

# Is Real-Time Feedback of Burn-Specific Patient-Reported Outcome Measures in Clinical Settings Practical and Useful? A Pilot Study Implementing the Young Adult Burn Outcome Questionnaire

Colleen M. Ryan, MD,\* † ‡ § Austin F. Lee, PhD,\* † ¶ # Lewis E. Kazis, ScD,\*\*  
 Gabriel D. Shapiro, PhD, MPH, † † Jeffrey C. Schneider, MD, † † §  
 Jeremy Goverman, MD,\* Shawn P. Fagan, MD,\* † † § Chao Wang, MS,\*\*  
 Julia Kim, BS, † † Robert L. Sheridan, MD,\* † § Ronald G. Tompkins, MD, ScD\*

Long-term follow-up care of survivors after burn injuries can potentially be improved by the application of patient-reported outcome measures (PROMs). PROMs can inform clinical decision-making and foster communication between the patient and provider. There are no previous reports using real-time, burn-specific PROMs in clinical practice to track and benchmark burn recovery over time. This study examines the feasibility of a computerized, burn-specific PROM, the Young Adult Burn Outcome Questionnaire (YABOQ), with real-time benchmarking feedback in a burn outpatient practice. The YABOQ was redesigned for formatting and presentation purposes using images and transcribed to a computerized format. The redesigned questionnaire was administered to young adult burn survivors (ages 19–30 years, 1–24 months from injury) via an iPad platform in the office before outpatient visits. A report including recovery curves benchmarked to a nonburned relatively healthy age-matched population and to patients with similar injuries was produced for the domains of physical function and social function limited by appearance. A copy of the domain reports as well as a complete copy of the patient's responses to all domain questions was provided for use during the clinical visit. Patients and clinicians completed satisfaction surveys at the conclusion of the visit. Free-text responses, included in the satisfaction surveys, were treated as qualitative data adding contextual information about the assessment of feasibility. Eleven patients and their providers completed the study for 12 clinical visits. All patients found the iPad survey and report "easy" or "very easy" to use. In nine instances, patients "agreed" or "strongly agreed" that it helped them communicate their situation to their doctor/nurse practitioner. Patients "agreed" or "strongly agreed" that the report helped them understand their course of recovery in 10 visits. In 11 visits, the patients "agreed" or "strongly agreed" that they would recommend this feedback to others. Qualitative comments included: "it helped organize my thoughts of recovery," "it opened lines of communication with the doctor," "it showed me how far I have come, and how far I need to go," and "it raised questions I would not have thought of." Only four of 12

\*Department of Surgery, Massachusetts General Hospital, Boston; †Department of Physical Medicine and Rehabilitation, Spaulding Rehabilitation Hospital, Boston; ‡Harvard Medical School, Boston; §Shriners Hospital for Children—Boston; ¶Research Center for Statistics and Actuarial Science in Medicine, School of Statistics, Xi'an University of Finance and Economics, Xi'an, China; #School of Insurance and Economics, University of International Business and Economics, Beijing, China; #Department of Mathematical Sciences, Bentley University, Waltham, Massachusetts; \*\*Center for the Assessment

of Pharmaceutical Practices (CAPP), Department of Health Policy and Management, Boston University School of Public Health; ††Department of Epidemiology, Biostatistics, and Occupational Health, McGill University, Quebec, Canada; and ††Lincoln Memorial University, DeBusk College of Osteopathic Medicine, Harrogate, Tennessee.

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Address correspondence to Colleen M. Ryan, MD, Massachusetts General Hospital/Harvard Medical School/Shriners Hospitals for Children-Boston, Massachusetts. Email: cryan@partners.org.

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provider surveys agreed that it helped them understand a patient's condition; however, in two visits, the providers stated that it helped identify a pertinent clinical issue. During two visits, providers stated that a treatment plan was discussed or recommended based on the survey results. Separately, qualitative comments from the providers included "survey was not sensitive enough to identify that this patient needed surgery for their scars." This is the first report describing clinical use of a burn-specific patient reported outcome measure. Real-time feedback using the iPad YABOQ was well received for the most part by the clinicians and burn survivors in the outpatient clinic setting. The information provided by the reports can be tested in a future randomized controlled clinical study evaluating impacts on physician decisions. (*J Burn Care Res* 2016;37:64–74)

The preponderance of outcomes research to date after burn injuries has focused appropriately on hard endpoints, such as mortality and morbidities, length of hospital stay, return to work, and costs of care. Burn recovery, championed by a ground-swell of patients' voices through organizations, such as the Phoenix Society, a national consumer organization of burn survivors,<sup>1</sup> is a complex concept that describes a burn survivor's processes of lifetime multidimensional coping rather than a solidly defined set of endpoints that can be easily measured. Nevertheless, the definition and measurement of this process of recovery is critical to understanding and improving quality of life in this population. If recovery could be measured from the patient's viewpoint in individuals and benchmarked to population standards, this information could be used to personalize care plans for burn survivors. Classically, the best clinical assessment of an individual survivor's burn recovery is done by multiple conversations over time with the patient during long-term follow-up in a burn center outpatient clinic that combines a multidisciplinary team of burn specialists, led by senior burn surgeons.<sup>2</sup> These caregivers ideally have a long rich experience with the particular patient and an in-depth knowledge of the condition. The current climate of medical practice, with financial pressures and shortages of burn surgeons and other specialized burn providers, underscores this process as there is often limited constrained time pressures placed on the provider. Objective, valid, and reliable measures integrated and combined with cutting edge information technologies can make this process more efficient and effective. Objective measurements of burn recovery in populations also allow comparison between different treatment paths leading to optimization of care. The progress of burn recovery can be derived from information elicited directly from the patient. Patient-reported outcome measures (PROMs) that address health-related quality of life (HRQoL) include items addressing symptoms as well as physical status, psychological status, and social and role functioning, all from the eyes of the patient

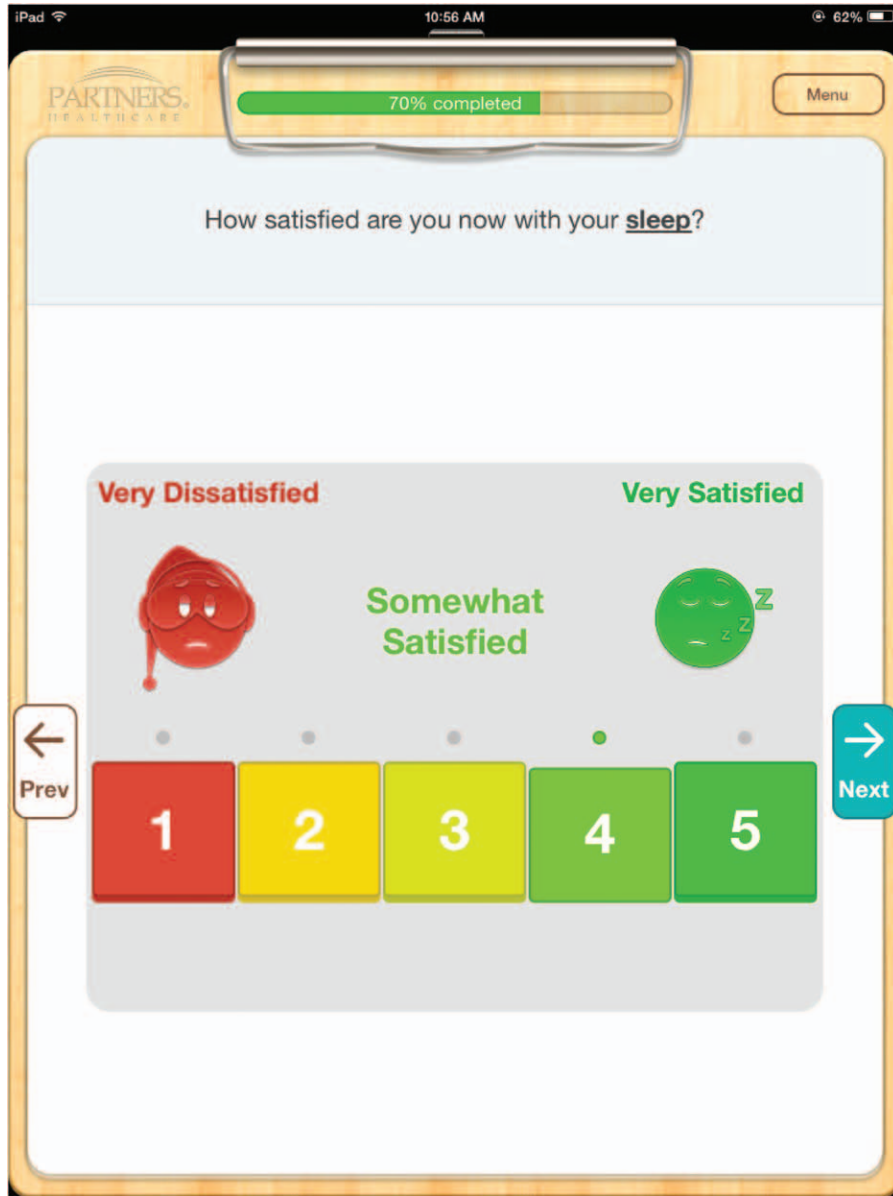
that gives their direct perspectives.<sup>3</sup> Black<sup>4</sup> describes several advantages of soliciting the patient's view for these measures. First, the measure addresses symptoms, disability, and HRQoL that are best assessed from the viewpoint of the survivor. Second, involving the patient in the decision-making process in the interaction with the provider is often welcomed and even helpful to the patient. Third, collecting information from the patient using structured questionnaires that generate reliable and valid metrics eliminates provider bias in the assessment of patient-based outcome assessments. Finally, the consideration of patients' views increases public accountability of healthcare systems from a societal perspective. PROM questionnaires are generally developed over years of research and require the participation of large groups of subjects to develop a databank. A databank such as this is useful to describe outcomes for a population and can be used by clinical researchers to optimize treatment approaches. Taken one step further, PROMs can also become an important tool for individual patient care. Using information technology and the electronic medical record to leverage these patient-centered metrics in combination with standard clinical assessments by an experienced clinician makes for an ideal situation to fulfill "meaningful use" objectives identified by such organizations as National Committee for Quality Assurance and the National Quality Forum.<sup>5</sup> This study examines how a PROM can be structured and implemented in a burn specialty practice to assess burn recovery at the individual patient level. There are currently no reports of computer-administered burn instruments used in real time as a clinical tool. In this study, we present the results of a pilot study using a real-time PROM administered via an iPad platform, with immediate delivery of a scored domain report to the patient and the clinician for use during their routine outpatient follow-up visit for burns. The purpose of the study is to explore the feasibility, potential clinical usefulness, and patient perspectives on implementing a real-time electronic disease-specific PROM in a burn specialty practice.

## METHODS

The overall goal of this project is to utilize a standardized patient-generated measure of multidimensional recovery in real time in an outpatient clinical adult burn practice. Because we were interested in measuring burn recovery, a burn-specific questionnaire was selected. The YABOQ is an instrument for young adult burn survivors that is condition-specific and multidimensional covering the important domains that are salient to the burned adult.<sup>6</sup> It is dynamic and structured for assessment of recovery over time, has credible psychometric properties as well as a sophisticated scoring system. Functional status is summarized by the YABOQ in 15 domains: physical function, fine motor function, pain, itch, social function limited by physical function, perceived appearance, social function limited by appearance, sexual function, emotion, family function, family concern, satisfaction with symptom relief, satisfaction with role, work reintegration, and religion. The 47-item YABOQ and relevant demographic questions were transcribed to a computer platform provided by Tonic Health (Palo Alto, CA). The items were paired with images provided via the platform to enhance clarity and ease of use of the instrument by the burned subject. Figures 1 and 2 illustrate sample YABOQ core and demographic questions in the iPad format. The Massachusetts General Hospital Institutional Review Board approved the study protocol. Further approval was obtained from the hospital's Internet security team to validate the safety of patient data in the cloud, and to allow entry of processed data through the institutional firewall back to the clinical setting. For this pilot study, we deidentified the data collected (using assigned study numbers rather than names or medical record numbers, removing specific dates, using only month and year for dates, and eliminating addresses). HIPAA compliance of the iPad platform was also carefully scrutinized, and returning data was received using the Diplomat Managed File Transfer system (Coviant Software Corporation, Wellesley, MA) that was then pushed to an Excel file (Microsoft, Redmond, WA) in the research database. The time to complete each survey question was automatically recorded by the iPad platform. The YABOQ measure is benchmarked over time from burn injury using data obtained from a population of age-matched burn survivors in addition to an age-matched adult nonburned reference group. The assessment of the recovery process uses recovery curves as a dynamic metric and displays improvement or the subject's progress against expected performance over time from the date of

the injury. The expected recovery is determined on the basis of statistical multivariate models previously developed and validated from a cohort of adult burn survivors.<sup>6</sup> The YABOQ database cohort currently describes the first few years after burn injury, so entry into the study was restricted to young adults between 1 and 24 months from the burn injury. For assessment of feasibility of implementation of this PROM, we chose to display recovery curves for two (physical function and social function limited by appearance) of the 15 domains. The two domains chosen were deemed of high importance to the clinician and patient. Once the data was input into the Excel file, the research assistant reidentified the data and applied the YABOQ algorithms for these two domains, (version 2014-A) that were previously developed as part of the original YABOQ study.<sup>6</sup> A sample report is illustrated in Figure 3. The recovery figure in the report included the predicted recovery curve along with the range of probable recovery (namely, the 95% confidence interval reflected by an upper and lower bounds) for burn survivors. The predicted or expected recovery for the patient was matched from burn survivors with similar age, gender, race, % total BSA (TBSA), face, and/or hands involvement; the actual observed domain score at a particular time point for the patient; and the score-50-line for the control group which served as the standard as a reference or benchmark. The report was given to the patient to bring into the examination room with their doctor. The unscored full questionnaire (answers to all questions, including the questions that make up the other 13 domains) with the patient's answers was also provided but not shown in this article (data available on request from the authors). The clinicians participating included two burn surgeons, a burn nurse practitioner and a burn psychiatrist. The use of these data was left up to the provider and the patient during the visit. Satisfaction surveys were designed to assess the utility of the PROMs with real-time feedback for each patient encounter. The satisfaction surveys used five-point Likert scales, and were completed by the patient and the doctor on the iPad at the conclusion of the visit. The satisfaction surveys for the providers were directed toward gauging the clarity and utility of the questionnaire and the scored and profiled information that was fed back to the clinician and patient in real time during the ambulatory care visit.

For the patients, questions in the satisfaction survey included ease of use, whether the questionnaire helped to communicate their symptoms to the doctor and to others, the importance of the information, and whether they would recommend the



**Figure 1.** YABOQ iPad Application. This figure illustrates a screen shot of typical iPad page of the core items of the YABOQ with images (courtesy Tonic Health, Palo Alto, CA). *YABOQ*, young adult burn outcome questionnaire.

survey to others. Both groups were given a list of all 15 YABOQ domains and were asked to check the domains that they might be interested in for future reports. Both surveys included opportunities for free text responses. The free text responses were treated as qualitative data adding contextual information to the assessment of feasibility.

### Pilot Study

Young adults (ages 19–30 years, 1–24 months from injury) scheduled for follow-up in the burn outpatient center between December 2013 and September 2014, who were 1 to 24 months from the burn

injury were approached for inclusion in the study in the waiting room. Subjects who were unable to read and understand English, who were deemed not appropriate by the attending surgeon due to health, mental issues or timing of the appointment, or who were enrolled in other studies requiring a questionnaire at the same time were excluded from the study. Once informed consent was obtained, a study number was assigned to the patient. The YABOQ was administered to the burned patient via an iPad platform in the office waiting area or the exam room before seeing the clinician. The iPads were password encrypted. Data was scored in the cloud using a study



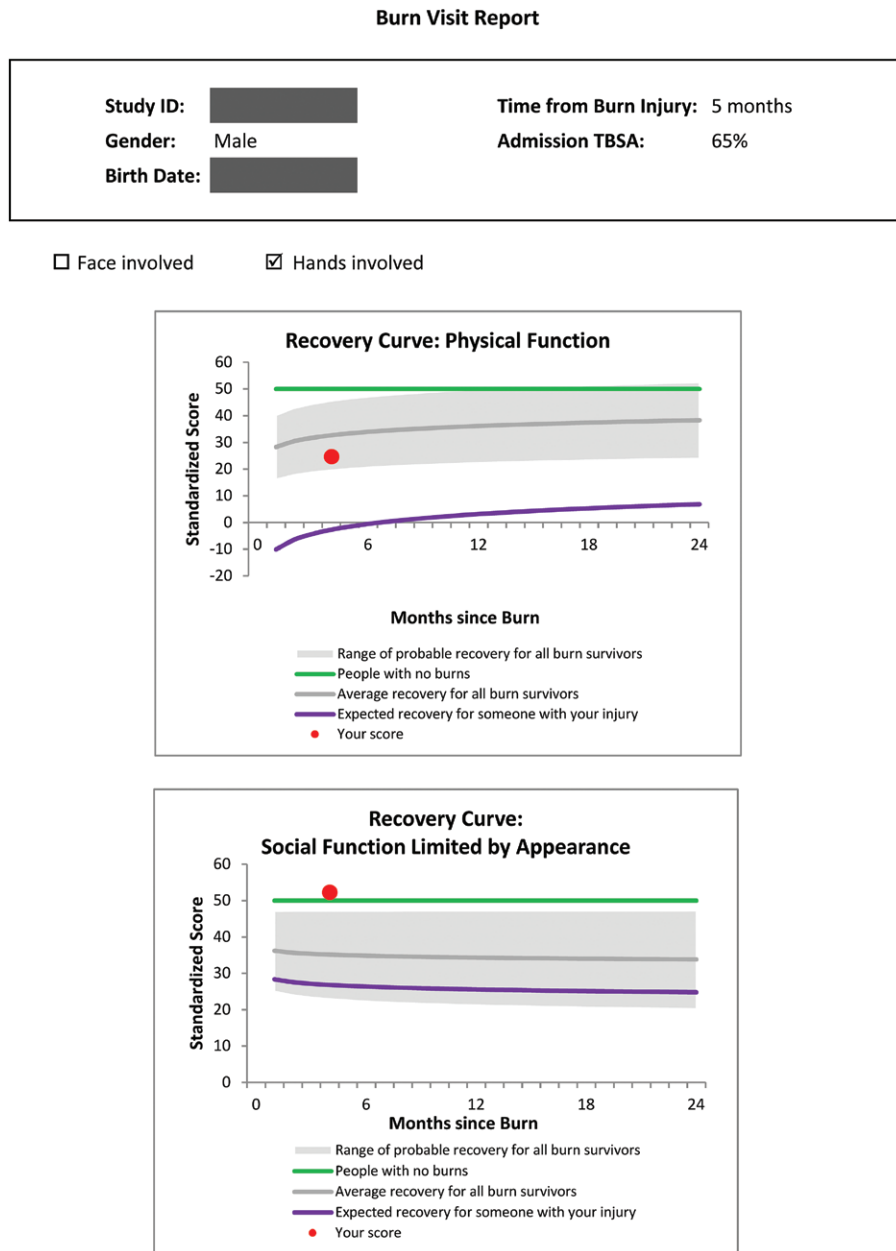
**Figure 2.** YABOQ iPad Application. This figure presents examples of YABOQ iPad format illustrating different demographic questions with images (courtesy Tonic Health, Palo Alto, CA). *YABOQ*, young adult burn outcome questionnaire.

identifier no longer matched with the patient names and hospital identifiers for this process. Returning data once scored was reassigned to the patient name using the patient study number. This all occurred within a few seconds. Reports were processed by the researcher and handed to the patient for use during the clinical visit. Each patient and doctor completed the satisfaction surveys at the conclusion of the visit.

## RESULTS

Fifteen patients gave informed consent to enter into the study. Of these, four subjects were unable to complete all elements of the study due to technical problems related to information processing including Internet connectivity and/or slowness

(two patients). Furthermore, there were compatibility difficulties and data lock-outs that would occur after periodic institution-wide security upgrades in operating systems interfering with receiving the data and printing of the report (two patients). These four patients were excluded from the analysis. Therefore, during 12 patient encounters, 12 patient and 12 provider satisfaction forms were completed. One subject was tested on two occasions. The mean burn size of the 11 patients that completed the YABOQ core and demographic questions was 13% TBSA burned (range: 1–65%). Seven patients had hand burns, three patients had face burns, and eight patients had skin grafts to close their wounds. The mean time to complete the core questions was  $8 \pm 4$  (SD) minutes; the range was 3 to 16 minutes. The 13 demographic



**Figure 3.** Recovery curve report. This figure presents a real-time benchmarked visit report for a study patient with a 65% TBSA burn with hand involvement, seen in the outpatient center 5 months after injury. This report was provided to the patient and the physician and contained two domain-specific recovery curves generated after application of the YABOQ algorithms to the patient’s answers input into the iPad platform. Each domain-specific recovery curve is normalized to an age- and sex-matched control group and documents expected changes in status over time since injury. The *horizontal line* is given for the reference nonburn group, set at 50. The predicted recovery curve for each domain for all burn survivors is in *gray* with the *shaded areas* above and below the curve denoting the 95% confidence intervals. The *purple line* indicates the recovery trajectory over time for survivors with similar injuries based on burn size and the presence of hand or face burns. The *dot* indicates the score for the patient on the day administered based on their answers. For physical function, this patient’s score is above the predicted score at 5 months for a man his age with a 65% TBSA burn, yet his score was below that score for all burn patients and below the nonburned reference group. The score for social function limited by appearance was above that predicted for all burn survivors and male survivors with 65% TBSA burns and hand burns 5 months from injury. These results indicate that he was doing very well that he could expect that his physical function would continue to improve, and that, so far, he was coping remarkably well in terms of his changes in appearance. A quick review of a patient’s score benchmarked to the recovery curves in each domain could provide a real-time screen for problems in multidimensional burn recovery and flag issues for discussion during the visit. TBSA, total BSA; YABOQ, young adult burn outcome questionnaire.

questions added another  $2 \pm 1$  minutes, or about 10 seconds per question.

### Results of the Satisfaction Surveys

The patients found the iPad questionnaire “very easy to use” (10 surveys) or “easy to use” (two surveys). In nine instances, the patients “agreed” (four surveys) or “strongly agreed” (five surveys) the questionnaire helped them communicate their situation to their doctor. Patients “agreed” (seven surveys) or “strongly agreed” (three surveys) that the report helped them better understand their course of recovery. Patients “agreed” (seven surveys) or “strongly agreed” (four surveys) they would recommend this tool to others. Free-text comments collected from patients included: “it helped organize my thoughts of recovery,” “it opened lines of communication with the doctor,” “it showed me how far I have come, and how far I need to go,” “I felt the questionnaire encompassed both the physical and emotional components that burn victims/survivors and their families struggle with and face daily. It was great!” and “it raised questions I would not have thought of.” Other suggestions included one participant who wanted to be asked about the appearance of the skin grafts (color, texture, etc.), and another who questioned the utility of the spirituality questions. Another patient, with a recent foot operation suggested that timing the questionnaire too close to a surgical procedure could throw off the results. The providers tested were senior academic attending staff, including doctors and a nurse practitioner, all with many years of experience in burn specialty practices. Five of 12 provider surveys noted agreement that it helped understand a patient’s condition during the visit and in two visits the providers stated that it helped identify an issue. In two visits, the provider noted that a treatment plan was discussed or recommended based on the survey results.

### Example Case

A 27-year-old male was injured in a factory explosion sustaining a 65% TBSA burn and smoke inhalation injury. His burns involved the trunk and all four extremities. He underwent nine operations to close his wounds, and one operation for a contracture release of his thumb during his initial hospitalization. His acute hospital course was complicated by sepsis and respiratory failure. He developed heterotopic ossification in both elbows. He returned home after 97 days in the acute hospital and an additional 45 days in inpatient rehabilitation. He participated in the study during a routine follow-up visit in the burn

outpatient clinic 5 months from the injury, which was 1 month after he returned home. In his core survey, he noted having mild pain and itching. It was easy for him to climb one flight of stairs, walk one block, and get in and out of bed. It was a little hard to climb three flights of stairs, walk three blocks, or bend over to pick something off the floor. It was doable but very hard to take part in recreational activities with others his same age, such as dancing, bicycling, skating, hiking, or jogging. Using a fork and spoon was met with some difficulties. In terms of his appearance, he felt that it was mostly true that the burn was unattractive to others, yet he felt it was mostly false that people would not want to touch him and he thought it was mostly false that his appearance made him unsure around strangers. Nevertheless, he stated that there was no problem with his ability to attend community gatherings, parties, or other social events because of his appearance. His appearance did not interfere with him going out with friends or interfere with his ability to be active in general. He felt angry and sad some of the time. He noted that over the past month, sometimes his family members had limited their time with themselves or others because of his burns, and sometimes, simple family activities, such as meals were interrupted because of the burn. Over the past month, family members expressed some concern about his pain, his burn recovery, and his future health. He was somewhat satisfied with his pain and itch relief, and his ability to do chores. However, he was somewhat dissatisfied with his sleep. There were no issues with sexual function and he had not yet returned to work due to the burn. On his recovery curve report (Figure 3) generated from the responses to the iPad in the clinic, for Physical Function, his score was above the predicted score at 5 months for a man his age with a 65% TBSA burn. Yet, his score was below that score for all burn patients in the database and below the nonburned reference group. The recovery curves for all burn patients and for patients like him at 5 months from the injury showed that continued improvement in the physical function domain toward the nonburned group, represented by the line at the 50 mark, would be expected for the next several months. His score for social function limited by appearance was above that predicted for all burn survivors and male survivors with 65% TBSA burns and hand burns 5 months from injury. It was, in fact, at the level of the nonburned reference group (Figure 3). These results indicate that he was doing very well, could expect that his physical function would continue to improve, and that, so far, he was coping remarkably well in terms of his

changes in appearance. The patient found the survey easy to use, and the report easy to read. He indicated (5/5) that the survey and report helped communicate the effects of the burn injury on his life to his doctor, and thought it would help him talk about his situation with others close to him. He found the information extremely useful, rating the value of the information as 10/10. The report made him more aware (4/5) of the course of his burn recovery. In his free text comments, he noted that taking the survey and reviewing the report helped him organize his thoughts on recovery. The provider, a senior burn surgeon with years of experience who cared for this patient during his acute hospitalization found that much of the information in the report was not new to him. However, sleep disturbance was identified on review of the questionnaire answers and this problem was addressed during the visit. While the issue of sleep likely would have come up in the course of a normal visit, the report allowed the conversation to focus on this point.

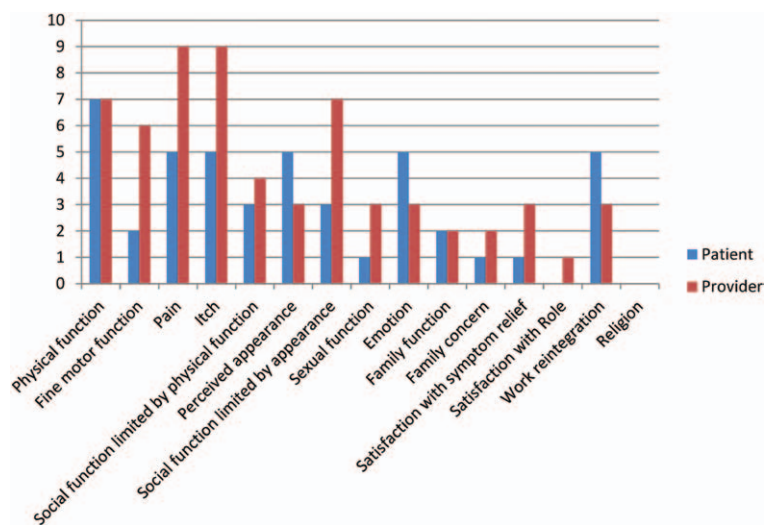
In another case, a patient with a complex foot wound was performing well below the expected or predicted physical level of functional status as depicted by the recovery curve. This issue was addressed during the visit. The doctor noted in the free text area: “the recovery curves are a crucial component of the report as they provide a good visual for the MD and the patient as to recovery progress.” Other comments from the patients and the providers noted that the questionnaire was not going far enough. One case involved a patient with a complex

hand injury and a contracture for which the outcome of the visit was recommendation for a reconstructive surgical procedure. The surgeon stated that the report generated by the instrument failed to sufficiently address scar or hand function issues that would benefit from operative intervention. Another patient wanted recovery curve information for the color, texture, and appearance of scarring.

Overall, the mean value of the information (on a scale of 1 to 10, with 10 indicating an extremely high value of importance and usefulness) was rated as 7 for the doctors and 8 for patients. Both the patients and the providers selected domains that they would be interested in seeing for future use; these are illustrated in Figure 4. Of note, with the exception of religion, all areas were of interest to patients and providers in this group. This suggests the YABOQ domains are judged valuable by either physicians and/or patients. Top domains of interest (with at least five) for the patients in this pilot study included physical function, pain, itch, perceived appearance, emotion and work reintegration; while providers were most interested in information on itch, pain, physical function, social function limited by appearance, and fine motor function.

## DISCUSSION

Large databases are often used by researchers to define and compare outcomes of populations to assess effectiveness of interventions or therapies. In the field of burns, this research has led to important



**Figure 4.** Domains of interest: providers and patients. Note the top areas (Young Adult Outcome Questionnaire, YABOQ domains) of interest to the patients (physical function, pain, work reintegration, emotion, perceived appearance, and itch) and the providers (itch, pain, physical function, and social function limited by appearance). YABOQ, young adult burn outcome questionnaire.



improvements in burn care. In this study, we focused on the use of a database at the individual patient level with the goal of personalizing care through the use of a reliable and valid patient-centered assessment focusing on burn-specific outcomes. We demonstrated the feasibility of employing a burn-specific PROM with real-time feedback in an outpatient burn clinic. The process was well received for the most part by the patients. The iPad survey was deemed easy to use. The YABOQ scores provided information that was helpful to the patients, helpful enough for them to recommend it to others. The potential usefulness of the instrument was illustrated by the free comments, such as “it opened lines of communication with the doctor,” “it helped organize my thoughts on burn recovery,” and “it showed me how far I have come and how far I need to go.” Both the patients and the doctors expressed interest in all domains of the YABOQ except religion indicating that this tool focuses on domains of interest to the users. No conclusions can be drawn on clinical utility of real-time YABOQ feedback for the measurement of burn recovery due to the small sample size in this study. However, the results are certainly encouraging. The potential power of the use of PROMS and the process of real-time benchmarking feedback as a clinical tool is illustrated by the ability to focus discussion based on a screen of condition-relevant symptoms and the perceived helpfulness of a visual representation of patient progress and expected prognosis.

### Considerations, Challenges, and Lessons Learned

Considerations for implementing a PROM for individual patient care have been reported by Snyder and Greenhalgh.<sup>7-9</sup> They outlined basic steps for the process of implementing a PROM into clinical practice. These steps were applied during this study. The first step in the process was to identify the goals of PROM application. In this case, our goal was to utilize a standardized patient-generated measure of multidimensional recovery in real time in an outpatient clinical burn practice. The challenging long-term purpose of this project is to make the assessment of recovery in burn survivors objective as well as more efficient and effective. At the individual level, we want the process to allow for screening of problems related to burn recovery, and to feed this information back to the clinician in a timely manner. The ideal tool should also monitor the individual's progress over time. We want a PROM that facilitates patient-centered care and improves communication between the doctor and

the patient. When using the measures in a multidisciplinary clinic, PROMs can improve communication about the patient between providers of various disciplines. Finally, aggregating individual responses across practices or institutions can, with proper standardization and risk stratification serve as a patient-reported outcome performance measure. Achievement of these goals will require research input from multiple burn centers in the upcoming years. Questionnaire selection is another important step. Categories of questionnaires include condition-specific vs generic, profile based (examining multiple scores across a broad range of domains) vs preference based (produces a single score that represents a summary measure, such as burden of disease). Questionnaires can assess domains using single or multiple items. The advantage of using single items is that they are shorter and quicker to administer, but multiple items usually provide more precise and valid data, and respond better to change over time. The instruments can be static or dynamic, with static instruments designed for a one-time use and dynamic questionnaires providing more information regarding progress over time. Because we were interested in measuring burn recovery, a burn-specific questionnaire was preferred. The burn field has several increasingly well developed and studied disease-specific PROMs, including the Burn-Specific Health Scale Brief<sup>10</sup> and the Burn Outcome Questionnaires (BOQs). The age-specific BOQs (BOQ0-4, BOQ5-18, BOQ11-18, and the YABOQ)<sup>6,11,12</sup> were developed by the Multi-Center Benchmarking Study Group with initial support by the American Burn Association and the Shriners Hospitals for Children. Of these, we focused on the YABOQ, an instrument for young adult burn survivors that is condition specific, profile based, and most domains are multi-item.<sup>6</sup> The PROM is dynamic and structured for assessment of recovery over time, has known credible psychometric properties and has advantages over the Burn-Specific Health Scale Brief given its sophisticated scoring system. The YABOQ measure is benchmarked over time from burn injury using data obtained from a population of age- and gender-matched burn survivors against a matched non-burned reference group. The assessment of the recovery process uses recovery curves as a dynamic metric, showing progress against expected performance over time from injury. Using the YABOQ as well as other BOQs in infants and children, recovery curves have demonstrated their research based and their practical applications for routine clinical use in defining burn recovery for specific populations.<sup>13-17</sup> The recovery curves provide a basis for interpretation

of the results with respect to an individual patient. The YABOQ has limitations and its use in clinical practice will require formal safety and efficacy testing. Also, the YABOQ is limited by age, literacy, and time from burn injury. While BOQs for children are available, a BOQ for other older adult age groups is also under development. The YABOQ database currently supports recovery trajectories up to 3 years from the burn injury. Inclusion of long-term survivors will allow longer-term recovery curves with the growing cohort of data. Additional psychometric testing will be needed to assess the YABOQ due to the new mode of administration in the clinic using the ipad. Other venues of research using generic assessments, such as the SF-36, SF-12, and VR-12 have indicated similar contextual effects with the paper and pencil approaches compared with computer-based administration of the questions over the Internet.<sup>18,19</sup> The algorithms will need to be maintained and periodically updated by adding new responses of burn survivors to ensure the future strength of the benchmarks or norms. Any changes to the items, both stem and response choices will also require additional psychometric testing. A central repository for maintenance of the dataset and future algorithm adjustment has been proposed. Finally, improved instruments using sophisticated testing technology, such as computer adaptive testing (CAT), could be developed using items derived from the YABOQ. CAT technology allows each subsequent question to be determined by the answer to the previous question, and lead to more precise and valid scoring. While the item bank behind the scenes is extensive, the number of questions posed to the respondent is very limited. A CAT for measuring community participation among burn survivors is currently under development in a project called Life Impact Burn Recovery Evaluation.<sup>20</sup> This project provides a model for the application of CAT to be applied to technologies, such as the use of an ipad in the clinic. The next step is to choose a mode of administration. Electronic administration of the instrument allows more efficient administration and data handling as well as the potential to interact directly with the electronic medical record. Clearly, some challenges of this study occurred surrounding issues with information technology in our individual institution currently undergoing an upgrade of the infrastructure. The use of a commercial platform specializing in HIPAA compliant medical data in the Cloud adds expense but provides a basis for other burn centers to have easier access to the instrument and ensures safety of patient information within the Cloud.<sup>21</sup> The Cloud also provides opportunities for merging data bases from various centers in a relatively

seamless fashion for purposes of enlarging the data and creating rich cohorts that can serve as benchmarks for expected recovery curves. A central repository of data could potentially be used to maintain and strengthen benchmark algorithms for future use. While the YABOQ ipad instrument is currently available for data collection via Tonic Health, additional programming work will be needed to apply the algorithms and automatically reproduce curves in the individual institution's medical record. The final major steps involve improving and assessing the clinical utility of the instrument administered. As part of this, treatment recommendations should be developed for patients not meeting the benchmarks, and these treatments can be assessed for efficacy and effectiveness. Consensus panels among experts in the field for generating clinical guidelines and testing whether interventions are associated with recovery is important for the potential future utility of these instruments. This new knowledge base, expected to evolve over time, allows for the provision of specific recommendations on the basis of the observed scores vs expected scores and how to impact on the scores. In this study, fewer clinicians than patients thought that the instrument was useful to understand the patient's situation during a particular encounter. These clinicians had a long relationship with the patients and likely addressed many of these issues during their usual course of treatment. These were senior caregivers who already had years of experience with burn survivors in their practice and therefore a sound base of knowledge in expected long-term outcomes. Therefore, the issues identified by the report and the expected recovery were not necessarily new information for them, but might be new for a trainee, fellow, or someone with less experience in the field. Still, the potential exists to make the time with the patient more meaningful and efficient by enabling the patient to provide an organized review of pertinent symptoms and responses from the YABOQ that consists of items among 15 domains that tap HRQoL from the patient perspective. This is administered and scored before the visit so that scored domains with individual items are highlighted during the visit and identify progress or lack thereof in a graphic report. Finally, with improvements in the scope, precision, and clinical validity of a burn survivor-specific PROM, applications such as decision support for therapeutic interventions such as reconstructive surgery and use of aggregated PROMs as quality monitors among different services or institutions and providers should be possible. Alternatively, disability and health of burn survivors could be assessed in comparison to populations with other disease states, such as other traumatic

events that include spinal cord injury or traumatic brain injury by linking the disease-specific instruments to global measures, such as the PROMIS measures.<sup>22</sup>

In summary, this is the first study to show preliminary evidence of the feasibility and potential utility of real-time use of a burn-specific PROM instrument in adult burn survivors. The qualitative data from this study support the hypotheses that the PROM can facilitate communication between patient and provider and help providers identify clinical issues to address. PROMs are a tool that can be useful to promote uniform and comprehensive multidimensional history taking during medical exams despite a financial climate that compresses face-to-face time with patients. Through further research including clinical testing, PROMs have the potential to be used to standardize variations in care and optimizing successful, cost-effective therapies.

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