

Patient Reported Outcomes for use in Routine Care: A Model Approach in Traumatic Burn Injuries

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Objectives of Presentation

- Development and Application of PROs in Children and Adults with Burn Injuries
- Examples of Applications
- Future use of PROs in the EHR.

Historical Perspective

- Over the past 25 years new approaches for health outcomes have been developed from the patient perspective
- The Shattuck Lecture by Paul Ellwood
- Mortality, morbidity and standard clinical outcome assessments are not sufficient for measurement of health outcomes.
- PROs developed over the past 20 years coupled with new technologies for feedback of PROs to clinicians and patients in real-time

Perspectives using PROs

Applications of PROs on Several Levels:

- **Population Based Studies:** for purposes of gauging the effectiveness of patient reported outcomes on large populations.
- **Clinical studies:** using quasi and randomized controlled designs for purposes of demonstrating efficacy/effectiveness of interventions using PROs as endpoints. Conducted in more homogeneous populations.
- **PROs at the individual subject level:** “N of 1” studies.

Clinical Studies

Clinical Studies

- Clinical Studies use PROs in inpatient or outpatient clinical settings
- Tailored to a condition or a disease and focus on the impact of targeted interventions.
- Many disease specific PRO measures are published in the literature and span a broad array of conditions.

Clinical Studies

- BURN Outcomes Questionnaires:
 - BOQ 0-4
 - BOQ 5-18
 - YABOQ 18-30

Burn Outcome Questionnaire Age 0-5 Years



BOQ Questionnaires

English and Spanish

Age 0-5 Years

Age 5-18 Years

Age 11-18 Years

The image displays three overlapping BOQ (Burn Outcomes Questionnaire) forms. The top form is for 'AGES 0 to 4' and is titled 'Burn Outcomes Questionnaire' and 'AMERICAN BURN ASSOCIATION/SHRINERS HOSPITALS FOR CHILDREN'. It includes a 'Marking Instructions' section and a 'Today's Date' field. The middle form is for 'AGES 5 to 18' and is titled 'Cuestionario de las Consecuencias de Quemaduras' and 'ASOCIACION NORTeamericana del QUEMADO/HOSPITALS SHRINERS PARA NIÑOS'. It includes a 'Instrucciones para marcar' section and a 'La fecha de hoy' field. The bottom form is for 'AGES 11 to 18' and is titled 'Cuestionario de las Consecuencias de Quemaduras' and 'Asociación Norteamericana del Quemado/Hospitals Shriners para Niños'. It includes a 'Instrucciones para marcar' section and a 'Fecha de hoy' field. Each form has a 'FOR OFFICE USE ONLY' section and a 'Today's Date' field. The forms are designed to be filled out by healthcare providers to assess the outcomes of burns in children.

Shriners Multi-Center Benchmarking Study

4 Sites

BOSTON

CINCINNATI

GALVESTON

SACRAMENTO

1295

Burn Children

AGE 0-4
N=615

AGE 5-18
N=680

Multi-Center Benchmarking Study

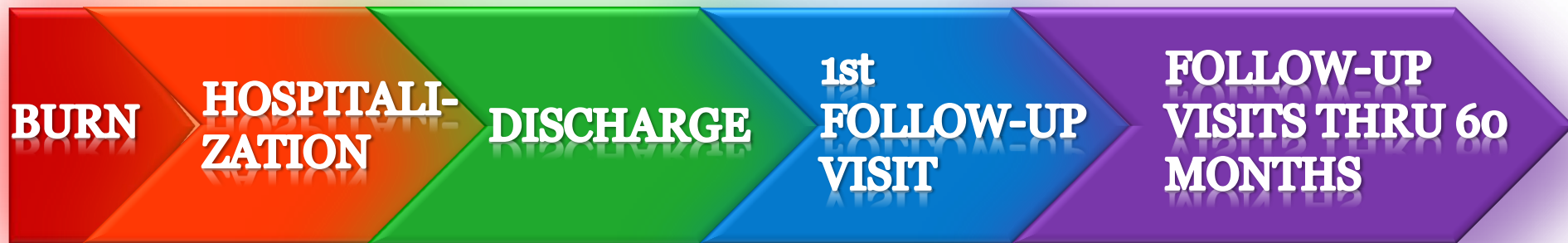
- Example of Predicted Recovery Curves Age 0-5 Years Overall and with Stratification by TBSA
- Rate of Recovery since Burn

Demographic and Clinical Characteristics N=1295

Variable	Mean	Min	Max
Age	7.1	0.0	18.8
% TBSA	32.5	0.3	99.0
Variable		%	
Gender (Male)		68.0	
Face Involved		56.8	
Hand Involved		57.8	
Race	White	38.9	
	Hispanic	45.8	
	Black	6.9	
	Other	8.4	

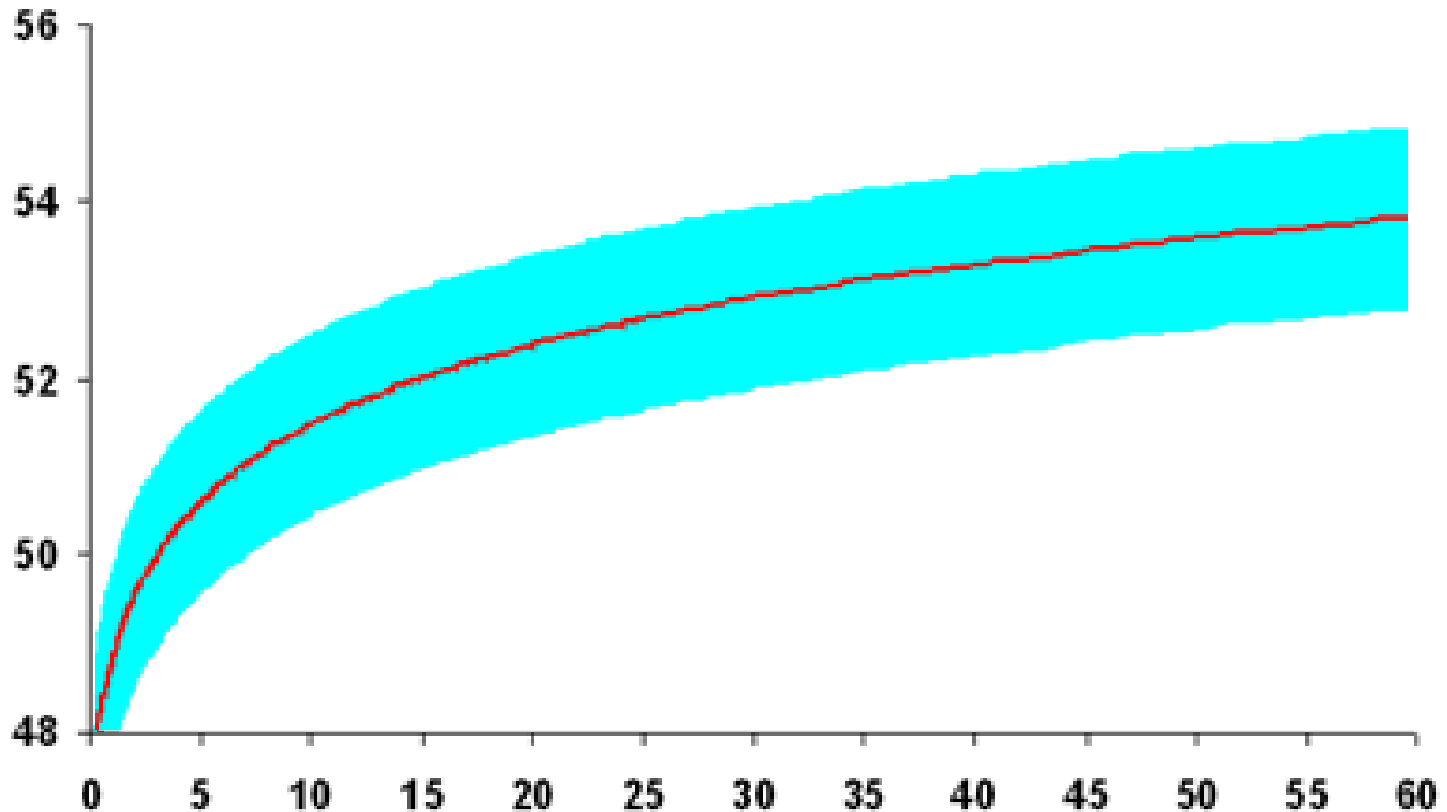
Time Line

Study Began from September 1999 to Present

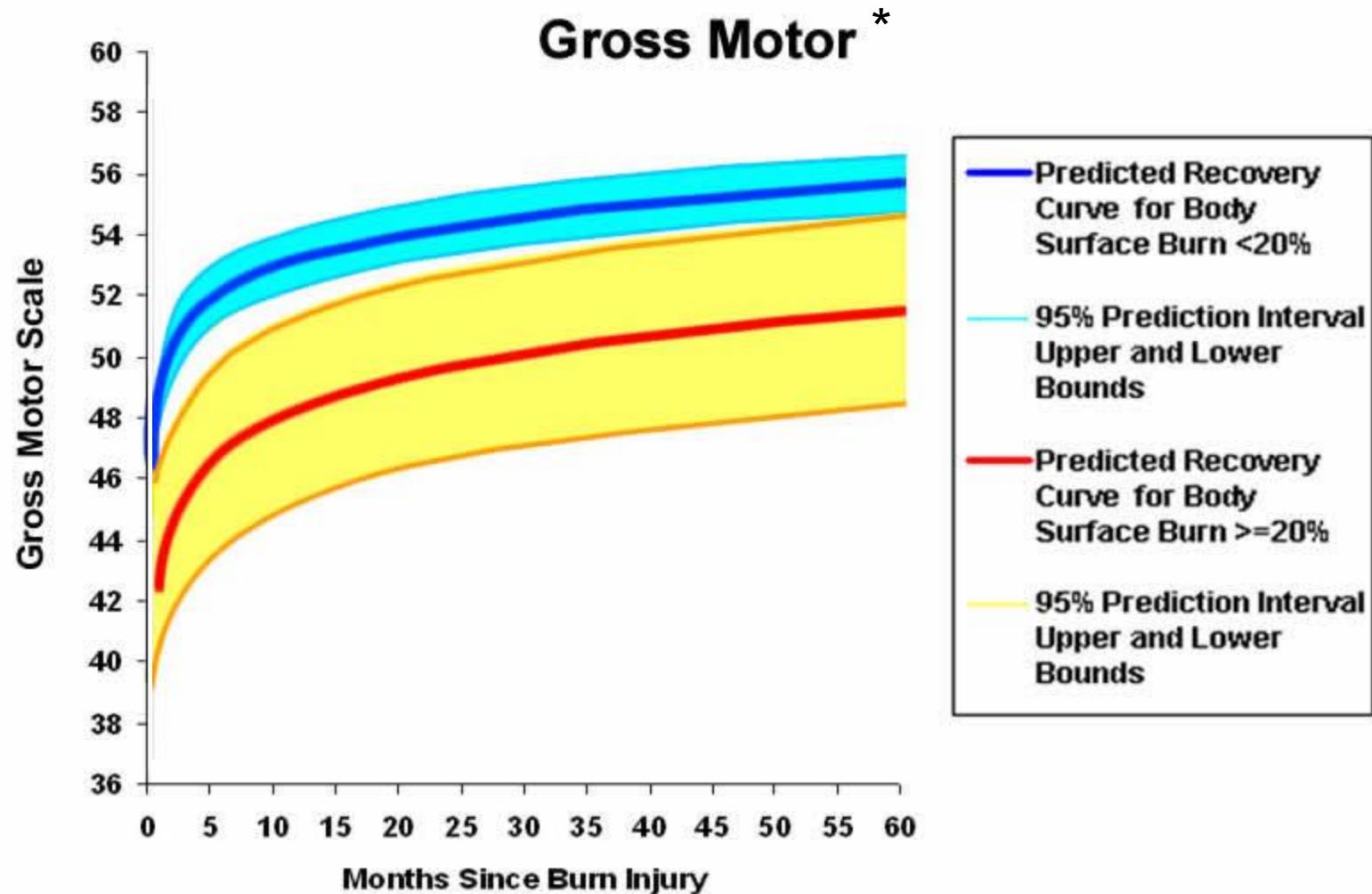


Predicted Recovery Curves Age 0-5 Years

Gross Motor**



Predicted Recovery Curves Age >0-<5 Years, Stratified by TBSA



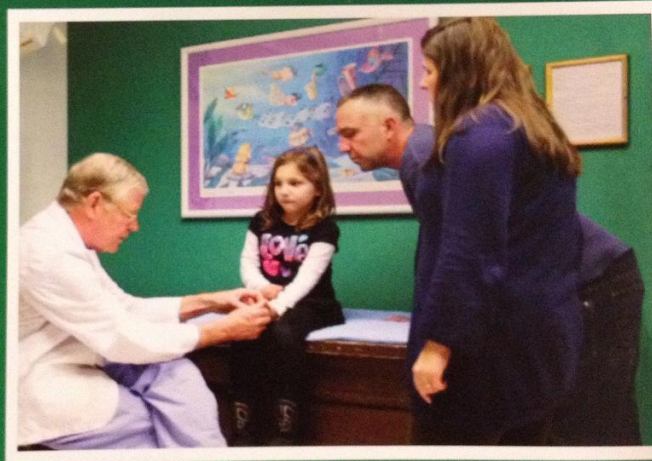
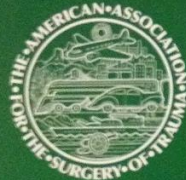
*** $p < 0.001$

**** $p < 0.0001$

The Journal of
**Trauma and
Acute Care
Surgery**

American Association for the Surgery of Trauma
Australian and New Zealand Association for the Surgery of Trauma
Eastern Association for the Surgery of Trauma
Trauma Association of Canada/L'Association Canadienne de Traumatologie
Western Trauma Association

**Shriners Hospitals for Children and the American Burn
Association: Burn Outcomes Program**



Sponsored by Shriners Hospitals for Children®

FOREWORD

The American Burn Association/Shriners Hospitals for Children Burn Outcomes Program: A progress report at 15 years

**Ronald G. Tompkins, ScD, MD, Matthew H. Liang, MD, MPH, Austin F. Lee, PhD, Lewis E. Kazis, ScD,
and Multi-Center Benchmarking Study Working Group*, Boston, Massachusetts**

ABSTRACT: The American Burn Association and the Shriners Hospitals for Children Outcomes Program has been in development for more than 15 years. Many of the tools and important findings are described in this special issue of *The Journal of Trauma*. This unique program in outcomes research introduces a model for outcome assessments from the patient-centered perspective with a cohort of 1,140 children with burn injury after hospitalization for up to 4 years. The findings represent a fundamental contribution to the field of burn care for monitoring outcomes from the perspective of the parent or child/adolescent. The Multi-Center Benchmarking Study of four burn centers serve as a model for collecting empiric scientific data on the variation and the expected trajectories of recovery in the most important domains of patient outcomes and can inform clinical decisions and the conduct of health service research. The dramatic progress in survival of children with severe burn injury and other advances in burn management can now move into a new phase of understanding the most cost-effective components of this care. (*J Trauma Acute Care Surg.* 2012;73: S173–S178. Copyright © 2012 by Lippincott Williams & Wilkins)

KEY WORDS: Multi-Center Benchmarking Study; Burn Outcome Questionnaire (BOQ); health outcomes; recovery curves.

Methods for assessment of health outcomes in children with burn injury: The Multi-Center Benchmarking Study

Lewis E. Kazis, ScD, Austin F. Lee, PhD, Michelle Hinson, RN, Matthew H. Liang, MD, MPH, Mary W. Rose, PsyD, Tina L. Palmieri, MD, Walter J. Meyer III, MD, Richard J. Kagan, MD, Nien Chen Li, MPH, MA, Ronald G. Tompkins, MD, ScD, and the Multi-Center Benchmarking Study Working Group, *Boston, Massachusetts*

BACKGROUND: The Multi-Center Benchmarking Study (MCBS) is an innovative program giving a new paradigm for monitoring health outcomes in children and adolescents with burn injuries.

METHODS: This article presents the methodologies for conducting a multicenter long-term cohort study of 1,140 children and adolescents with small to large burn injuries followed from the acute burn discharge at four burn centers for up to 4 years. The components for this project include a broad and rich range of patient-centered health assessments tailored to children with burn injury, an infrastructure for obtaining relevant clinical data.

RESULTS: Burn Association Burn Outcome recovery curves are described for estimating equations, with adjusted accrual rates are as high as 90% for extremity function, patient compliance, and levels of change over time.

CONCLUSION: The methods implemented in this study will improve the quality of life of children with burn injury.

KEY WORDS: Health outcomes; Multi-Center Benchmarking Study

The effects of facial burns on health outcomes in children aged 5 to 18 years

Petra Warner, MD, Teresa K. Stubbs, RN, BA, Richard J. Kagan, MD, David N. Herndon, MD, Tina L. Palmieri, MD, Lewis E. Kazis, ScD, Nien-Chen Li, MPH, MA, Austin F. Lee, PhD, Walter J. Meyer III, MD, Ronald G. Tompkins, MD, ScD, and the Multi-Center Benchmarking Study Working Group, *Boston, Massachusetts*

BACKGROUND: There are many potential long-term effects of facial burns in children and young adults. We evaluated the outcomes of children and young adults with and without facial burns with respect to physical, psychological, and social domains of health-related quality of life (HRQoL). In addition, we examined the role of sex and socioeconomic status on HRQoL in these patients.

METHODS: Parents of children aged from 5 to 18 years with burn injury completed the American Burn Association/Shriners Hospitals for Children Burn Outcomes Questionnaire when survival was ensured at their original burn center admission and at regular 6-month intervals during the first 2 years and annually up to 4 years after their acute care discharge. Generalized estimating equations with mixed models were used to evaluate the course of recovery with risk adjustments for time since burn, presence of facial burns, and clinical and other sociodemographic characteristics.

RESULTS: Patients with facial burns paralleled the recovery of patients without facial burns, but their mean scores remained lower during the 4 years, with the lowest scores in the domains of appearance, emotional health, and parental concern. Teenagers had improved recovery rates when compared with younger children. Males scored lower with respect to family disruption but recovered at faster rates than females over time, and parents with higher education scored lower for parental concern during the 4 years of follow-up.

CONCLUSION: Psychosocial concerns predominate in the recovery of children who sustain facial burns and are significantly greater than those observed in children in whom the face is not involved by burn injury (*J Trauma Acute Care Surg.* 2012;73:S189-S196. Copyright © 2012 by Lippincott Williams & Wilkins).

LEVEL OF EVIDENCE: Prognostic study, level III.

KEY WORDS: Facial burns; Multi-Center Benchmarking Study; Burn Outcomes Questionnaire; recovery.

Impact of hand burns on health-related quality of life in children younger than 5 years

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BACKGROUND:	The purpose of this multicenter study was to evaluate the impact of hand burn injury in preschool children younger than 5 years on health-related quality of life, including both physical and psychosocial function, in the 5 years after burn injury.
METHODS:	This prospective case series assessed children younger than 5 years admitted to four pediatric burn centers. Each child's family completed the American Burn Association/Shriners Hospitals for Children Burn Outcome Questionnaire (BOQ), a validated and reliable assessment tool, which measures the physical and psychosocial functioning of the child with burn injury ages 0 year to 5 years, at base
RESULTS:	using generalized estimating equation A cohort of 438 patients was follow surface area (TBSA) was 28% (22.4 of the areas tested, with the most pr and appearance. These findings app impact of hand burns was noted in
CONCLUSION:	Children with hand burns have signi
LEVEL OF EVIDENCE:	Epidemiologic/prognostic study, level III
KEY WORDS:	Hand burns; Multi-Center Benchmarking Study Working Group

The effect of family characteristics on the recovery of burn injuries in children

Robert L. Sheridan, MD, Austin F. Lee, PhD, Lewis E. Kazis, ScD, Matthew H. Liang, MD, Nien-Chen Li, MA, MPH, Michelle I. Hinson, RN, Helena Bauk, RN, MSN, Walter J. Meyer III, MD, Teresa K. Stubbs, RN, BA, Tina L. Palmieri, MD, Ronald G. Tompkins, MD, ScD, and the Multi-Center Benchmarking Study Working Group, Boston, Massachusetts

BACKGROUND:	Interactions between family members and characteristics of family life and function may affect a child's recovery from burn injury. We prospectively examined the relationship between family characteristics and physical and psychosocial recovery from burns.
METHODS:	The families of 399 burned children aged 5 years to 18 years admitted to one of four Shriners Hospitals for Children for management of acute burns completed the Family Environment Scale within 7 days of admission and then the American Burn Association/Shriners Hospitals for Children Burn Outcome Questionnaire (BOQ) at baseline, 3, 6, 12, 18, 24, 36, and 48 months. Generalized estimating equations with random effects for the time since burn were used to track recovery of the BOQ patient-centered domains associated with baseline family characteristics during the course of the study.
RESULTS:	The children had a mean age of 11 years and burn size of 32% total body surface area burned. Higher Family Environment Scale scores in cohesion, independence, organization, and active recreational orientation were associated with significantly better rates of recovery in multiple BOQ domains of health-related quality of life. Higher scores in conflict and achievement orientation predicted statistically significant impaired recovery. Higher expressiveness predicted greater difficulty with school reentry.
CONCLUSION:	Family characteristics affect the recovery of children after serious burns. Some of these may be amenable to focused anticipatory family interventions to help optimize outcomes. In particular, those characteristics that impair school reentry should be targeted. (<i>J Trauma Acute Care Surg.</i> 2012;73: S205-S212. Copyright © 2012 by Lippincott Williams & Wilkins)
LEVEL OF EVIDENCE:	Epidemiologic/prognostic study, level III.
KEY WORDS:	Pediatric burns; Multi-Center Benchmarking Study; Burn Outcome Questionnaire (BOQ); health outcomes; family functioning.

Adolescent survivors of burn injuries and their parents' perceptions of recovery outcomes: Do they agree or disagree?

Walter J. Meyer, III, MD, Austin F. Lee, PhD, Lewis E. Kazis, ScD, Nien-Chen Li, MPH, Robert L. Sheridan, MD, David N. Herndon, MD, Michelle I. Hinson, RN, Theresa K. Stubbs, RN, BA, Richard J. Kagan, MD, Tina L. Palmieri, MD, Ronald G. Tompkins, MD, ScD, and the Multi-Center Benchmarking Study Working Group, Boston, Massachusetts

BACKGROUND:	This study analyzed the concordance of parent and child in assessing the progress of child and adolescent survivors of burn injuries using health outcomes.
METHODS:	The American Burn Association/Shriners Hospitals for Children Burn Outcomes Questionnaire (BOQ) was completed by 355 pairs of parents and their 11- to 18-year-old adolescents who experienced a burn injury. These patients completed BOQ child/parent questionnaire pairs at four regional pediatric burn care centers nationally during the first 4 years postburn. The BOQ includes 12 scales that range from physical to emotional health. Predicted recovery curves for each scale (dependent variable) were obtained from generalized linear models, with the independent variables the logarithmic transformation of the time since burn and parent/child as the j
RESULTS:	Mean differences between the parent and the recovery curves over time for the parent where the adolescent rating was better parent ($p < 0.01$). School reentry was rated hi by the parent ($p = 0.012$).
CONCLUSION:	Analysis of the BOQ completed by adolescents with burn injury. These results suggest that the adolescents, with the exception of appearance, it
LEVEL OF EVIDENCE:	Epidemiologic/prognostic study, level III.
KEY WORDS:	Acute burns; Burn Outcomes Questionnaire

Test performance characteristics of a case-finding psychosocial questionnaire for children with burn injuries and their families

J. Michael Murphy, EdD, Lewis E. Kazis, ScD, Nien-Chen Li, MPH, MA, Austin F. Lee, PhD, Michelle I. Hinson, RN, Gwyne W. White, BA, Frederick J. Stoddard, MD, Tina L. Palmieri, MD, Walter J. Meyer III, MD, Matthew H. Liang, MD, MPH, Ronald G. Tompkins, MD, ScD, and the Multi-Center Benchmarking Study Working Group, Boston, Massachusetts

BACKGROUND:	The Long-Form Psychosocial Questionnaire (LFPQ) includes full versions of the Child Stress Reaction Checklist, the Family Environment Scale, and the Parenting Stress Index. Condensed versions of these measures were used to create a Short-Form Psychosocial Questionnaire (SFPQ) that could be used as an indicator of child well-being and specific areas of child, parent, and family functioning in children aged 0 years to 18 years with burn injury.
METHODS:	Parents of 830 children aged 0 years to 18 years with acute burn injury from the Shriners Hospitals for Children Multi-Center Benchmarking Study completed the LFPQ at baseline and follow-up visits up to 48 months at four major burn centers. The internal consistency reliability and variability of the LFPQ explained by the SFPQ for each of the measures were calculated. The construct validity of the SFPQ measures was determined by factor analysis. The magnitude of the change for the SFPQ measures during 48 months of follow-up was examined.
RESULTS:	The internal consistency reliability of the short-form measures ranged from 0.62 to 0.90. The variability of the long-form measures explained by the short-form measures was 61% for the Child Stress Reaction Checklist (average of six long-form scales), 60% for the Family Environment Scale (conflict), and 90% for the Parenting Stress Index (average of 13 scales). Factor analysis supported the construct validity of the model for the short-form measures. The magnitude of change for the short-form measures showed clinical improvement for 48 months.
CONCLUSION:	The SFPQ is both a reliable and valid assessment for evaluating the psychosocial functioning of children following burn injuries. (<i>J Trauma Acute Care Surg.</i> 2012;73: S221–S228. Copyright © 2012 by Lippincott Williams & Wilkins)
KEY WORDS:	Multi-Center Benchmarking Study; Short-Form Psychosocial Questionnaire; CSRC; PSI; FES.

Measuring the cost of care for children with acute burn injury

Kathleen Carey, PhD, Lewis E. Kazis, ScD, Austin F. Lee, PhD, Matthew H. Liang, MD, Nien-Chen Li, MPH, Michelle I. Hinson, RN, Martha K. Lydon, RN, BSN, Helena Bauk, RN, MSN, Gabriel D. Shapiro, MPH, Ronald G. Tompkins, MD, ScD, and Multi-Center Benchmarking Study Working Group, Boston, Massachusetts

BACKGROUND:	There have been few studies on costs of burn treatment. Furthermore, quantifying the actual cost of care at the patient level is hindered by anomalies of our insurance system. This article presents a practical method for determining the cost of caring for pediatric burn patients, using a cohort of patients from the Multi-Center Benchmarking Study at the Shriners Hospitals for Children-Boston and allows an estimate of resource use that may be linked to need or to best practices, without the confounding variable of inconsistent billing practices.
METHODS:	We estimated the cost of hospitalization for a cohort of 230 pediatric patients who sustained burn injuries. In a simulation of billing patterns of all US hospitals between 2001 and 2009, we applied Shriners Hospitals for Children use data to two external sources of cost information. For the hospital component of costs, we used the Healthcare Cost and Utilization Project Kid's Inpatient Database, and for the physician component of costs, we used the Medicare fee schedule.
RESULTS:	Patients had a mean of 1.9 hospitalizations over 3 to 4 years. The mean total cost of hospitalization was \$83,535 per patient, and the median total cost was \$16,331 in 2006 dollars.
CONCLUSION:	This is the first effort to estimate the early hospital costs of caring for children and young adults with burns in specialty hospitals and to establish a referent for quantifying the cost of caring for patients with acute burns. It lays the groundwork for studies relating costs of specific interventions to their effects on patient-centered outcomes. (<i>J Trauma Acute Care Surg.</i> 2012;73: S229–S233. Copyright © 2012 by Lippincott Williams & Wilkins)
LEVEL OF EVIDENCE:	Economic analysis, level III.
KEY WORDS:	Costs of care; children; acute burns; Multi-Center Benchmarking Study; Burn Outcome Questionnaire.

Discussion

- The Shriners Hospital for Children Boston is implementing feedback of Questionnaires using BOQs in real time during the clinic visit.
- Results indicate favorable responses by Children and their parents.
- Systems for implementing routine feedback in the clinic are being planned. Additional studies are currently underway.

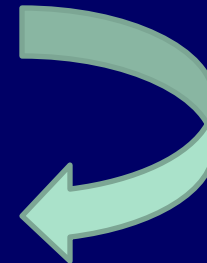
Electronic Health Records



IPAD

A photograph of a stack of three medical reports. The top report is a 'Checkup/Annual Report' from the Department of Medical Services. It contains fields for patient information, medical history, and a list of services provided. The reports are printed on white paper with black text and some red headings.

Report

A screenshot of a web-based medical records application. The window title is 'Medical Records' and the URL is 'MedicalRecords/5.1.USR'. The interface has a menu bar (File, Edit, View, Insert, Format, Records, Scripts, Window, Help) and a toolbar. The main content area is titled 'Medical Records' and has tabs for 'General', 'Doctors', 'Medication', 'History', and 'ID'. The 'Doctors' tab is selected, showing a list of medical professionals. The list is organized into four columns: 'Doctor (Primary)', 'Doctor (Specialist)', 'Doctor (Vision)', and 'Other Care Givers'. Each column contains a table with columns for Name, Last Visit, Address, Phone, Fax, and Emergency. The 'Doctor (Primary)' column lists Dr. Diane Spellman and Dr. Jack Smith. The 'Doctor (Specialist)' column lists Dr. Bill Smith and Dr. William Tyson. The 'Doctor (Vision)' column lists Dr. Jack Smith. The 'Other Care Givers' column lists Steve Miller and Doris Winters. The bottom of the window has a status bar with the text 'For Help, press F1' and a 'NUM' button.

Benchmarking Recovery Following Burn Injury using PROMS

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Clinical Significance of Global QoL Outcome Measures

- We can provide patients and their families information regarding the illness/recovery that is important for care decisions
- Screen for a wide range of medically related issues
- Allows payers to plan for future needs
- If we can measure it, we can optimize care

Young Adult BOQ

- **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**
- **Religion**

YABOQ Feedback Study

- YABOQ administered via ipad in office prior to seeing clinician
- Data is processed , algorithms applied and a report generated that the patient brings into the room to their clinician.



Data Collection Platform for YABOQ Feedback Study

❖ Tonic Health



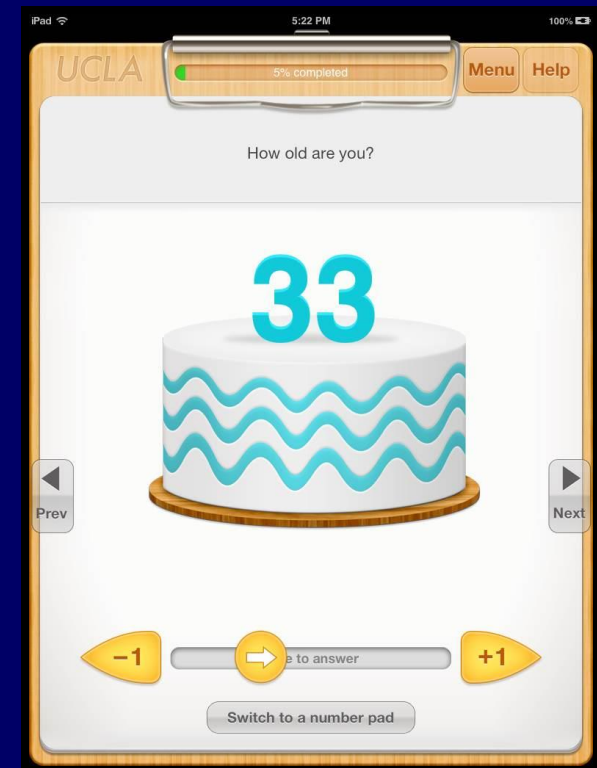
- ✓ Intuitive, interactive, and fun user interface.
- ✓ Tested extensively with – and overwhelmingly approved by – a wide range of patients (including lower income, lower education, geriatrics and those who have never used an iPad).
- ✓ Fully HIPAA-compliant.
- ✓ Can tie into any EHR, including EPIC.

Full Integration with Epic

- ❖ Tonic is capable of integrating with any existing EHR, including Epic.

We tie into Epic in one of three ways, depending on customer preference:

- ✓ Send certain data into the exact fields in the record (such as a patient's demographic data, social history, allergies, and medications).
- ✓ Generate a PDF and associate it to the patient's record (at the encounter level or patient profile level).
- ✓ Pass the data through as a note in text form.



NOTE: Tonic has passed all security and privacy reviews at Kaiser, and has been certified as an approved mobile vendor.



Sample BOQ Questions

iPad 8:25 AM 68%

american burn association 36% completed Menu

In the past month because of the burn injury, would you say your child has seemed unresponsive to affection?

Very True Not True

1 2 3

Don't Know



Prev Next

iPad 8:25 AM 68%

american burn association 40% completed Menu

In the past month because of the burn injury, would you say your child has seemed too fearful or anxious?

Very True Not True

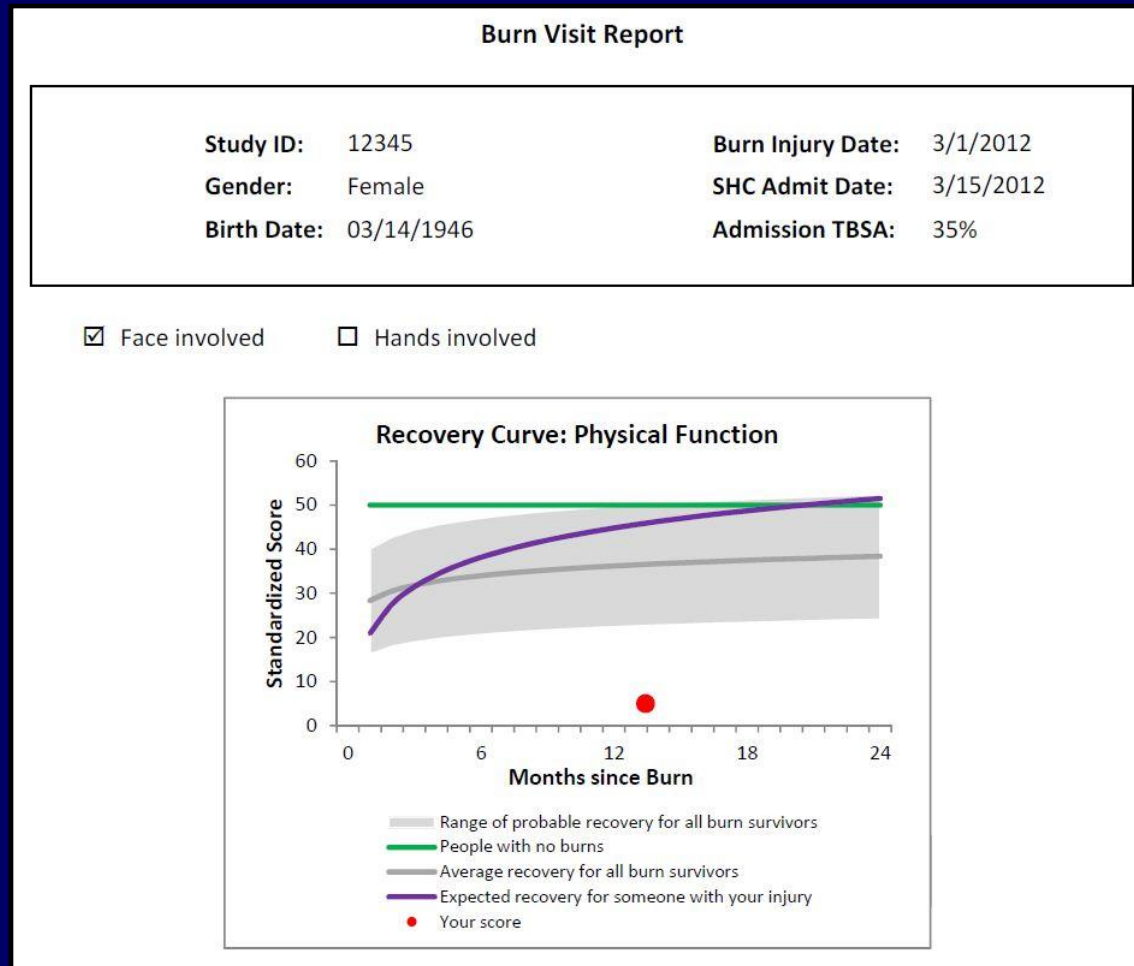
 

1 2 3

Don't Know

Prev Next

YABOQ Real-time Feedback



Provider Satisfaction

YABOQ Feedback

- Did not disrupt clinic flow
- Clearly presented
- Often helped understand the patient's condition
- 20% reports helped identify an issue where a treatment plan was discussed or recommended.

Patient Satisfaction

YABOQ Feedback

- Easy to use
- Enabled them to better communicate their symptoms to their doctor and to others
- Improved understanding of the expected course of recovery
- Likely to recommend to others

Patient Comments

- When other people fill it out it will help me see how I am doing
- It helped organize my thoughts on my recovery
- It was satisfying and reassuring to hear the news
- It opened lines of communication between the doctor and I
- It showed me how far I have come and how far I have to go
- Potentially raised questions I would not have thought of

