the potential to enhance communication between patients and providers in individual clinical settings.[1,2] Furthermore, long-collected clinical registries can be broadened in their coverage and their information leveraged to benchmark burn recovery through the use of PROMs.[3,4]

The implementation of this concept in clinical practice requires careful consideration of the instruments administered. The choice of questionnaire(s) to be administered to the patient for use in a clinic visit can be tailored to the individual situation. Ideally, this would include administration of a combination of generic and condition-specific PROMs.[2] Generic instruments such as the 36-item Short Form Survey (SF-36) and the Patient-Reported Outcomes Measurement System (PROMIS) have been used to assess recovery in burn survivors.[5–7] While generic instruments are useful for comparing disabilities and symptoms across populations with different conditions, condition-specific PROMs can provide unique information related to a known set of symptoms and outcomes for a particular condition, such as burns. Condition-specific instruments are increasingly used for patient assessment and improvement of health care quality in burn care.

Several condition-specific PROMs have been used in the field of burn care.[8] The Burn Specific Health Scale-Brief (BSHS-B) is widely used, but has methodological issues with scoring and psychometric properties, leading to problems with reliability and validity.[9–11] The age-based Shriners Hospitals for Children/American Burn Association Burn Outcome Questionnaires (BOQs) are reliable and valid tools, but there is no BOQ suitable for administration to adults over the age of 30.[8]

In addition to choice of questionnaire, a seamless method of electronically capturing the data and integrating the results into the electronic medical record (EMR) without interrupting clinic flow is essential. Currently, there are no burn-specific instruments that are fully computerized and well integrated with a medical record system. These assessments require brevity of the questionnaire for practical use in the clinic setting and integration with the EMR. Real-time use is facilitated by direct download of the survey results into the patient's electronic chart.

Our hospital system began developing a system-wide PROMs program as a performance improvement tool, administering the PROMIS-10 (a 10-item generic short form of

PROMIS) and displaying changes in the calculated scores over time in the medical record. As this program was rolled out, the Adult Burn Outcome Questionnaire (ABOQ), a 15-item burn-specific instrument derived from the American Burn Association/Shriners Hospitals for Children Young Adult Burn Outcome Questionnaire (YABOQ) was administered to outpatients with burn injury.[3] This study describes the development of the ABOQ, assesses the clinical validity of the ABOQ in adults and determines whether the ABOQ provides additional information when compared with the PROMIS-10.

METHODS

Instruments Used

PROMIS® is a set of person-centered measures sponsored by the U.S. Department of Health and Human Services that evaluates and monitors physical, mental, and social health in adults and children.[12,13] The 10-item generic short form, PROMIS-10, provides brevity and potential for administration as a large population survey to assess overall health in multiple domains.[14] Among the available burn-specific PROMs, the American Burn Association/ Shriners Hospitals for Children Young Adult Burn Outcome Questionnaire (YABOQ) is a reliable, valid measure that is scored using algorithms that include a normative population. The YABOQ has been piloted clinically for use in real time at the individual patient level.[1] Clinical validity has been established by examining changes in outcomes related to burn size.[15]

Development of the Metric Including Tablet Application

Items included in the ABOQ were derived from the previously validated 47-item YABOQ.[3] These 47 items, based on the original YABOQ survey data, underwent factor analysis using the Varimax rotation method, yielding two factors with 67% of variance explained. These two factors represented physical and psychosocial domains for the YABOQ. Furthermore, using regression analysis, 95.8% of the variance in the physical domain could be explained by nine items and 94.6% of variance in the psychosocial domain was explained by six other items. We used these 15 items as the basis for the creation of a short form ABOQ.[16] The graphical presentation of the selected items on the tablet was the same as that used for the YABOQ in a previously published work.[1]

Administration of the Metrics

The 15-item ABOQ and the PROMIS-10 were administered as part of a performance improvement project via an online tablet platform (Tonic Health, Menlo Park, CA) to patients aged 18 or older and less than 24 months from burn. The tablet-based survey uses a Tonic Health platform that was previously described for the YABOQ.[1]

The surveys were administered in burn outpatient waiting rooms at three different hospitals within the hospital network over a period of approximately 18 months (from February 23, 2015 to August 15, 2016). This was part of a pilot quality improvement initiative, and patients were not recruited specifically for this study. Participation was voluntary and considered part of normal care. The tablet was available for use by English-speaking, literate burn patients who attended the clinics. Because the electronic PROMs was new, clinicians

were concerned about clinic flow and administration of the questionnaires was then left to the discretion of the charge nurse/ward clerk of the clinic if the patient arrived early enough and was willing to fill out a survey for the doctor. Technical issues such as Wi-Fi connectivity during periods of construction also limited access to the survey. Permission was later obtained from the Institutional Review Board to review the collected results for research purposes.

Demographic information including time from burn, burn size (self-reported), burn location, gender, and age were also collected along with the surveys. Results at the item level for the ABOQ and at the composite level for the PROMIS-10 were available in real time in the EMR for clinical use by physicians once completed by the patient.

Statistical Analysis

Clinical and demographic characteristics of the study population were summarized using means (± *SD*s) and proportions. All ABOQ items and PROMIS-10 items and scales were appropriately coded so a higher score denotes a better outcome. Question 15 (“After your burn injury, did you return to work or school?”) of the ABOQ was excluded from analysis because it is a stem question regarding return to work. Question 16 (“If you answered yes to question 15, following your return to work or school after the burn injury, how would you rate your acceptance by peers?”) was also excluded, as it is a branch question from question 15 (see Appendix), and there were insufficient data for analysis. All analyses were performed using SAS software version 9.4 (Cary, NC).

Clinical validity of ABOQ items was evaluated by measuring correlations between each of the items and burn size, as well as the presence or absence of facial and hand burns. External validity of the ABOQ was measured in relation to the PROMIS-10 using correlational analysis as well as multivariate canonical analysis. In the correlational analysis, R-squares were measured for ABOQ items and PROMIS-10 items and composite scales. In the canonical analysis, we determined the maximum correlations (−1 to 1, with higher absolute values representing higher correlation) that could be achieved between linear combinations (called canonical variates) of ABOQ items and those of PROMIS-10 items. Overall association between ABOQ items and PROMIS-10 items was tested using Wilks’ lambda and Pillai’s trace tests.

RESULTS

Retrospective Review of the Collected Data

Retrospective review indicated a total of 149 administrations for ABOQ and PROMIS-10, of which 138 occurred within 24 months of the burn. Among the 138 administrations, 105 subjects had 1 survey, 12 had 2 surveys, and 3 had 3 surveys. For this study, we used only the first administration of the survey, yielding 120 unique patients at baseline administration. Of those, 75 patients had complete data on all items in both PROMIS-10 (10 items) and ABOQ (14 items).

For the sample of 120 subjects, the mean (SD) age at burn was 41.6 (*SD* 16.1) years, mean time from burn to survey was 3.3 (4.7) months, and mean burn size was 14.2% (19.4%)

TBSA burned (Table 1). Means and SDs of baseline ABOQ and PROMIS-10 items are provided in Table 2.

Nine out of 14 ABOQ items were significantly correlated with TBSA (correlations ranging from −0.25 to −0.46, $P < .01$ to $< .0001$), whereas only two items were significantly correlated with facial burn and one item with hand burns (Table 3). The canonical correlation of the 14-item ABOQ with TBSA was 0.68 ($P = .0002$).

Canonical correlation analysis was performed on the sample of 75 subjects who had complete items on both YABOQ and PROMIS-10. Out of 10 possible pairs of canonical variates between ABOQ and PROMIS-10, the first three pairs (and only three pairs) yielded significant canonical correlations of $r = .87$ ($P < .0001$), 0.75 ($P = .0003$), and 0.71 ($P = .0235$). The overall test of the relationship between two instruments was also significant by Wilks' lambda ($P < .0001$) and Pillai's trace ($P < .0001$) (Table 4).

At the item level, among the 14 ABOQ items, 28 to 48% (this percentage is an R-square representing the "percent of variance accounted (explained) for by a statistical model", same concept applies throughout this work) of the variation of five items representing the domains of Pain, Physical Function, Emotion, Satisfaction with Role, and Satisfaction with Symptom Relief was explained by PROMIS-10 items and composite scales (Figures 1 and 2). Only 18 to 22% of the variance in three items representing Sexual Function and Family Function (two items: family activities interrupted and family time limited) was explained by the PROMIS-10. For the remaining six items, representing the domains of Itch, Perceived Appearance, Social Function Limited by Physical Function, Social Function Limited by Appearance, Family Concern, and Fine Motor Function, only 3 to 14% of variance was explained by the PROMIS-10. Only 29% of the variation of the ABOQ physical function score was explained by the PROMIS-10 composite physical scale.

DISCUSSION

The Ideal Disease-Specific PROM and General Approach for Instrument Validation

An ideal disease-specific PROM is a measure that can best reflect patient symptoms, functional status, psychosocial well-being, health-related quality of life, and other disease-specific aspects of the condition. The ideal PROM should also possess optimal psychometric properties, including acceptability, internal consistency, reliability, and validity.[17–20] This study aims to develop an instrument to meet those traits for adult burn survivors.

The validity of the patient reported outcome instrument should be tested in terms of predictive validity, content validity, and construct validity. ABOQ items were derived from the previously validated 47-item YABOQ, thus already supporting their content and construct validities.[3]

For psychometric predictive validity, testing of an instrument is performed using a sample that is representative of the target population. A sample of 120 subjects was used for this purpose in the current study. In the context of clinical instrument development, internal, external, and clinical validity are important for application of an instrument in assessing

new target populations.[21,22] To measure the clinical validity of the ABOQ items, we examined the internal validity with correlations between each of the items and several key burn-specific clinical variables, including burn size, as well as the presence or absence of facial and hand burns. And we measured the external validity of ABOQ items by using the generic PROMIS-10 instrument for correlational analysis as well as multivariate canonical analysis.

Administration and Clinical Validity of the ABOQ

This is the first study to present a brief burn-specific metric—ABOQ—for administration to burn survivors over the age of 18 for real-time use in routine clinical care. ABOQ measures outcomes across a range of relevant clinical domains. This questionnaire was administered in three hospitals and proved successful for seamless incorporation directly into the electronic medical record. To examine the clinical validity of the new metric, ABOQ scores were compared to a noncondition-specific, fixed form quality of life assessment, the PROMIS-10, as well as to an important clinical variable, burn size. Results showed ABOQ was validated using burn size and PROMIS-10 batteries. Findings further demonstrated the ABOQ also added important clinically relevant information beyond that provided by the generic PROMIS-10 measure.

ABOQ Compared With Generic Instruments

The ABOQ was not designed to replace generic instruments such as the PROMIS-10. Rather, the goal was to add clinically important information to that provided by generic measures, such as the PROMIS-10. Statistically speaking, results show there is a no inconsequential proportion of variance in ABOQ items that is not accounted for by PROMIS-10. The above-mentioned low *R*-squares (3–48%) indicate that ABOQ items provide additional health-related information specifically relevant to the burn population beyond that measured by the generic PROMIS-10 instrument.

The more focused the interest in a specific symptom or set of symptoms as well as item content unique to a condition, the more likely a condition-specific instrument will be preferred.[23,24] The principal advantage of condition-specific PROMs is the possibility for improved relevance and responsiveness.[25] Condition-specific instruments also enable differentiation of patient groups at the level of specific symptoms or patient concerns.[25] Finally, generic measures may not capture important condition-specific concerns because of lack of responsiveness to disease-specific or focal changes. Generic instruments may therefore underestimate changes in health status of specific patient populations over time.[26] Future work using a longitudinal repeated measures design could assess this for generic measures vs the ABOQ.

The relevancy of generic measures is in the ability to distinguish across different demographic and clinical groups but with less focus and granularity. Compared with disease-specific measures, generic measures also have certain advantages. They are by definition adaptive to a wider variety of conditions and can be widely used in practice, quality improvement, or performance measurement programs.[23,27] Generic measures are preferred in target populations with mainly healthy individuals or people with multiple

comorbidities. Their principal advantage is that they can be applied to individuals without disease as well as those with acute and chronic conditions and allow for comparisons across diverse groups and populations; in addition, generic instruments can efficiently differentiate groups on indexes of overall health and well-being.[25]

Generic measures and disease-specific measures are not mutually exclusive in terms of their applications, which can be used in combination with different stages and circumstances of patient care to maximize the benefits of each.

ABOQ Compared With Other Similar Instruments

Compared to other burn scales such as the Burn Specific Health Scale-Brief (BSHS-B) and the Brisbane Burn Scar Impact Profile (BBSIP), ABOQ has several distinctive innovations. The ABOQ can be used to screen multiple burn-specific domains in a short time, providing unique value compared to other similar instruments. Because most ABOQ domains are captured by a single item, the brevity of the scale and its wide coverage on multiple clinically important domains efficiently provide clinicians with a snapshot of a burn patient's clinical situation. While shorter forms of questionnaires are inevitably less sensitive than the longer forms, careful and thorough psychometric development and calibration based on the most powerful items from the parent instruments has led to their retaining a high degree of accuracy, and hence their increasing popularity in clinical practice and research on clinical outcomes and population health.[28] In addition, all the mentioned instruments can serve as first-order screening tools, but to assess individual domains in more depth, other instruments or clinical follow-up by clinician may provide richer additional information.

The BBSIP mainly focuses on the impact of burn scars on quality of life among adults and children. The number of items varies from 17 to 26 among different forms.[29,30] The primary limitation of this instrument is the small sample size during its development and resulting limitations in psychometric testing.[29,30] The BSHS is composed of 114 items and is used to quantify dysfunction and distress across six major domains of health. It is also commonly used to quantify the recovery of quality of life after a burn,[9,10,31] as is the short form of BSHS, the Burn Specific Health Scale-Brief (BSHS-B). As a condition-specific assessment, the BSHS has undergone multiple iterations.[32–38] However, it is not age specific and covers a limited range of domains. In addition, it lacks a benchmark for clinical improvement over time; therefore, it is difficult to determine what the expected recovery should be and how that differs from the comparison population of non-burned adults.[10] BSHS-B also has methodological issues with scoring and psychometric properties, leading to poor reliability and validity.[9–11]

Clinical Significance

Collected scores using ABOQ reflect adult patients' clinical function in multiple domains, such as motor function, social function, and emotional well-being. This allows identification of adult populations at risk for poor outcomes and in need of greater support.[8] Using ABOQ, unexpectedly low scores could be used as a trigger for clinicians to conduct further evaluation or referral.[2]

One chief advantage of the new ABOQ instrument is that it is short and can be administered rapidly. BOQs have long been used to discern differences in multidimensional outcomes related to important clinical characteristics.[8] Future benchmarking efforts would allow for use of the ABOQ data for performance improvement purposes and to establish best practices. Furthermore, the integration of ABOQ into the EMR would allow a comprehensive and well-documented system for widespread, secure and highly defined use with custom access levels for clinicians and researchers in different hospital networks. This innovative use of ABOQ, combined with real-time feedback to patients and clinicians benchmarked to population norms over time from injury, is a major step in the personalization of burn follow-up care.[1,39]

Future Work, Challenges, and Limitations

The currently recommended method for clinical use of the ABOQ is as a structured review of domains: clinicians scan unscored PROM results during a visit, and if low or unexpected results are observed, they can follow up with patients and consider further clinical steps such as referral to specialist care or psychosocial services.

In the future, we envision a system wherein low scores in certain ABOQ domains trigger additional specific questionnaires to assess particular areas. For example, patients with low scores on emotional function would receive a depression questionnaire to assess that aspect of their mental health. Clinicians could then act on results from these follow-up questionnaires to target interventions to patients with low scores, thus significantly improving quality of care.[2]

ABOQ can be administered both traditionally (with pen and paper) and electronically. Current barriers to electronic administration of the ABOQ include training of the staff, internet connectivity for the tablet system, patient burden, and completeness of data. In addition, because each domain in ABOQ except “Family Function” has only one item, the instrument lacks granularity and sensitivity relative to longer forms. Solutions to these challenges are follows: first, upgrade the infrastructure for questionnaire administration, for example more tablets, better Internet connectivity, ensure compatibility with electronic medical record systems; second, educate and train providers on use of the instruments in daily clinical work flow; third, redesign and strategize the administration of instruments using patient portals to email the ABOQ questionnaires before the visit to reduce administrative burden at the clinical site; finally, educate and emphasize to patients the importance of the questionnaire to improve adherence. In the process of accomplishing these goals, the development of the ABOQ and its implementation in real time is an initial step in advancing future use of PROMs in clinical practice.

In the future items posed to patients could be further reduced through the development and implementation of item response theory.[40] Item response theory uses computer-adaptive testing technology with large item banks, which allows selected items from a large pool some of which may be less relevant to a person’s ability or status, minimizing the burden of administration without sacrificing measurement precision.[41,42] An example of this technology is the development of the Life Impact Burn Recovery Evaluation (LIBRE) project[43,44] Future use of computer-adaptive testing technology in combination with metrics

such as ABOQ will further improve adherence and enhance measurement precision, leading to more efficient administration and improvement of the quality of care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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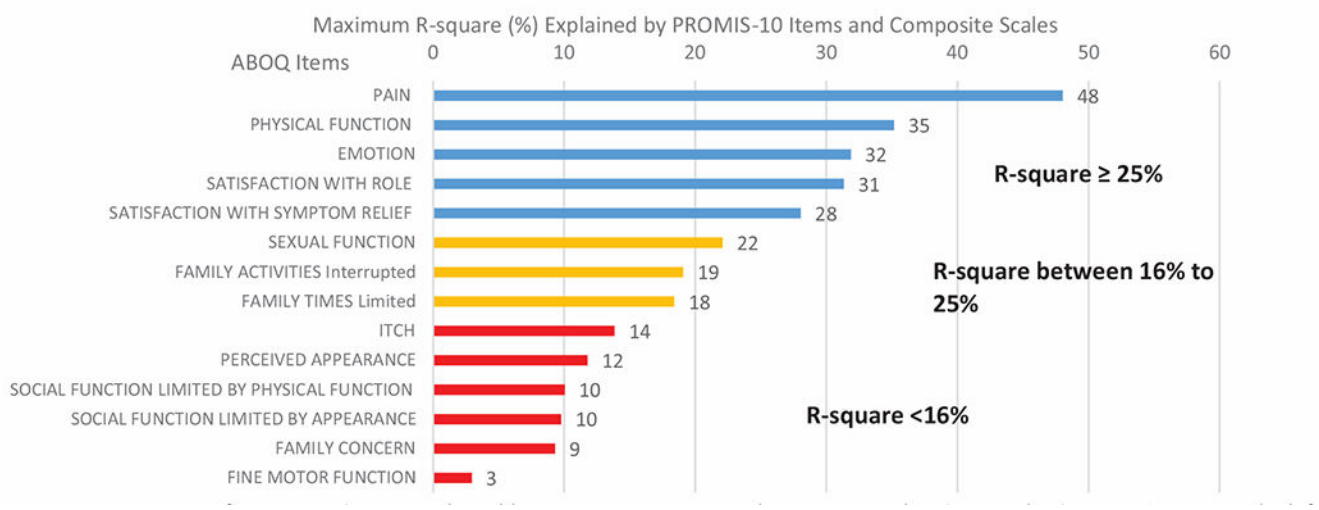

Figure 1.

Maximum *R*-square for items in ABOQ explained by PROMIS-10 items and composite scales. Among the ABOQ 14 items on the left side, domains in blue bars can be explained as much as 28 to 48% by PROMIS-10 items and composite scales; domains in orange bars however can only be explained by a maximum of 18 to 22%. The remaining items in red bars can be explained by not more than 3 to 14% by PROMIS-10 items and composite scales.

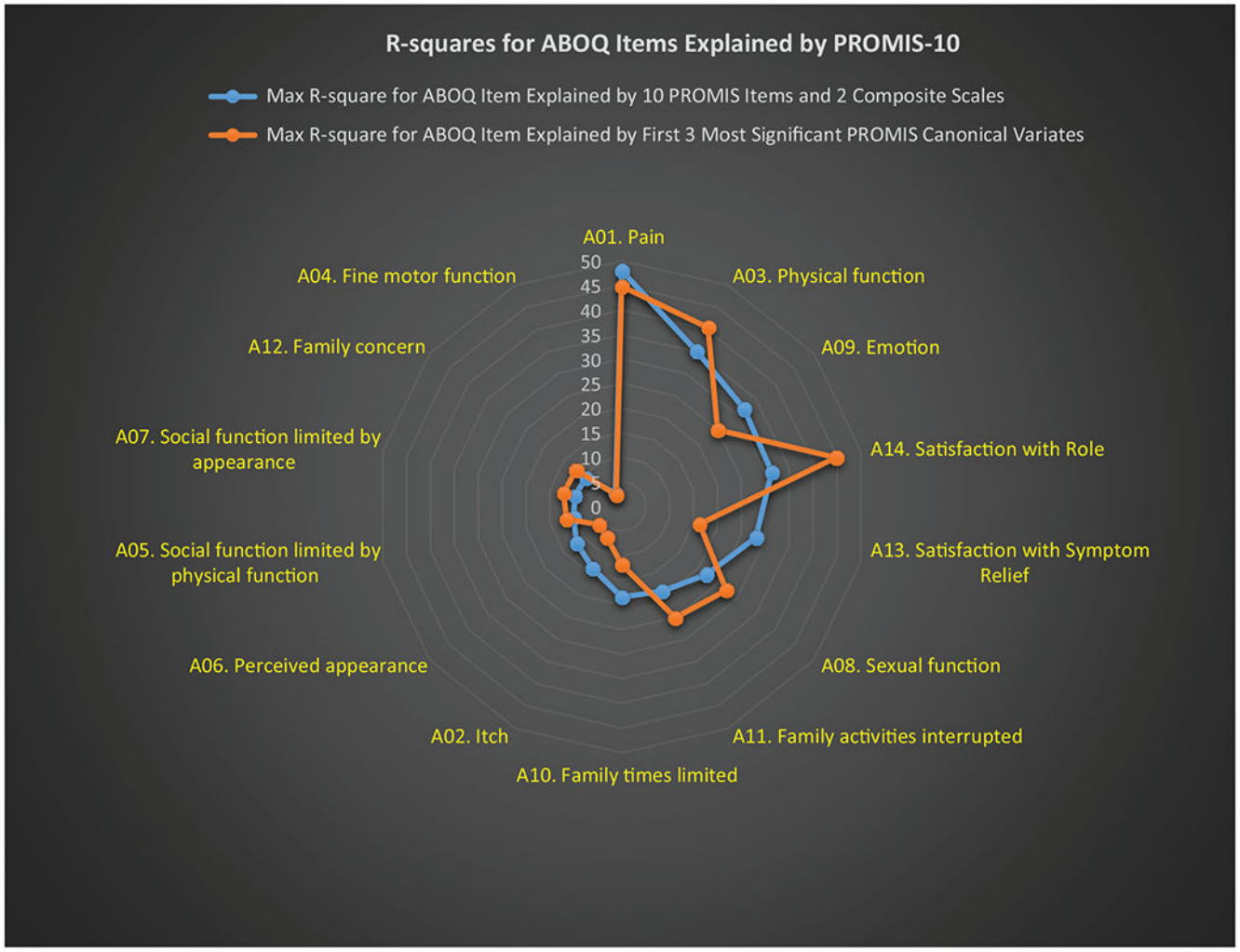

Figure 2.

In the radar chart, there are five circles, each circle represents a different values of *R*-square from 10 to 50%. The blue line shows the maximum *R*-square for ABOQ items explained by 10 PROMIS items and two composite scales, for example Pain has *R*-square of 48%, Physical function of 35%, and Fine motor of 3% (see Figure 1). The red line shows the maximum *R*-square for ABOQ items explained by first three most significant PROMIS canonical variates, for example Pain, 45% and Physical function, 40%. To be noted, Satisfaction with role has 31% explained by PROMIS items and composite scales; but it is explained with much higher *R*-square of 45% by first three canonical variates.

Table 1.

Patient characteristics ($N = 120$)

Variable	Mean	*SD*	Minimum	Maximum
Age at burn	41.6	16.1	18.0	80.0
Months from the day of burn injury to survey	3.3	4.7	0.0	19.6
Burn size% (TBSA)	14.2	19.4	0	96
	N		**%**	
Male	81		67.5	
White [*]	88		74.6	
Education > high school [†]	39		40.6	
Face burned	16		13.3	
Hand burned [‡]	22		18.3	

[*] Other races: Asian, 6; black or African American, 9; Hispanic or Latino, 4; others, 11; declined, unknown and missing, 2.

[†] Based on $N = 96$ non-missing values.

[‡] Left hand burned, 13; right hand burned, 9.

Table 2.

Item content of ABOQ and PROMIS measures

ABOQ	Mean (*SD*)	Theoretical Range	PROMIS	Mean (*SD*)	Theoretical Range
A1. Pain	3.2 (1.5)	1–5	P1. General Health	3.8 (1.0)	1–5
A2. Itch	3.1 (1.4)	1–5	P2. General Quality of Life	3.7 (1.2)	1–5
A3. Physical Function	3.3 (1)	1–5	P3. Physical Health	3.5 (1.1)	1–5
A4. Fine Motor Function	2.3 (1.3)	1–5	P4. Mental Health	3.6 (1.2)	1–5
A5. Social Function Limited by Physical Function	0.8 (0.4)	0–1	P5. Satisfaction with Your Social Activities and Relationships	3.6 (1.2)	1–5
A6. Perceived Appearance	3.5 (1.4)	1–5	P6. Usual Social Activities and Roles	3.5 (1.2)	1–5
A7. Social Function Limited by Appearance	0.8 (0.4)	0–1	P7. Everyday Physical Activities such as Walking, Climbing	3.6 (1.2)	1–5
A8. Sexual Function	3.5 (0.9)	1–5	P8. Emotional Problems such as Feeling Anxious, Depressed or Irritable	3.5 (1.3)	1–5
A9. Emotion	3.8 (1.2)	1–5	P9. Fatigue on average	3.6 (1.0)	1–5
A10. Family Function (time limited) *	4.0 (1.2)	1–5	P10. Pain on average	6.5 (2.8)	1–10
A11. Family Function (activities interrupted) *	4.4 (1)	1–5	Composite for physical *	14.4 (3.9)	5–20
A12. Family Concern	3.1 (1.4)	1–5	Composite for mental *	14.7 (5.1)	5–20
A13. Satisfaction with Symptom Relief	3.6 (1.2)	1–5			
A14. Satisfaction with Role	3.3 (1.3)	1–5			

All ABOQ and PROMIS items and scales were appropriately coded so a higher score denotes a better outcome.

*A10. Family Function: Over the past month, how often has your burn injury limited your family's ability to have time for themselves or time with friends? A11. Family Function: Over the past month, how often has your burn injury interrupted simple family activities like meals?

†PROMIS composite scores are not part of PROMIS-10 items.

Table 3.

Correlations between ABOQ items and burn size and location

ABOQ Item	Burn Size (TBSA)	Face Involved	Hands Involved
A1. Pain	−.18	.26**	−.01
A2. Itch	−.38****	.02	.16
A3. Physical Function	−.27**	.14	.10
A4. Fine Motor Function	−.12	.09	−.04
A5. Social Function Limited by Physical Function	−.25**	−.09	.16
A6. Perceived Appearance	−.37****	−.10	.15
A7. Social Function Limited by Appearance	−.12	.12	.23*
A8. Sexual Function	−.35***	−.02	.19
A9. Emotion	−.46****	.01	.11
A10. Family Function	−.29**	−.15	.13
A11. Family Function	−.17	−.10	−.08
A12. Family Concern	−.08	−.03	−.07
A13. Satisfaction with Symptom Relief	−.41****	.11	.04
A14. Satisfaction with Role	−.35***	.26**	.04

**** $p < .0001$;

*** $P < .001$;

** $P < .01$;

* $P < .05$ for test of correlation.

Table 4.

Canonical correlations between 14-item ABOQ and 10-item PROMIS

Pair of Canonical Variates	Canonical Correlation	*P*
1	.87	<.0001
2	.75	.0003
3	.71	.0235
4	.63	.31
5	.52	.77
6	.43	.93
7	.37	.96
8	.32	.98
9	.18	.99
10	.15	.93

P value is for testing the canonical correlations in the current row and all that follow are 0. Wilks' lambda test[45] $P < .0001$ and Pillai's trace test[45] $P < .0001$ for the overall association between ABOQ items and PROMIS-10 items.