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Examination of the Burn Injury Model Systems and the Multicenter Benchmarking Outcome Measures Using the International Classification of Functioning, Disability and Health

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Examination of the Burn Injury Model Systems and the Multicenter Benchmarking Outcome Measures Using the International Classification of Functioning, Disability and Health

by

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Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas Medical Branch

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas Medical Branch

May, 2015

Dedication

I dedicate this dissertation to my mom and dad, Dawn and John Osborne, and to my husband, David Kauvar, for all of your support; and to my golden retriever, Malcolm, who always sat by my side as I wrote.

Acknowledgements

I acknowledge my dissertation committee, Drs. Kenneth Ottenbacher, Rune Simeonsson, James Graham, Walter Meyer and Oscar Suman for their guidance and mentorship throughout my time as a doctoral student at UTMB. Christina Peterson patiently taught me the ICF linking technique and graciously assisted me in the linking process for this project. I acknowledge the staff at the ICF Research Branch in Nottwil, Switzerland who taught me so much about the ICF. Their work towards the global advancement of rehabilitation is truly an inspiration.

Examination of the Burn Injury Model Systems and the Multicenter Benchmarking Outcome Measures Using the International Classification of Functioning, Disability and Health

Publication No._____

Candice L Osborne, PhD

The University of Texas Medical Branch, 2015

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The Burn Injury Model Systems and the Multi-Center Burn Study are two nationwide, multi-center burn injury databases that use patient-reported outcome measures to collect data regarding patients' experiences after burn injury. The data are collected in the hope that this knowledge will enable medical teams and patients to work together to improve the outcomes of rehabilitation interventions. Though the main outcome measures for both datasets were meticulously devised and demonstrate good psychometric properties; the question remains whether or not these measures collect data that encompass the entire experience of burn patients over time. Are there areas that are not being explored? Are there topics that would be better understood with more in-depth probing? The World Health Organization's International Classification of Functioning, Disability and Health (ICF) is a classification system widely used to examine the depth and breadth of outcome measures in many areas. However, its application in the field of burn recovery has been minimal. This study used the ICF to determine the comprehensiveness of burn injury outcome measures to generate a preliminary Core Set that will serve as a foundation for the future development of a pediatric burn injury ICF Core Set.

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List of Abbreviations

ABA	American Burn Association
BMS	Burn Model Systems
BOQ	Burn Outcomes Questionnaire
GSBS	Graduate School of Biomedical Science
HS	Health Status
ICF	International Classification of Functioning
ICF-CY	International Classification of Functioning- Child and Youth
MCBS	Multicenter Benchmarking Study
NIDRR	National Institute on Disability and Rehabilitation Research
QOL	Quality of Life
TBSA	Total Body Surface Area
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life-BREF
UTMB	University of Texas Medical Branch

Chapter 1 Introduction

In recent decades, numerous advancements in burn care have resulted in a dramatic decrease in mortality and morbidity among severely burned patients. Today, burn survival is the rule, rather than the exception.[1] As a consequence of improved survival, the number of burn patients with severe disability has increased drastically. In response, the burn care community has shifted focus from increasing burn survival to managing issues of morbidity, function, and the psychosocial wellbeing of burn survivors.[2,3] [4] [5] Despite this shift in focus, burn rehabilitation research and the development of burn specific rehabilitation outcome measures remains in its infancy.[6]

The Burn Injury Model Systems and Multi-Center Benchmarking Study are two multi-center projects collecting patient-reported outcomes on the long-term experiences of patients with burn injuries. The Model Systems is funded by the National Institute on Disability and Rehabilitation Research and the Benchmarking Study is a funded by the American Burn Association and Shriners Hospital for Children. The data are intended to enable medical teams and patients to work together to improve rehabilitation interventions that foster individuals' return to work, school, and daily activities. Though the main outcome measures for both datasets were meticulously devised and demonstrate good psychometric properties, the question remains whether or not these measures collect data that encompass the entire experience of burn patients over time. Are there areas that are not being explored? Are there topics that would be better understood with more in depth probing? Do we form a true understanding of life after burn injury based on these outcome measures? This study aims to answer these questions and more using The World Health Organization's (WHO) International Classification of Functioning, Health and Disability (ICF).

The ICF is a classification system widely used to examine the depth and breadth of human functioning and disability encompassed by outcomes measures.

To date, over 100 studies utilizing the ICF standardized linking technique have examined the comprehensiveness of outcome measures. The results have been published in 58 peer-reviewed journals spanning 50 different focus areas across diagnoses, settings, languages and countries.[7-13] The widespread international application of the ICF framework to interventions and outcome measures, across diagnoses and areas of specialty, allows clinicians and researchers around the world to interpret and compare outcomes. The ICF framework provides a common global language that fosters communication among and between patients, clinicians, researchers and policy makers.[14] In 2002, the ICF Core Set project was established. Through a standardized process, health condition-specific ICF categories are selected for an ICF Core Set. A Core Set provides a basic international standard of what aspects should be measured to best describe the functioning and disability of an individual diagnosed with a specific health condition.[15]

The utility of the ICF has not yet been widely applied in the field of burn recovery intervention and research.[16,17] The two central goals of this study were: 1) to assess the comprehensiveness of the main outcome measures in two widely used national databases: the Burn Injury Model Systems and the Multi-Center Benchmarking Study using the ICF and the ICF-Child and Youth (ICF-CY) version frameworks; and 2) to contribute to the preliminary identification of ICF categories for the development of an ICF Core Set for burn patients. The following specific aims served to accomplish the central goals:

Specific Aim 1

The first specific aim of the study was to link, classify and describe the concepts included in the Burn Injury Model Systems outcome measure using the ICF framework. This includes the identification of the nature of concepts included in and excluded from the outcome measure (1a) and the differentiation of perspectives (quality of life, health status, and environment) included in the Burn Injury Model Systems outcome measure (1b).

***a) Hypothesis 1*:** Ninety percent of the Burn Injury Model Systems outcomes measure items will be linkable to the ICF

b) Hypothesis 2: Forty percent of the concepts in the Burn Injury Model Systems outcome measure will be classified as 'activities and participation', thirty percent of the items will be classified as 'body structure', twenty percent of the items will be classified as 'environment', and ten percent of the items will be classified as 'body function'.

c) Hypothesis 3: Sixty percent of the items in the Burn Injury Model Systems outcome measure will be described as the health status perspective, thirty percent of the items will be described as to the quality of life perspective, ten percent of the items will be described as environment.

Specific Aim 2

The second specific aim was to link, classify and describe the concepts of the Multi-Center Benchmarking Study outcome measure using the ICF-CY framework through the identification the nature of concepts included in and excluded from the outcome measure (2a) and the differentiation of the perspectives (quality of life, health status, and environment) included in the Multi-Center Benchmarking Study (2b).

***a) Hypothesis 1*:** Ninety percent of the Multi-Center Benchmarking study outcome measure items will be linkable to the ICF.

b) Hypothesis 2: Sixty percent of the items in the Multi-Center Benchmarking Study outcome measure will be classified as 'activities and participation', twenty percent of the items will be classified as 'body structure', ten percent of the items will be classified as 'body function', and ten percent of the items will be classified as 'environment'.

c) Hypothesis 3: Seventy percent of the items in the Multi-Center Benchmarking Study outcome measure will be described as the health status perspective, twenty

percent of the items will be described as qualify of life, and ten percent of the items will be described as environment.

Specific Aim 3

The third specific aim used the data generated by specific aims 1a and 2a to preliminarily identify pertinent ICF categories to be included in the development of an ICF core set for pediatric burn injury.

Product: Based on information generated from aims 1a and 2a, a preliminary ICF Core Set that is representative of all ICF domains will be developed. This preliminary Core Set will serve as a foundation for the future development of a pediatric burn injury ICF Core Set.

In short, this study uses the ICF standardized linking techniques endorsed by the WHO to link and analyze all linkable concepts included in both the NIDRR Burn Injury Model Systems data project and the Multi-Center Benchmarking Study project. The results of this research provide a quantitative and qualitative evaluation of the comprehensiveness with which we are able to capture the health and functioning of burn injury patients over time using the outcome measures studied. It will provide the basis for the development of a burn injury ICF Core Set, and it will initiate the much-needed integration of the ICF into the field of burn injury rehabilitation.

Chapter 2 Background

The Databases

To study the rehabilitation outcomes of a growing number of burn survivors, both the Burn Injury Model Systems (funded by NIDRR) and the Multi-Center Benchmarking Study (a collaborative study among the American Burn Association and Shriners Hospital for Children Outcomes Program) have created burn injury outcomes databases. In both projects, longitudinal data are collected from severely burned patients in an effort to formulate a comprehensive understanding of the factors that impact long-term patient outcomes. [18,19] There are other large burn injury databases such as the National Burn Information Exchange (NBIE), created in the early 1960s, which collected data to study the quality of care at a number of burn facilities as well as determine changes in survival patterns over time. [20] The American Burn Association (ABA) Patient Registry originated in 1990 and continues to collect demographic data and other outcomes.[21,22]

The Burn Injury Model Systems (BMS) and the Multi-Center Benchmarking Study (BOQ) data collection efforts differ from the NBIE database and the ABA registry in that they strive to collect data providing a comprehensive picture of the arc of burn recovery over time. Their outcome measures are designed to capture the incremental experiences of burn patients during recovery.[18,19] A multi-dimensional understanding of the nuances of long term burn recovery is essential to the development and provision of the most efficient and effective post-burn rehabilitative care and is the reason that the Burn Injury Model Systems and the Multi-Center Benchmarking Study were selected for this project.

The Outcome Measures

Multi-center Benchmarking Study Burn Outcomes Questionnaire (BOQ)

In 2001, a consensus panel of experts from the ABA and Shriners Hospitals for Children burn hospitals developed the Burn Outcomes Questionnaire (BOQ) for the Multi-Center Benchmarking Study. The BOQ has since proven reliable, valid, and responsive to change among a burn population over time.[23] Developers of the BOQ

created the outcome measure based on numerous domains pertinent to specific age groups (see appendix A for BOQ questions). The BOQ 0-5 years includes ten domains: play, language, fine motor, gross motor, behavior, family, pain, appearance, satisfaction and worry. [24] The BOQ 5-18 years was developed to capture outcomes within domains such as upper extremity function, physical function and sport, transfers and mobility, pain, itch, appearance, compliance, satisfaction with current state, emotional health, family disruption, parental concern, and school re-entry.[25] BOQ assessment data are collected from patients admitted to Shriners Hospitals for Children for acute treatment of burns greater than 20% total body surface area (TBSA) or less than 20% (TBSA) with injuries to critical areas (hands, feet face and/or genitals). [18] Patients are assessed at discharge from acute care and at 6, 9, 12, 18, 24, 36, and 48 months thereafter. As of 2012 data have been collected from over 1,100 patients.[18]

Burn injury model systems

In 1994 The NIDRR founded the Burn Injury Model Systems program to explore post-burn impairment and rehabilitation issues. Developers of the Burn Injury Model Systems outcome assessment created a tool to support NIDRR's overarching priorities: 1) community reintegration barrier identification and 2) strategy development to overcome those barriers. [19] Burn Injury Model Systems data are collected in several areas: demographics, injury complications, patient disposition and functional and psychological surveys . [19] The variables selected were chosen to examine the factors that influence patient outcomes such as disability, distress, and societal reintegration.[19] The majority of the questions were selected from the following pre-established instruments: Special Form (SF)12, SF10 Health Survey for Children, The Satisfaction with Appearance Scale, Community Integration Questionnaire, and The Satisfaction with Life Questionnaire (see appendix B for BMS questions). Initially, three burn facilities collected data for the project. In 1997 that number grew to four. Data are collected from both adults and children with severe burns (> 20% TBSA in adults; > 10% in children or elderly; burns of the hands, face, feet, genitalia, or joints regardless of TBSA; electrical burns; any burn

associated with inhalation injury) at discharge from acute care and 6, 12, and 24 months thereafter. [19] As of 2007, Burn Injury Model Systems data have been collected from over 4,500 patients. [19]

Outcome measure content validity

Though the main outcome measures for both the BOQ and Burn Injury Model Systems datasets were meticulously devised and demonstrate good psychometric properties, [18,19] the question remains as to whether or not these measures encompass the entire recovery and rehabilitation experiences of burn patients. Are researchers who use these data sets able to determine the full picture of burn recovery over time? An internationally-accepted system devised in 2002 and revised in 2005 [14] allows investigators to link outcome measure concepts to a classification framework known as the ICF in order to answer the aforementioned question as well as to compare and contrast measures based on the framework's domains. In this project, specific Aims 1a and 2a use this linking system to classify and describe all concepts included in and excluded by each of the outcome measures to explore the content validity of the data currently collected in both the Burn Injury Model Systems and Multi-Center Benchmarking Study projects.

Utilizing the International Classification of Functioning (ICF)

In 2001 the WHO endorsed the ICF followed by the Children and Youth version (ICF-CY) in 2007. [26] Developed through an international collaborative effort, the ICF is an integrative framework based on a model of functioning and disability containing four main components: body functions, body structures, activities and participation, and environmental factors. Each component contains five to nine chapters. The chapters are further broken down into 1,424 categories, as demonstrated in the figure below.

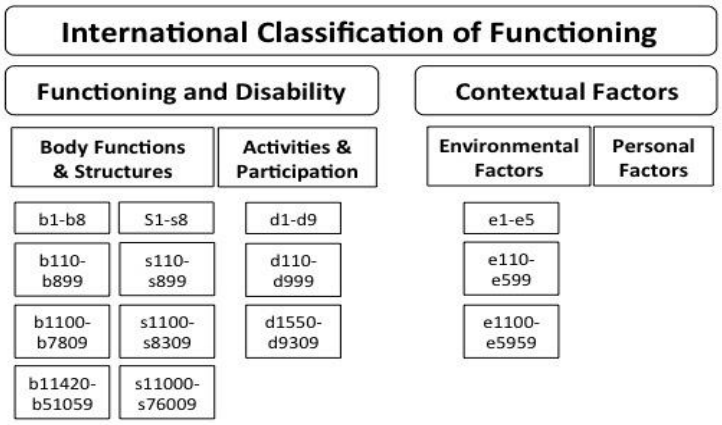

Figure 1. ICF component breakdown[27]

Several ICF validity studies have been conducted worldwide from an array of professional perspectives.[26] In total, the ICF categories have been found to be both exhaustive and precise, which suggests that the framework encompasses the range of human experiences and provides a unified and standardized language that can be used worldwide to classify and describe health and health-related domains.[26]

With this universal language, researchers, clinicians and policy makers are able to describe and document disability and function. Use of the ICF uniform language affords the opportunity to comprehend the impact of disability worldwide on both individual and societal levels. This universal framework provides an opportunity for global information exchange and the ability to pool and compare internationally-collected data. Because individuals with severe burn injuries are surviving at a high rate, research in the area of severe burn rehabilitation is a pressing need if long-term functional outcomes are to be improved. Despite its clearly demonstrated utility in other fields, the ICF's much-needed application to the field of burn recovery research remains sparse. [16,17]

A standardized linking technique

A standardized linking technique allows researchers to link and compare outcome measures using the ICF framework.[14] Below is an example of linking information from a patient interview. Further explanation of the standardized linking technique can be found in Chapter 3: Methods.

Division of text when a change in meaning is discerned	Linking Unit	ICF Code
Sometimes I s-s-stutter and can't find the right word to use, but only when I am around strangers for the first time.	-Sometimes I s-s-stutter -can't find the right word to use -only when I am around strangers for the first time	-b3300 Fluency of speech - b16710 Expression of spoken language - d730 relating with strangers

Table 1. Example of linking technique from a patient interview
Provided by and used with permission of the ICF Research Branch

Recently, the standardized technique was updated to include a method for interpreting outcome measure item perspectives.[27] This allows an investigator to determine if an item is assessing quality of life (QOL) versus health status (HS). As measurement of QOL gains more attention, it is important to differentiate between QOL measures and HS measures. Both concepts measure biological, psychological and social health, however it is the way in which each domain is measured that determines whether health status or quality of life is being assessed. [28]

When a health status assessment is used to measure QOL or a QOL assessment is used to measure health status the results can be misleading. [29] For example, a person who reports poor health may also report a diminished quality of life. On the other hand, a person who reports having excellent health with no depression or anxiety may also report a diminished quality of life for various other reasons. Furthermore, efforts made to improve one's health may diminish one's

quality of life, such as in the management of diabetes. [30] To delineate what is actually being measured (QOL versus health status) in each of the burn assessments, specific aims 1b and 2b will determine the overall perspective by identifying the perspectives of each item within the measures.

The development of ICF core sets

The ICF Core Sets are a joint project of the ICF Research Branch and the Classification Assessment Surveys and Terminology Team of the WHO. The objective of the project is to develop internationally agreed-upon sets of ICF categories to be used as basic standards to describe, evaluate, and research the functioning and disability of individuals with specific diagnoses.[15] Currently the ICF has endorsed 32 core sets for diagnoses in the areas of musculoskeletal, cardiopulmonary, neurologic and other disorders. **No Core Sets have been developed for burn injury.**

Core sets are developed through a two-phase method. The first phase consists of gathering and integrating information. Surveys are conducted among individuals with a specific diagnosis of interest and among experts that manage the care of individuals with the specified diagnosis. A systematic review is conducted to compile the most widely used outcome measures employed in studies of the specified diagnosis. Those outcome measures are then linked to the ICF using the standardized linking technique discussed above in order to identify the ICF categories most commonly assessed among individuals with the diagnosis.

In phase two, a panel of experts recruited from around the world carries out a Delphi formal decision-making process to narrow the focus of ICF categories. The panelists are trained in the ICF framework and classification system prior to decision-making. Core set ICF categories are then selected though the process of discussion and voting. [15] In the current project, specific aim 3 uses the data generated by specific aims 1a and 2a to identify pertinent ICF categories that may be included in the development of an ICF core set for burn injury. Production of a burn injury core set would not only provide an international standard of measurement and reporting that could be used to describe the functioning and disability of burn

injury patients worldwide, but it would also guide burn clinicians in the assessment, treatment, and further study of burn injury.

Chapter 3 Methods

To classify and describe the concepts within both the Burn Injury Model Systems and the Multi-Center Benchmarking Study outcome measures, all linkable concepts within the assessments were linked to the ICF or the ICF-CY using Cieza and collegues' standardized linking system.[31] The following instruments were linked: BOQ 0-4, BOQ 5-18, BOQ 11-18, BOQ-Young Adult/short form, Burn Injury Model Systems initial questionnaire and follow-up 0-4, Burn Injury Model Systems initial and follow-up 5-13, Burn Injury Model Systems initial and follow-up 14-18, and Burn Injury Model Systems adult follow-up. The pediatric (0 to 18 years) assessments were linked to the ICF-CY, and adult assessments were linked to the ICF.

Linking Assessment Concepts to the ICF

The concepts within each outcome measure item were linked to the ICF classification system. A concept was defined as a single health aspect or an environmental factor with an impact on health.[32] Concepts could correspond to either a single word or a phrase. The ICF classification system contains four main components represented by the letters b, s, d, and e [body function (b), body structures (s), activities and participation (d) and environmental factors (e)]. Below is an illustration of the ICF model, the ICF definitions for each component and a chart that offers examples of chapter topics that explain each component.

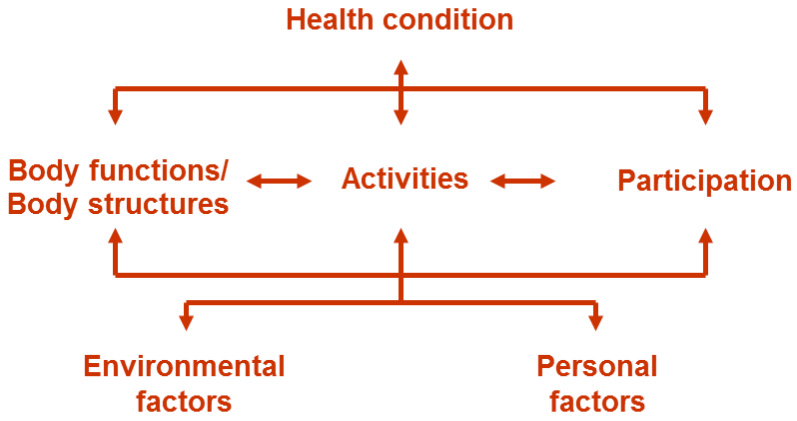

Figure 2. The ICF model created by the WHO.

1. Body **Functions** are physiological functions of body systems (including psychological functions).

2. **Body Structures** are anatomical parts of the body such as organs, limbs and their components.

3. **Activity** is the execution of a task or action by an individual.

4. **Participation** is involvement in a life situation.

5. **Environmental Factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. [33]

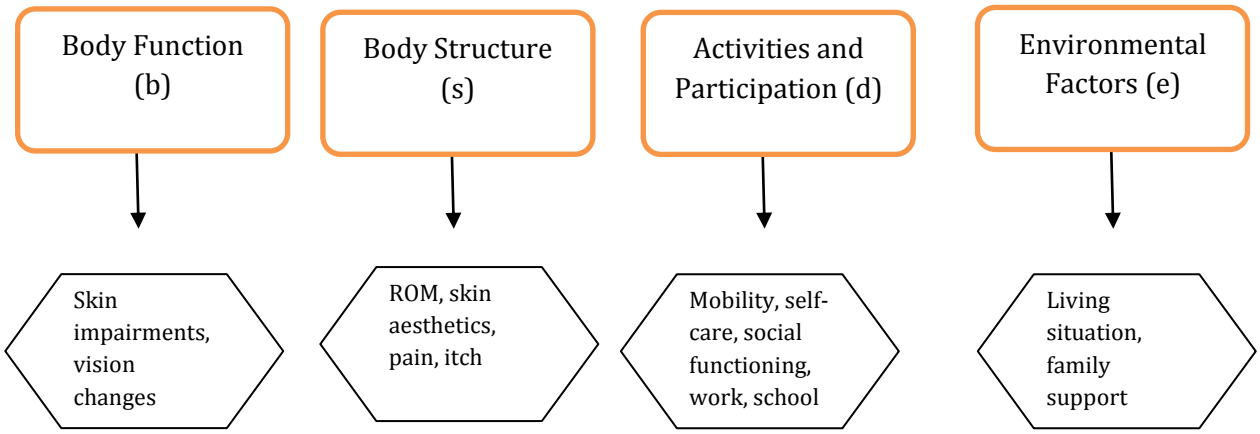

Figure 3. Examples of ICF chapters within each component

Each component is broken down into chapters, which are represented by a one digit number. The chapters are then broken down into category levels. The categories represent the individual units of the ICF. Each chapter contains two, three or four levels of categories. The second level is represented by a two digit number, the third and fourth levels are represented by one digit numbers each. Stamm and colleagues[12] linked outcome measures used to assess function with the ICF in patients with osteoarthritis. The following is an example from their work.

Item: Please assess the pain you had during the last 48 hours caused by your finger joint condition.-- *Score for Assessment and Qualification of Chronic Rheumatoid Affections of the Hand (*SACRAH) question #19

First, all concepts within the item are identified. One item can contain multiple concepts. In the item example above there is one concept, **pain in joints**. The concept falls under the ICF component **'*body structure* (b)'**. It is then linked to chapter two of the component **'*sensory functions and pain* (b2)**'. The second level, one level beyond chapter identification, is **'*sensation of pain* (b280)'**. The third level is **'*pain in body part* (b2801)'**. The code is complete at the fourth level **'*pain in joints* (b28016)'**. Each concept within each item must be linked in this manner. It should be noted that a researcher must consider hundreds of categories for each component to ensure that each nuance within a concept is captured with the utmost precision. Therefore, it is paramount that the researchers involved be trained in the linking technique to increase the reliability of concept coding.

Standardized linking rules

Each item of the Burn Injury Model Systems and the Multi-Center Benchmarking Study outcome measures was linked using this procedure. See table 2 for a list of linking rules with examples. Each item can contain more than one concept. Where this was the case, each concept was coded in the same manner as above. Thus, one item could contain several codes. Concepts were linked to levels three and four when possible. More general concepts often could not be linked at higher levels.

A concept that did not contain enough information to make a decision regarding an ICF category link was labeled nd (not definable). Concepts that were "not definable" but included general health, physical health, mental health or quality of life topics; were labeled nd-gh (not definable –general health), nd-ph (not definable-physical health), nd-mh (not definable-mental health), or nd-qol (not definable-quality of life).[31] Concepts that were not defined in the ICF were labeled nc (not covered by ICF). Concepts that referred to a diagnosis or health condition were labeled hc (health condition).[31]

Personal factors that were not defined by the ICF were classified as no code-pf (personal factor). Personal factors are defined in the ICF as:

> The particular background of an individual's life and living, and comprise features of the individual that are not part of the health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level. [27]

According to the revised standardized linking rules of 2005, all concepts that fulfill the above stated criteria could be labeled as 'personal factors'. However, recently there has been a call to reconsider the use of the label 'personal factor'. [34] Those who support the reconsideration of the label suggest that the component is not defined because it contains no specific categories. Because there are currently no specified codes within the 'personal factor' component, the consequences of using the component are unknown. Furthermore, the lack of personal factor codes undermines the fundamental principles of the ICF; to provide a standard universal language rooted in science.[34] Without codes to describe personal factor concepts, the power and scientific basis of a classification system ceases to exist.[34] Thus, the global community has been advised to refrain from using 'personal factor' label until the component has been systematically reviewed and revised to meet the standards of other categories. [34] Accordingly, the 'personal factor' category was not included in this study. The standardized linking rules and a flow chart that demonstrates the linking process is displayed below.

Rule	Rule Description	Example
1	Acquiring knowledge of ICF(CY) chapters, domains, and categories	
2	Linking each meaningful concept to the most precise category	B28010 (pain in head and neck)
3	Do not use the so-called "other specified" ICF categories, additional information shall be documented	E4 (Attitudes)
4	Do not use the "unspecified" ICF categories, use lower level of category	
5	Designation not definable (nd) should be used when meaningful concept is not sufficient	If the concept refers to health, the designation should be nd-gh . If the concept refers to quality of life, the designation should be nd-qol
6	If a meaningful concept is clearly a personal factor defined by ICF (CY), this can be documented pf	pf gender, age This linking rule was not included in this study
7	If there is no evidence of a meaningful concept and no personal factors are identified, then assign the concept nc	nc
8	If a meaningful concept refers to health conditions or diagnosis if should be assigned hc	hc diabetes, asthma

Table 2. Linking Rules as Described by Cieza et al[11,15,31]
Abbreviations: nd-gh (not definable-general health), nd-qol (not definable-quality of life), pf (personal factor), nc (not covered), hc (health condition)

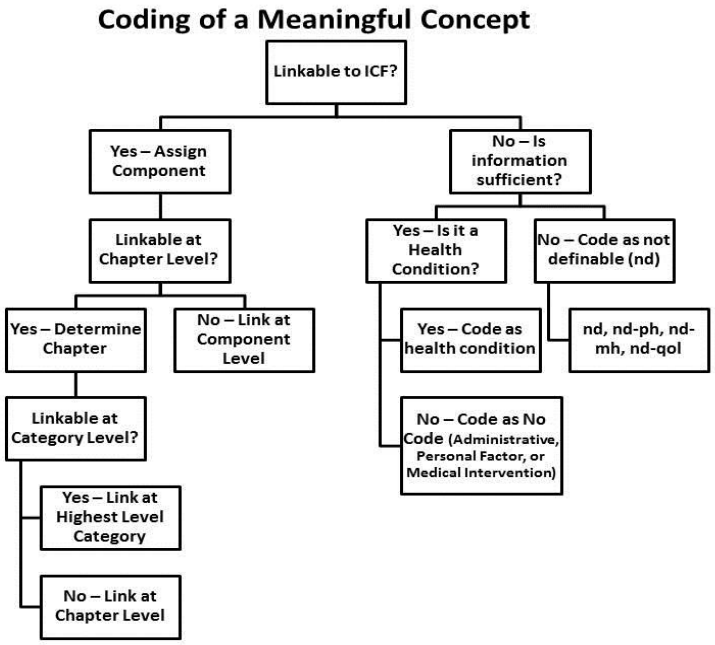

Figure 4. Linking process flowchart

Coding for quality of life vs. health status

In addition to linking each concept to the ICF, the perspective of each item was separately coded based on the World Health Organization's (WHO) definitions of QOL, health status (functioning, disability), and environmental barrier/facilitator. The definition of each perspective is derived from a previous ICF linking study conducted by Fayed and colleagues. [28] These definitions are based on the authors' understanding of WHO terminology included in the WHOQOL-BREF and the ICF-CY standard classification documents. The WHO definitions were selected because they are rigorous and were developed based on input from numerous professional perspectives and stakeholders around the world. These definitions were used to determine the perspective of each item in this study. The definitions are as follows:

1. **QOL**: QOL perspectives reflect individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns

2. **Health (functioning):** functioning perspectives refer to the interaction or the individual components of body functions, activities, and participation

3. **Health (disability):** Disability perspectives probe impairment, activity limitations, and/or participation restrictions

4. **Environmental (barriers)**: Barriers perspectives reflect environmental factors that hinder the functioning of an individual

5. **Environmental (facilitators):** Facilitators perspectives reflect environmental factors that promote or allow for the functioning of an individual [35 27 28]

The QOL approach is generally operationalized with terms such as "importance," "satisfaction," and "feelings about." [13] A QOL item probes an individual's perception. These items were coded as 'QOL.' Health status questions probe one's functional status or level of impairment or activity limitation. These items were coded "health (functioning)" or "health (disability)." Finally, items regarding factors in the environment that serve either as barriers or facilitators were coded as "environmental (barrier)" or "environmental (facilitator)."

Linking reliability

To establish the inter-rater reliability of the linking process, a second researcher with ICF linking experience linked ten percent of all the questions included in the dataset. The concepts within each question were mutually agreed upon prior to linking. Questions linked by the second researcher were randomly selected. Both researchers agreed upon a list of additional linking rules that were created specifically for the linking of the BOQ and BMS assessments to the ICF. The rules addressed issues related specifically to the coding of these assessments and may not apply in other linking scenarios. The rules were as follows:

1. Code "burn injury" and "burn" as "hc" for "health condition" because burn injury has an ICD10 code.

2. All items deemed "personal factors" code as "no code"

3. When the assessment refers to the patient's "work/job" code as "remunerative employment" unless context clearly insinuates otherwise

4. Interventions (ie hydrotherapy, stretching, splinting, garments, casts etc) code as "no code-intervention"

5. Many of the prefixes contain a phrase/concept referring to "activities". The activities are further defined within each of the questions; therefore do not code the word "activities" in the prefix, code the specific activities presented in the question.

6. When a concept refers to area of the body burned use the skin related structure codes rather than other structure codes. The skin related codes are more appropriate for burn injury.

The level of agreement between the first and second researcher was established using percentage agreement and kappa statistics. Kappa values range between 0 and 1, where 1 indicates perfect agreement and 0 specifies no additional agreement beyond what is expected by chance. Kappa coefficients above 0.61 are considered to be good. [36] Linking codes that were not agreed upon between the two researchers were decided upon by a third researcher, also trained in the ICF and ICF standardized linking technique.

A quantitative and qualitative analysis

Once concepts from the Burn Injury Model Systems and the Multi-Center Benchmarking Study outcome measures were linked to the ICF, a descriptive analysis of each instrument was used to determine:

1. The frequency with which specific concepts are linked to each ICF component/chapter/level
2. The nature of the concepts covered within each instrument
3. The components/chapters/levels not covered by each assessment
4. The concepts in each assessment not covered by the ICF (nc)
5. The representativeness of each ICF component within each instrument
6. The content density (concepts per item)
7. Concepts unable to be linked to the ICF
8. The proportion of each instrument that examined each perspective: QOL, health status, or environmental factors

The results of the BMS and BOQ assessment analyses were then compared to the linking results of the most commonly used pediatric burn injury assessments, which were linked at a chapter level in a systematic review conducted by Van Baar and colleagues in 2006[16]. Based on the BMS and BOQ linking results, a preliminary list of Core Set category candidates that are representative of the four ICF domains was developed to serve as a foundation for the future development of a pediatric burn injury ICF Core Set.

Chapter 4 Multi-Center Benchmarking Study

Introduction

The dramatic increase in survivors of severe burns over the past three decades has resulted in a shift in focus from preventing mortality to understanding of the health outcomes over time among burn patients.[6,37] These patients are a complex population, presenting with deficits that impact numerous aspects of life including aesthetic appearance, relationships, psychological and emotional health, physical functioning and social interaction.[6] Because severe burn injury can result in a myriad of complicated deficits that have long term effects; the measurement of burn outcomes is complex and remains in its infancy.[6] It is crucial that the burn community develop a more robust plan to measure outcomes in order to demonstrate that advancements in medical treatment and rehabilitation are benefiting patients.[6] However, likely due to a lack of consensus within the burn community, best practice guidelines describing fundamental assessment domains for burn injury have yet to be established. [6,16] Recently, many international disease-specific initiatives have called for the development of recommendations regarding which specific domains to address and what outcome measures to use to best assess those domains.[6]

To address these challenges, a universal framework that provides a global language for understanding functioning following burn injury is needed.[31] This will not only provide the necessary guidance for disease-specific domain focus and measurement, but it may also improve outcomes research around the world.[31] The International Classification of Functioning, Disability and Health (ICF) was approved by the World Health Organization (WHO) in 2001 as the universal framework to be used to classify and describe body function, body structure, activities and participation and environmental factors. To date, over 100 studies utilizing the ICF standardized linking technique to examine the comprehensiveness of outcome measures have been published in 58 peer-reviewed journals spanning 50 different focus areas across diagnoses, settings, languages and countries.[7-13] Despite this

broad application, the much-needed guidance of the ICF has not yet been widely applied in the field of burn recovery intervention and research. [16,17]

The objective of this study was to link, classify, and describe the concepts of the Multi-Center Benchmarking Study outcome measure known as the Burn Outcomes Questionnaire (BOQ) using the ICF and the ICF-CY (Children and Youth version) to determine the depth and breadth of concepts covered by the BOQ instrument. The ICF standardized linking technique was used to determine if there are areas in the BOQ that are not being explored or topics that would be better understood with more in depth probing. By linking the BOQ to the ICF, we were able to determine if the information gleaned from this widely used multicenter assessment is providing researchers and clinicians with a thorough understanding of life after burn injury, what areas are missing, and where there is room for improvement.

A secondary objective was to define the perspective of each item to determine what percentage of the BOQ assessments measure health status (disability and functioning), quality of life (QOL), and environmental factors. It is vital that this distinction be determined to understand precisely what the BOQ instrument is measuring. The terms "health status" and "quality of life" are not interchangeable, though this is a common mistake.[30] [29] [38] Quality of life is a personal perception of a situation based on one's culture, value system, personal goals, standards and concerns. [35] A person's health status is shaped by biopsychosocial elements pertaining to health conditions, physical and emotional performance and social barriers or facilitators.[39] [28] Researchers and clinicians using the data produced by these assessments should be aware of the assessments' perspectives, so that the information is used appropriately. Failure to determine the perspective of a measure may result in misleading conclusions that only serve to hinder progress towards understanding life after burn injury.

The Multi-Center Benchmarking Study is one of three active large, multi-center burn data collection projects in the United States.[18,19,21] The study began in

1996 with a consensus panel of experts from the American Burn Association (ABA) and Shriners Hospitals for Children burn hospitals.[23] The panel's aim was to develop a burn-specific outcome instrument that documented the needs of severe burn patients across stages of life development.[23] The panel created a theory-based measure that captures the post-burn experience of patients and their families which has proven reliable, valid, and responsive to change among burn survivors over time.[23]

The developers of the BOQ created the instrument based on numerous domains pertinent to specific age groups. The BOQ 0-5 years was created based on the following ten domains: play, language, fine motor, gross motor, behavior, family, pain, appearance, satisfaction and worry. [24] The BOQ 5-18 years was developed to capture outcomes within domains such as upper extremity function, physical function and sport, transfers and mobility, pain, itch, appearance, compliance, satisfaction with current state, emotional health, family disruption, parental concern, and school reentry.[25] The BOQ young adult (YA) was developed based on the following domains: physical function, fine motor function, pain, itch, social function, satisfaction with appearance, sexual function, emotion, family function, family concern, satisfaction with symptom relief, satisfaction with role, work reintegration, and religion. [40] Data are collected from children admitted to Shriners Hospitals for Children with acute burn injuries greater than 20% total body surface area (TBSA) or less than 20% TBSA with injuries to critical areas (hands, feet face and/or genitals). [18] Patients are assessed at discharge from acute care and at 6, 9, 12, 18, 24, 36, and 48 months thereafter. As of 2012 the Multi-Center Benchmarking Study has collected data from over 1,100 patients.[18]

The standardized linking technique developed by Cieza and colleges[31] was used to link all linkable concepts within the BOQ assessments to the ICF or the ICF-CY to determine the following:

1. The frequency with which specific concepts were linked to each ICF component/chapter/level
2. The nature of the concepts covered within each instrument

3. The components/chapters/levels not covered by each assessment
4. The concepts in each assessment not covered by the ICF (nc)
5. The content density (concepts per item) for each item
6. The similarities and differences in the concepts covered by instruments between each age group
7. Concepts unable to be linked to the ICF
8. The proportion of each instrument that examines each perspective: QOL, health status, or environmental factors

We hypothesized that *(Hypothesis 1)* ninety percent of the Multi-Center Benchmarking study outcome measure items from the BOQ versions would be linkable to the ICF and; *(Hypothesis 2)* sixty percent of the items in the Multi-Center Benchmarking Study outcome measure would be linked to the ICF component 'activities and participation', twenty percent of the items would be linked to 'body structure', ten percent of the items would be linked to 'body function', ten percent of the items would be linked to 'environment' and; *(Hypothesis 3)* seventy percent of the items in the Multi-Center Benchmarking Study outcome measure would be described as health status perspective, twenty percent of the items would be described as QOL perspective, and ten percent of the items would be described as environmental perspective.

Methods

Materials

The following Multi-Center Benchmarking Study assessments were linked and analyzed: BOQ 0-4, BOQ 5-18, BOQ 11-18, and BOQ YA.

Analytic procedure

The linking methods are explained in detail in Chapter 3: Methods. This section will present a general description of the methods used to complete this study. All of the items contained within each of the assessments were reviewed, and all meaningful concepts within each item were identified and linked to the ICF using a standardized linking technique. An item could contain more than one concept, and each concept was coded separately to the third and fourth level of the ICF when possible. A meaningful concept was linked to the ICF unless the concept was not

linkable or the ICF did not contain a code that accurately described the concept. Such concepts were labeled as the standardized linking technique requires; 'nd' (not definable), 'nc' (not covered), 'hc' (health condition), 'ndgh' (not definable-general health) or 'ndqol' (not definable-quality of life). All concepts deemed personal factors, interventions, or administrative in nature were labeled as 'no code'. Although the standardized linking technique states that all concepts that describe personal factors such as gender, race, age, lifestyle, habits, education, and others shall be labeled 'pf' (personal factor); a recent call was made to refrain from the use of the 'pf' label until the use of the category can be systematically reviewed and revised to meet the standard by which the other ICF categories have been held.[34] Because the category does not contain specific personal factor codes, it cannot be used to accurately classify and describe personal factor concepts. The category has not been scientifically established; therefore the consequences of using the 'pf' label are unknown.[34] In this study, all personal factor concepts were coded 'no code' and were considered not linkable.

Each of the assessments contains questions that are initiated with a prefix. Several questions can fall under one prefix. For example, in the BOQ 0-4 the prefix states, "over the past month, how often has this child's health or behavior:". Following the prefix are 5 questions such as, "interrupted family meals" and "limited parents' ability to work". The assessment prefixes were entered into the database only once. Therefore, concepts within each prefix are linked to the ICF only once. They are not repeatedly linked with each question to which they apply. Table 4, located at the conclusion of the Results section, shows the number of prefixes included in each assessment and the total number of concepts identified within those prefixes. Repeating the prefix concepts with each question would result in an inflated concept density per question. See Table 3 below for a description of the standardized linking rules.

Rule	Rule Description	Example
1	Acquiring knowledge of ICF(CY) chapters, domains, and categories	
2	Linking each meaningful concept to the most precise category	B28010 (pain in head and neck)
3	Do not use the so-called "other specified" ICF categories, additional information shall be documented	E4 (Attitudes)
4	Do not use the "unspecified" ICF categories, use lower level of category	
5	Designation not definable (nd) should be used when meaningful concept is not sufficient	If the concept refers to health, the designation should be nd-gh . If the concept refers to quality of life, the designation should be nd-qol
6	If here is no evidence of a meaningful concept and no personal factors are identified, then assign the concept nc	nc
7	If a meaningful concept refers to health conditions or diagnosis if should be assigned hc	hc diabetes, asthma

Table 3. Linking Rules as Described by Cieza et al [11,15,31]
Abbreviations: nd-gh (not definable-general health), nd-qol (not definable-quality of life), pf (personal factor), nc (not covered), hc (health condition)

In addition to coding the concepts within each item, the perspective of each item was also determined based on the terminology included in the World Health Organization Quality of Life-BREF (WHOQOL-BREF) and the ICF-CY standard classification documents. The WHO definitions were selected because they are rigorous and were developed based on input from the perspectives of numerous professionals and other stakeholders around the world.[13] The definitions are as follows:

1. **QOL**: QOL perspectives seek to determine individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns

2. **Health (functioning):** functioning perspective refers to the interaction or the individual components of body functions, activities, and participation

3. **Health (disability):** Disability perspectives probe impairment, activity limitations, and/or participation restrictions

4. **Environmental (barriers)**: Barriers perspectives reflect environmental factors that hinder the functioning of an individual

5. **Environmental (facilitators):** Facilitators perspectives reflect environmental factors that promote or allow for the functioning of an individual [35 27 28]

A QOL approach is generally operationalized with terms such as "importance," "satisfaction," and "feelings about." [13] A QOL item probes an individual's perception about health or life. Such items were coded 'QOL.' Health status questions probe one's functional status or level of impairment or activity limitation. These items were coded 'health (functioning)' or 'health (disability)'. Questions that referred to a person's health status but were neither function nor disability-related were coded as 'health status (general)'. Finally, items regarding factors in the environment that serve either as barriers or facilitators were coded as 'environmental (barrier); or 'environmental (facilitator).'

Reliability

To establish the inter-rater reliability of the linking process, a second researcher with extensive ICF linking experience linked 10% of the questions included in a database created to store and analyze burn assessment concepts and their ICF codes. The concepts were mutually agreed upon prior to linking. Questions to be linked by the second researcher were randomly selected, and the level of agreement was established using percentage agreement and kappa statistics. Kappa coefficients greater than .61 are considered good.[36] Linking codes that were not agreed upon between the two researchers were determined by a third researcher also trained in ICF linking technique.

Results

Linking to the ICF

A total of 551 concepts were identified among the 353 items included in all of the BOQ assessments. Two hundred and ninety BOQ concepts (53%) were linkable to the ICF or ICF-CY (See Table 4 below for overall results). The linking results were similar between the BOQ assessments as many similar and identical items appear throughout each of the assessments.

Linked Concepts				
	BOQ(0-4)	BOQ(5-18)	BOQ(11-18)	BOQ YA
Number of prefixes	14	10	10	13
Number of question concepts	116	129	128	107
Number of prefix concepts	20	16	16	19
Total number of concepts	136	145	144	126
Content density (concepts per question)	1.3	1.4	1.4	1.3
Concept density (concepts per prefix)	1.4	1.6	1.6	1.5
Concepts linked to ICF components				
Body structure	0	0	0	0
Body function	25	22	22	21
Activities and Participation	36	48	48	37
Environmental factors	11	9	9	4
Total: linked concepts	72	79	79	62
Concepts unable to be linked				
Concepts considered health conditions (hc)	32	30	30	39
Concepts not definable (nd)	7	8	8	8
Concepts nd:general health	4	6	6	2
Concepts nd:physical health	0	0	0	0
concepts nd:quality of life	1	2	2	1
Concepts nd:mental health	0	0	0	0
Concepts not covered (nc)	8	6	6	2
Concepts no code	12	14	13	12
Total: unlinked concepts	64	66	65	64

Table 4. Linking of the Burn Outcomes Questionnaire concepts to the ICF

Of the 121 concepts that were randomly extracted from the database and coded by two coders, the coders agreed that a concept was linkable or not linkable 82% of the time. A kappa value of .67 indicated that agreement was good regarding the coding of concepts that were linkable to the ICF at the chapter level. A third coder was required for 31 concepts (26%) to resolve differences. The results are presented by assessment below.

BOQ 0-4

Concepts linkable to the ICF

Seventy-two of the 136 concepts (53%) identified in the BOQ 0-4 assessment were linkable to the ICF CY. Linkable concepts in this assessment represented three of the four ICF components. The figures below demonstrate the number of concepts classified per ICF chapter.

Of the 72 linkable items included in this assessment, 25 concepts (35%) were linked to the component *body functions (b)*. *Body functions (b)* component chapters represented in this assessment included: mental functions (b1) (14 concepts out of 72), sensory functions and pain (b2) (five concepts), and functions of the skin and related structures (b8) (6 concepts). The category most often coded among concepts linked to *body functions (b)* was 'emotional functions' (b152). The next most coded category was 'sensations related to the skin' (b840). 'Sensation of pain' (b280) was the third most frequent concept.

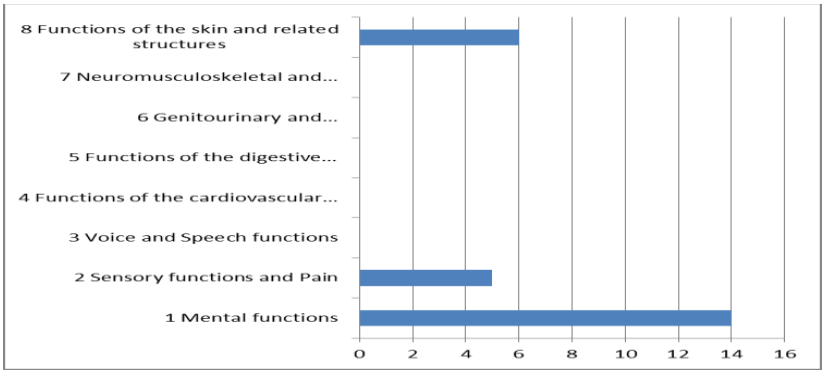

Figure 5. Burn Outcomes Questionnaire 0-4 Body Functions (b). X-axis represents the number of concepts

Of the 72 linkable concepts included in the BOQ 0-4, 36 concepts (50%) were linked to the *activities and participation (d)* component of the ICF. All of the *activities and participation* ICF chapters (1-9) were represented at least once in this assessment. The chapters coded most often were mobility (d4) (9 concepts), self-care (d5) (8 concepts) and major life areas (d8) (6 concepts). The most common

category code was 'engagement in play' (d880).

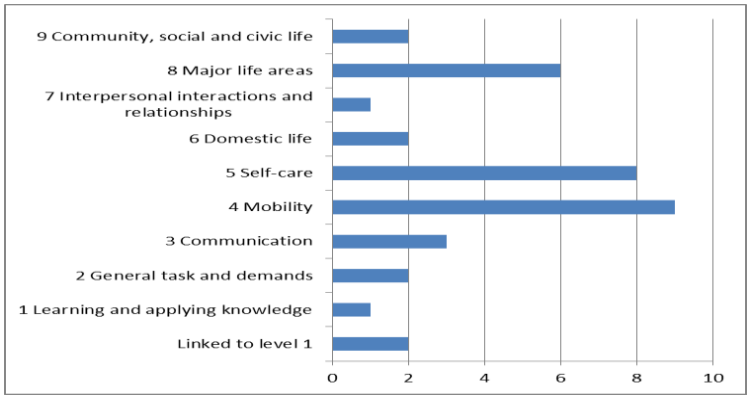

Figure 6. Burn Outcomes Questionnaire 0-4 activities and participation (d). X-axis represents the number of concepts

Of all linkable items in the BOQ 0-4, 11 concepts (15%) were linked to the chapter, *environmental factors (e).* Items were linked to four out of five chapters included in this component. The chapters most often linked were products and technology (e1) (4 concepts) and services, systems and policy (e5) (4 concepts).

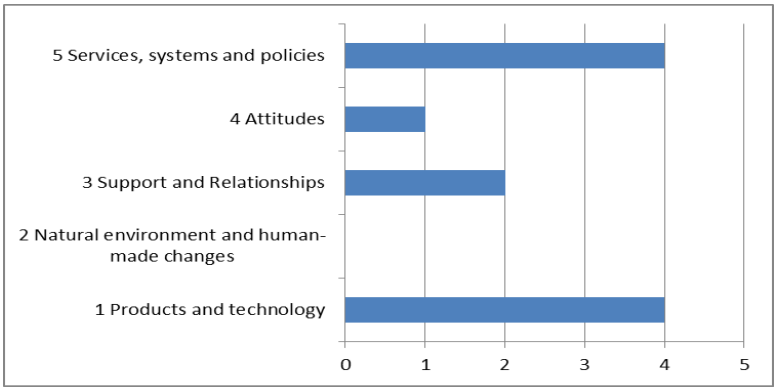

Figure 7. Burn Outcomes Questionnaire 0-4 environmental factors (e). X-axis represents the number of concepts

The ICF component, *body structures (s)*, was not represented in the BOQ 0-4. This ICF component includes anatomical parts such as organs, limbs. *Body structure (s)* codes can be used to describe impairment. For children and adolescents, impairments may include delays or lags in growth or development of body structure.[39] None of the BOQ 0-4 items were representative of this component.

Concepts not linkable to the ICF

Sixty-four out of the total 136 concepts (47%) included in the BOQ 0-4 was not linkable to ICF. However, it should be noted that health conditions (hc) are not considered linkable to the ICF because the ICF was created for use in conjunction with the International Classification of Diseases (ICD) codes, an international system used to classify diseases and other health issues. [26,41,42] Therefore, a health condition such as burn injury is coded using the ICD classification system rather than the ICF classification system. In the BOQ 0-4 the phrase 'burn injury' appears over 15 times. Each time the phrase was coded 'hc' (health condition). Furthermore, the assessment queries the patient regarding the diagnostic presence of 15 additional health conditions. Each of these conditions was also considered not linkable and coded as 'hc'. Therefore, it seems that a large percentage of the assessment was unable to be linked to the ICF, though in actuality many of these items are linked to a separate classification system used in conjunction with the ICF. With the removal of the 'hc' items from the analysis, 30% of the concepts included in the assessment were not linkable, rather than the previously stated 47%.

Among those concepts considered not linkable to the ICF, 12 out of 64 unlinkable concepts (19%) were coded 'no code'. 'No code' includes all concepts considered personal factors, medical interventions, or administrative items such as "who is filling out this questionnaire?" Thirteen percent were coded as 'nc' (not covered). For these concepts, the ICF does not provide a code that describes the meaning of the concept. For example, BOQ 0-4 item [27] "Destroys own things". The ICF does not offer a code that describes the destruction of one's property. Eleven percent of concepts which were unable to be linked were coded as 'nd' (not definable). These concepts were considered too vague to be coded by the ICF. For example, BOQ 0-4 item [35] "Over the past month, how often has this child's health or behavior limited parents' ability to have time for themselves or time with friends." The concept, "ability to have time for themselves" is not definable in a such way that the meaning can be linked to the ICF. The remainder of codes not linkable

to the ICF, 5 out of 64 concepts (8%), were coded as 'ndgh' (not definable-general health) or 'ndqol'(not definable-quality of life).

BOQ 5-18 and 11-18

Concepts linked to the ICF

The BOQ 5-18 and 11-18 are fundamentally the same assessment. The BOQ 5-18 contains one more question than the BOQ 11-18, and that question serves purely administrative purposes. The other difference between the assessments is the intended responder. The questions in the BOQ 5-18 are to be completed by a parent or guardian. The BOQ 11-18 is written to be completed by the patient. For example, the BOQ 11-18 assessment asks questions such as, "how often do you need help from another person for walking and climbing?". The same question will be asked in the BOQ 5-18 assessment as, "how often does this child need help from another person for walking and climbing?". These two questions cover the same concepts and receive the same ICF codes. Therefore, the coding for the two assessments was identical and will be discussed as one.

Seventy-nine of the 145 concepts (54%) identified in the BOQ 5-18 and 11-18 were linkable to the ICF. Like the BOQ 0-4, concepts were linked to three of the four ICF components. Of the 79 of linkable concepts, 22 concepts (15%) were linked to the component, *body functions (b)*. Five of the eight *Body functions (b)* chapters were represented in the BOQ 5-18 and 11-18. The chapters most often coded included; mental functions (b1) (12 concepts out of 79), sensory functions and pain (b2) (5 concepts), and functions of the skin and related structures (b8) (3 concepts). Chapters with only one concept each included; functions of the cardiovascular, hematological, immunological and respiratory systems (b4) and neuromusculoskeletal and movement-related structures (b7). The *body functions (b)* categories most often represented included 'emotional function' (b152), and 'sensation of pain' (b280).

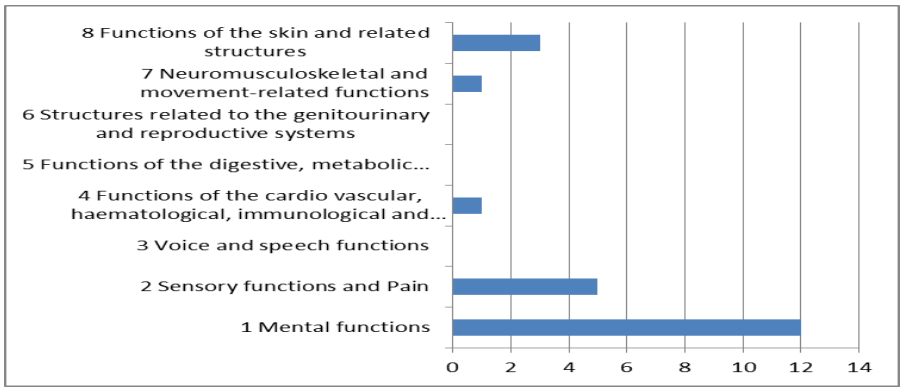

Figure 8. Burn Outcomes Questionnaire 5-18 and 11-18 body functions (b). X-axis represents the number of concepts

Forty-eight out of 79 linked concepts (60%) were linked to the component, *activities and participation (d).* Seven of the nine *activities and participation (d)* chapters were represented in the BOQ 5-18 and 11-18. Chapters most frequently linked to *activities and participation (d*) concepts were mobility (d4) (13 out of 48 concepts) and community, social and civic life (d9) (12 concepts). Categories most often represented included recreation and leisure (d920), specifically sports (d9201). The next most frequently coded categories were managing one's own behavior (d250) and managing medications and following health advice (d 57020).

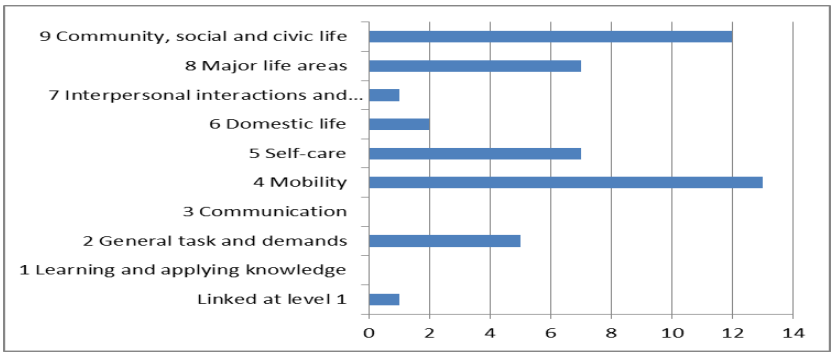

Figure 9. Burn Outcomes Questionnaire 5-18 and 11-18 Activities and Participation (d). X-axis represents the number of concepts

Nine out of 79 linked concepts (11%) were coded as *environmental factors (e).* Concepts were linked to three out of the five *environmental factors (e)* chapters. The chapter represented most often was services, systems and policies (e5) (5 out

of 9 concepts). The chapters, Support and Relationships (e3) and Attitudes (e4), were represented by two concepts each. The most common categories coded were special education and training services (e5853) and health services (e5800) with two concepts coded for each. As with the BOQ 0-4 assessment, the ICF component, *body structures (s)* was not represented in the BOQ 5-18 or 11-18.

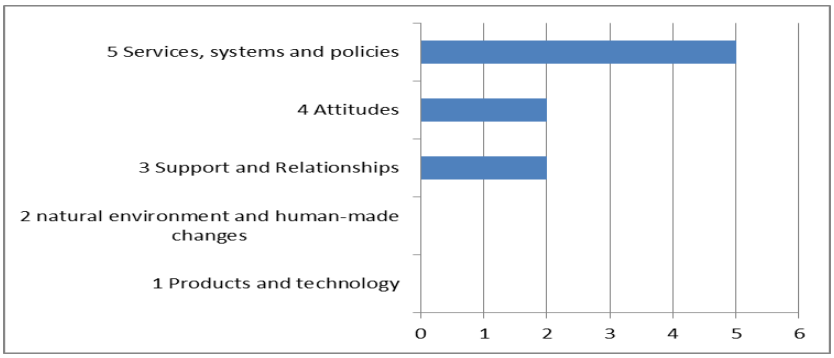

Figure 10. Burn Outcomes Questionnaire 5-18 and 11-18 environmental factors (e). X-axis represents the number of concepts

Concepts not linkable to ICF

Sixty-six out of 145 concepts (45%) in the BOQ 5-18 and 11-18 were considered not linkable to the ICF CY. However, as with the BOQ 0-4, a large portion of the concepts deemed unable to be linked were health conditions ('hc') linked through the ICD system (30 concepts). Without the inclusion of health conditions in the analysis, only 25% of the assessments are considered unable to be linked.

Fourteen out of 66 unlinked concepts (21%) of the BOQ 5-18 and 11-18 were coded as 'no code'. Eight concepts (12%) of each assessment was coded as 'nd' (not definable). Six of the unlinked concepts (9%) were coded as 'nc' (not covered). Six concepts (9%) were coded as 'ndgh' (not definable-general health). Two concepts (3%) were coded as 'ndqol' (not definable-quality of life).

BOQ Young Adult (YA)

Concepts linkable to the ICF

Sixty-two concepts of the 126 concepts (49%) included in the BOQ YA were linkable to the ICF. Three of the four ICF components were represented.

Twenty-one out of 62 linked concepts (34%) were linked to the *body*

functions (b) component. Four out of eight *body functions (b)* chapters were represented in this assessment. The chapter most often coded within this component was mental function (b1) (nine out of 62 concepts). Five out of 62 concepts were coded as genitourinary and reproductive functions (b6). Four concepts were coded as sensory functions and pain (b2). Three concepts were coded as functions of the skin and related structures (b8). Categories coded most often, in order of frequency, were 'emotional functions' (b152), 'functions of sexual arousal phase' (b6400), 'sensations related to the skin' (b840), and 'sensations of pain' (b280).

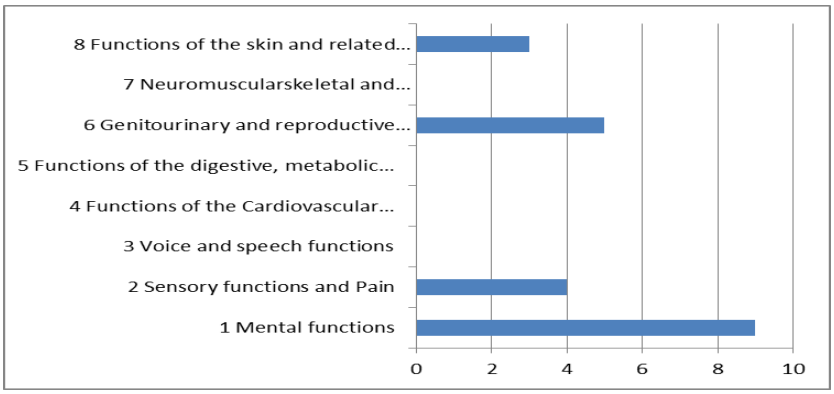

Figure 11. Burn Outcomes Questionnaire Young Adult body functions (b). X-axis represents number of concepts

Thirty-seven out of 62 linked concept (58%) of the BOQ YA were ascribed to the *Activities and Participation (d)* component. Seven of the nine *activities and participation (d)* chapters were represented in this assessment. Sixteen out of 62 concepts were linked to the chapter, community, social and civic life (d9). Nine concepts were linked to the chapter, major life areas (d8). Six concepts were linked to the chapter, mobility (d4). Chapters, general task and demands (d2) and self-care (d5), domestic life (d6), and interpersonal interactions and relationships (d7) were represented at least once in the BOQ YA. The categories represented most included: recreation and leisure (d920), specifically, socializing (d9205) and sports (d9201), and school education (d820).

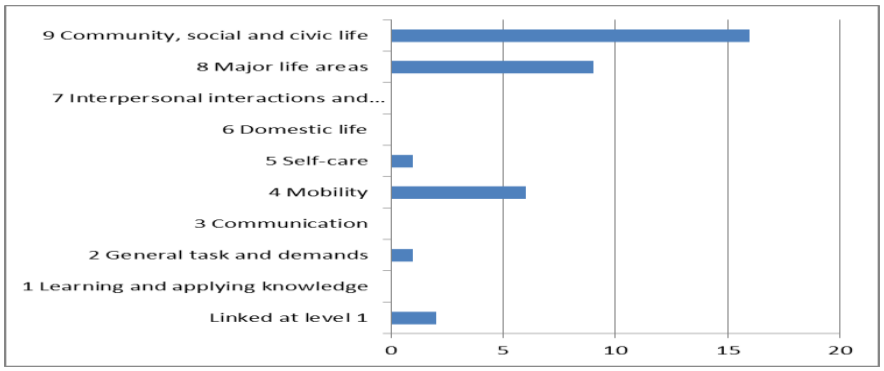

Figure 12. Burn Outcomes Questionnaire Young Adult activities and participation (d). X-axis represents number of concepts

Four out of 62 linked concepts (6%) of the BOQ YA concepts were coded as the component, *environmental factors (e).* Three of the five chapters are represented. Two concepts were coded with the chapter, attitudes (e4), one concept was attributed to the chapter, support and relationships (e3), and one concept was attributed to the chapter, services, systems and policies (e5). The following categories were represented: health professionals (e355), individual attitudes of acquaintances, peers, colleagues, neighbors and community members (e425), individual attitudes of people in positions of authority (e430), and health services (e5800).

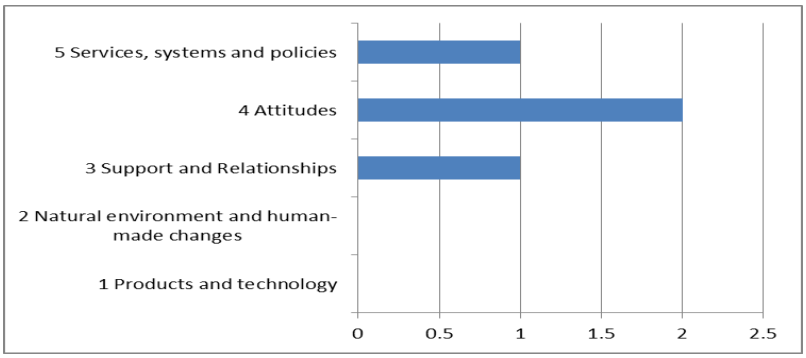

Figure 13. Burn Outcomes Questionnaire Young Adult environmental factors (e)

Concepts not linkable to the ICF

Sixty-four out of 126 total concepts (52%) included in the BOQ YA were unable to be linked to the ICF. Similar to other BOQ assessments, 39 concepts were

considered 'hc' health conditions. As such, these 39 concepts would be coded using the ICD system. When the health conditions are not included in the distribution, 21% of the assessment was unable to be linked to the ICF. Twenty-one percent of the concepts were labeled as 'no code'. Twelve percent were coded as 'nd' (not definable). The remaining five concepts were coded as 'ndgh' (no definable-general health), 'nc' (not covered), or 'ndqol' (not definable-quality of life).

Perspectives

The perspective distribution between the BOQ 0-4, BOQ 5-18 and BOQ 11-18 was similar. Overall, 70% of the BOQ 0-4 and 68% of the BOQ 5-18 and 11-18 were of the health status perspective. Of the perspectives, the most highly represented was health status (disability): BOQ 0-4 (43%), BOQ 5-18 (38%), and BOQ 11-18 (39%). Twenty to 25% of the questions for each of the assessments were attributed to the health status (functioning) perspective. The Quality of Life perspective was assigned to 8-13% of questions for each of assessment. Both environmental (facilitator) and health status (general) perspectives were attributed to questions less than 3% of the time. Seventeen to 20% of the questions included in each of the assessments were unable to be assigned to one of the five perspectives.

The BOQ YA assessment resulted in a different distribution of perspectives than the assessments described above. Overall, 65% of the assessment was of a health status perspective. Similar to the assessments above, the majority (54%) of the questions were of the health status (disability) perspective. Sixteen percent of the questions were attributed to the QOL perspective. Health status (functioning) perspective was assigned to 10% of the questions. Health status (general) and environmental (facilitator) perspectives were assigned to less than 3% of the questions. Sixteen percent of the questions were unable to be assigned a perspective. The environmental (barrier) perspective was not used in any of the BOQ assessments.

Perspectives	BOQ0-4	BOQ11-18	BOQ5-18	BOQYA	Grand Total
Environmental (facilitators)	1	2	2	2	7
Environmental (barriers)	0	0	0	0	0
Health Status (disability)	39	35	35	44	153
Health Status (functioning)	22	24	24	8	78
Heath Status (general)	2	2	2	1	7
Quality of Life	8	12	12	13	45
Other	18	15	16	14	63
Total number of questions	90	90	91	82	353

Table 5. Perspectives represented by Burn Outcomes Questionnaire assessments
Numbers represent counts.

Discussion

The goal of this study was to link, classify and describe the concepts included in the BOQ outcome measures using the ICF framework. This was accomplished by identifying and quantifying all concepts contained in the assessments using the ICF framework, a globally accepted and validated tool. [26] Overall, only about half of the concepts contained within each assessment were found to be linkable to the ICF. However, the frequently-appearing concept "burn injury" is considered a health condition which is linked to the ICF's partner document, the ICD. If we consider these health conditions as linked concepts (because they are classified through the ICD), then approximately 70% of concepts in each assessment would be considered linkable to the ICF or its partner document, the ICD.

Linking: what's missing and what are the implications

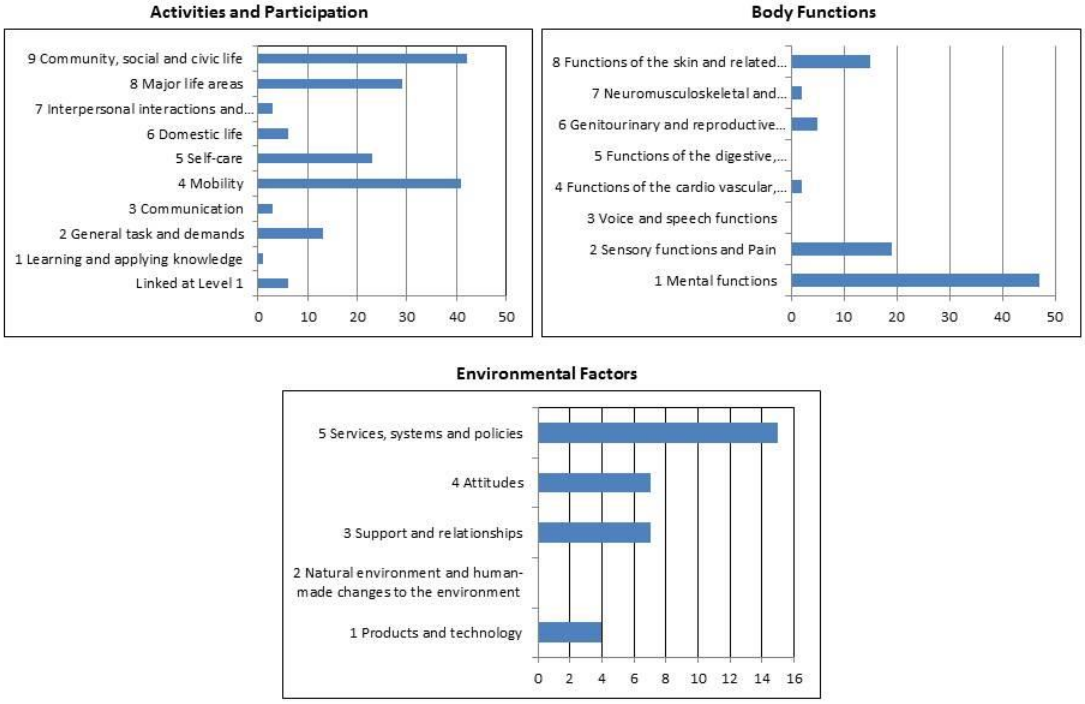

Figure 14. Linkable concepts by chapter for all Burn Outcomes Questionnaire assessments. X-axes represent the number of concepts

Fifty-three percent of the BOQ concepts were linked to the ICF, a smaller amount than our hypotheses of 90%. Overall, the majority of BOQ linkable concepts (58%) were linked the ICF component, *activities and participation*, similar to our hypothesis of 60%. Within that component; community, social and civic life (d9) and mobility (d4) were most frequently linked. All nine of the *activities and participation* chapters were represented in the BOQ 0-4. Seven of the nine chapters were represented in the BOQ 5-18 and 11-18. Those not represented include learning and applying knowledge (d1) and communication (d3). In the BOQ YA, seven of the nine chapters were represented. Those omitted included: learning and applying knowledge (d1) and communication (d3).

The next most common component was *body functions* (31%). Body functions was represented less frequently than our hypothesis of 42%. This component was overwhelmingly represented among each of the BOQ assessments by the chapter, mental functions (b3), which includes functions of appropriateness, regulation and range of emotion, affect or liability of emotion. *Body functions (b)* chapters that were not represented in the BOQ 0-4 included: voice and speech functions (b3); functions of the cardiovascular, hematological, immunological and respiratory systems (b4); functions of the digestive, metabolic and endocrine systems (b5); genitourinary and reproduction functions (b6); neuromusculoskeletal and movement-related functions (b7); and functions of the skin and related structures (b8). Chapters that were not represented in the BOQ 5-18 and 11-18 included: voice and speech functions (b3); functions of the digestive, metabolic and endocrine systems (b5); and genitourinary and reproductive functions (b6). The BOQ YA did not include the chapters: voice and speech function (b3), functions of the cardiovascular, hematological, immunological and respiratory systems (b4), functions of the digestive, metabolic and endocrine systems (b5); and neuromusculoskeletal and movement-related functions (b7).

As a patient ages out of a BOQ assessment, he or she completes the next age appropriate assessment. To truly understand recovery over time, consistency of ICF topics (ICF chapter representation) from assessment to subsequent assessment is imperative. As demonstrated above, some chapter topics appear in an assessment, but cannot be followed across time as they are not included in a previous or subsequent assessment. The components, *activities and participation (d)* and *body functions (b)* are well-represented in the BOQ assessments, while *body structure (s)* and *environmental factors (e)* appear very seldom or are completely absent. Developers of future BOQ editions should take into consideration the over-representation of some topics within the assessment. For example, in the BOQ 0-4 the chapter, mental functions (b1), is represented 14 times out of a total of 25 *body functions (b)* concepts. In the BOQ YA the *activities and participation (d)* chapter, community, social and civic life (d9), is represented 16 times out of 35 *activities and*

participation (d) concepts. A more even distribution of concept topics would allow for the inclusion of important ICF chapter topics that are currently under- or unrepresented without drastically increasing the length of the assessments.

The magnitude of impact of environmental factors on participation in activity is vastly underrepresented in the BOQ assessments. The component, *Environmental factors (e),* was represented by 11% of linkable concepts in all BOQ assessments combined, similar to our hypothesis of 10%. The majority of these concepts were linked to the chapter services, systems and policies (e5). In the BOQ 0-4 the *Environmental factors (e)* chapter, natural environment and human-made changes to environment (e2), was not represented. In the BOQ 5-18 and 11-18 *Environmental factors (e)* chapters that were not represented included: products and technology (e1) and natural environment and human-made changes to environment (e2). The BOQ YA does not include *environmental factors (e)* chapters including: products and technology (e1) and natural environment and human-made changes to environment (e2).

Specific attention should be granted to the area of environmental factors. Children with disabilities participate less frequently in community activities and at lower levels of involvement when they are able to participate in community activity compared to children without disabilities.[43] Parents of children with disabilities report less environmental supportiveness within their communities. For instance, the availability and adequacy of public transportation, programs and services, information, equipment and supplies, and time and money was reported to be "usually not available or adequate" by parents of children with disabilities.[43] Because participation has been established as a key indicator of health and well-being throughout the span of life;[44-46] environmental barriers and facilitators that impact participation such as physical layout, sensory quality, physical demands of activity, cognitive demands of activity, social demands of activity, relations with peers, attitudes, weather conditions and safety should be considered for inclusion in the BOQ assessments to ascertain a true understanding of post-burn participation in

activity, and thus a more comprehensive understanding of overall health and well-being after burn injury. [43,47]

The component, *Body structures,* was not linked to any meaningful concepts in the BOQ assessments. This suggests that the assessments were not designed to assess function, disability, health or quality of life based on specific burn location. The outcomes cannot be grouped based on anatomical burn location without additional information from medical records. Also of note, without specification of affected body structure; pediatric structural development delays and/or lags secondary to injury are not addressed or quantified using these assessments and cannot be observed over time. The addition of body structure specification in future editions of the assessment may enrich data outcomes in two ways: (1) allowing researchers the ability to examine outcomes based on specific burn location and (2) increasing the applicability of the ICF to the BOQ through the use of the ICF qualifier scale, which is designed to indicate the extent or magnitude of impairment as well as define the nature of the change to a specific structure.[27] By specifying burn location and magnitude of impairment, researchers can conduct more focused studies that will better inform clinicians and therefore result in a more appropriate and honed rehabilitation plans based on the nature of a patient's burn injury.

Most of the concepts that could not be linked to the ICF were considered health conditions and are therefore defined by ICD, rather than ICF codes. Overall, the 'no code' label was the next most frequently represented code among unlinked concepts. In general, these concepts consisted of clinical interventions or 'personal factors' as defined by the ICF. Though infrequent, remaining unlinked concepts were either not covered (nc) by the ICF or were not defined (nd) clearly enough to be linked. For example, "destroys own things" and "seems unresponsive to affection" both taken from the BOQ 0-4, are concepts that imply characteristics of emotional dysfunction. However, their meanings are suggestive and not manifest and, therefore, were considered unable to be linked to the ICF. While these concepts are an important piece of the evaluation of patients following burn injury, their meaning is latent and could not be linked. This demonstrates that some meaning was lost in

the linking process. Similar results were attained among studies that used the ICF linking process to examine concepts included in assessments of adults with burn injury [17], health-related quality of life among children [11], and persons diagnosed with depressive disorder. [48]

Age appropriateness of the BOQ 0-4 assessment

Close to one-fourth of all burn injuries worldwide occur in children under the age of 16, with the majority of those occurring in children under five.[49] Of patients seriously injured enough to be transferred to specialized burn centers, fewer than 3% die as a result of their burn.[50] This results in a large percentage of surviving severe burn patients under the age of five. The BOQ 0-4 is designed to gather data within a population that ranges from infant to preschooler. However, as children grow from age zero to five they pass a myriad of gross motor, fine motor, speech-language, cognitive and social-emotional milestones.[51] It is difficult to measure function and disability among a population through such an extreme developmental range using a single assessment. For example, BOQ question #9 asks, "For each item, please fill in the blank that best describes your child *in the past month because of the burn injury*. Scoops with a spoon and brings to mouth." Answer choices include, "very limited or unable", "somewhat limited" or "not limited, able to perform in most situations". The question asks how capable the child is or is not of performing the task as a result of the burn injury. A child typically does not develop the fine motor skills to use a spoon until the age of three. [52]A parent of a normally developed one year old who does not feed with a spoon due to lack of skill development rather than burn injury is forced to choose "very limited or unable" even though the child is not limited by injury but by normal lack of development. A parent of a four year old child with severe upper extremity burns may choose the same answer, "very limited or unable", in this case the child's inability to feed with a spoon is secondary to their burn injury rather than lack of development. The assessment contains over 20 milestone-related questions, though the majority of these questions are not age appropriate through the full age range of zero to four years. [51] Zero to four is the most likely age range for burn injury to occur [49] as well as a crucial period of

physical, cognitive an emotional growth and development [51]. To capture the true impact of burn injury within this population, the assessment should be age-appropriate based on developmental milestones. Currently the BOQ 0-4 is not sensitive enough to collect accurate data over time within this population. The addition of an answer choice that allows parents or guardians to indicate that a child's developmental stage does not include the ability to perform the task in question would provide a stopgap measure. However, the division of the 0 to 4 years age range into developmentally-similar smaller groups would allow for the development of age appropriate assessments that accurately measure the impact of severe burn injury throughout a range of developmental stages over time.

The perspective of the BOQ assessments

The health status perspective was represented by a factor of 6 to 1 over the QOL perspective in the BOQ assessments. The majority of those questions which represented the health status perspective were further classified as the health status (disability) perspective. Only approximately 13% of the questions in each assessment represented the quality of life perspective. The environmental factors perspective appeared in the BOQ 0-4 only once and in the remaining assessments a total of two times each. This distribution was similar to our hypothesis of 70% of items representing the health status perspective, 20% representing the QOL perspective and 10% representing the environmental status perspective.

Despite the predominance of the health status perspective at the expense of the QOL perspective, BOQ data are used in several published studies examining post-burn quality of life and health-related quality of life. Confusing the concepts "quality of life" and "health status" brings the validity of these studies into question. Theoretically, when an assessment question does not directly probe the concept one intends to measure, the content validity of that question is impacted.[28] Therefore, when a researcher uses a health status assessment to examine quality of life the very foundation of that study should be questioned. The WHO explains quality of life as the self-perception of one's physical, emotional and social functioning. [35] For

instance, the BOQ 0-4 asks, how much of the time is the child awakened because of itching. This question probes an aspect of health status. It does not question the parent or child about quality of life. We can only know how often awakening due to itch occurs. A child or proxy may report awakening several times a night due to itching, but this may not affect his or her quality of life. Whereas as second responder may state that he or she awakens only once a week due to itching, and this may have a dramatic impact on his or her quality of life. We cannot know the magnitude of impact, if any, that awakening secondary to itch has on the quality of this child's life based on the question example stated above. Therefore, it is considered a health status question. We cannot assume the responder's quality of life based on the answer.

When the perspective findings are combined with the linking findings they lead to the conclusion that, in general, the BOQ assessments can be used to determine health status outcomes, particularly in the areas of activities and participation and body functions. The BOQ assessments can measure symptom and functional changes over time, but they are very limited in their ability to determine changes in quality of life as a result of the determined symptom or functional changes. A separate section in the assessments or a separate assessment all-together, which asks questions that specifically target self-perceptions of quality of life based on all four of the ICF domains, would provide researchers and clinicians valid data regarding both health status and quality of life in burn patients over time.

Also of note is the large number (64%) of health status questions which ask about the magnitude of disability compared to the amount of health status questions (33%) that ask about the magnitude of functional ability. As discussed by Fayed and colleagues[28] in a previous ICF linking study of pediatric cancer assessments, negatively worded assessment content can place an emotional burden upon patients or their proxies. [53] Question wording, order, and/or time frame can profoundly influence a respondent's answer selections.[54] Users of BOQ data should take into account that questions which probe impairment levels, activity limitations and participation restrictions provide information regarding disability, and question

that positively ask about performance levels or abilities provide information about patient functioning.[28] Researchers and clinicians who use BOQ assessment data should be cognizant of BOQ question perspectives and the essence of the question content, so that they can best interpret and convey study outcomes to readers.

Study limitations

A limitation of this study was the potential for bias in the ICF linking outcomes. Ideally, two trained coders would map all of the items within each of the outcome measures and establish a kappa score based on the results. In this study, one trained coder linked all of the items within each of the outcome measures. A second trained coder linked ten percent of the items in the database that included linking outcomes for all BOQ assessments as well as linking outcomes for a second set of burn injury assessments. This potentially biases the results of the linking towards the assessment of a single coder. A second potential limitation was the incompleteness of the ICF framework. While the ICF has been heavily researched and widely applied; it is a living document that is subject to reviews, updates and revisions. The BOQ assessments contained some clear, well-defined concepts that could not be defined by the ICF. In these cases, although the concept was clear, the meaning could not be linked to the ICF and was, therefore, lost secondary to the linking process.

Conclusion

By linking the BOQ assessments to the ICF framework, we have determined that the assessments cover a broad range of activities and participation topics. Topics related to body functions, specifically mental functions, were also well represented. Future developers of subsequent editions of the BOQ should consider the addition of concepts that will provide users of BOQ data with information regarding the impact, or lack thereof, of environmental factors as well as the experience of the patient as impacted by burn injury to specific body structures. Reconstruction of the BOQ 0-4 assessment into age-appropriate developmental milestone sections would improve the integrity of the data. Researchers and clinicians currently using BOQ data should be keenly aware of the perspectives

represented by these assessments. Because the majority of the items included in these assessments address the health status of the patients, the answers to those questions should not be used to determine quality of life.

Chapter 5 Burn Model Systems Assessments

Introduction

Research on the long-term effects of burn injury has been restricted due to a dearth of longitudinal data collected from a large sample of patients.[55] In 1994 the National Institute on Disability and Rehabilitation Research (NIDRR) committed to overcoming this problem by developing the Burn Model System (BMS) program to examine the effects of burn injury over time. The multi-centered BMS program collects data across a myriad of domains including disability, distress, societal reintegration, injury complications, disposition, physical function, and emotional and psychological function. [19] A panel of burn injury experts selected the assessment questions from pre-established instruments including the Special Form (SF)12, the SF10 Health Survey for Children, the Satisfaction with Appearance Scale, the Community Integration Questionnaire, and the Satisfaction with Life Questionnaire. Age-based initial and follow-up assessments are used to collect BMS data from both adults and children with severe burns [> 20% total body surface area (TBSA) in adults; > 10% in children or elderly; burns of the hands, face, feet, genitalia, or joints regardless of TBSA; electrical burns; any burn associated with inhalation injury] at discharge from acute care and 6, 12, and 24 months thereafter. [19] As of 2007, BMS data have been collected from over 4,500 patients. [19] The goal of the program is to ensure high-quality research through the collection and management of robust and valid data to develop and hone clinical rehabilitation practices to best meet the needs of this population.[55]

Although the BMS assessments have been deemed to be valid and to possess good psychometric properties[19], To determine the true exhaustiveness of all relative domains included in the assessments, this study linked the BMS assessments to the International Classification of Functioning, Disability and Health (ICF). The ICF was approved by the World Health Organization (WHO) in 2001 and its children and youth (CY) version in 2007. [26] The ICF framework is a comprehensive taxonomy used to classify and describe health and health-related domains through the use of a universal language.[26] Today, the ICF is used around the world for policy

development, economic analysis, research, clinical evaluation, and treatment planning. [33] In 2002, a standardized linking method was established which enabled the linking of health-related assessments to the ICF. Through this linking process, researchers can evaluate and describe health-related assessment tools based on the ICF's comprehensive framework which includes over 1400 categories that fall under four major life domains: body function, body structure, activities and participation and environmental factors. [56]

The primary objective of this study was to link, classify, and describe the concepts of the BMS outcome measures using the ICF and ICF-CY to determine the depth and breadth of concepts included in the assessments. The ICF standardized linking technique was used to determine if there are relevant domains not included in the BMS assessments or topics that might warrant further probing. In linking the BMS assessments to the ICF and ICF CY we were able to determine if information garnered from the multi-center BMS program is providing researchers and clinicians with a comprehensive understanding of life after burn injury, what information may be missing, and where there is opportunity for improvement.

A secondary objective was to define the perspective of each question included in the assessments to determine what portion of the assessments addressed health status (disability and functioning), quality of life (QOL), and environmental factors (barriers and facilitators). Determining the overall perspective of an assessment is crucial to understanding of the data it provides. The terms "health status" and "quality of life" cannot be interchanged, as they have very different meanings.[29,30,38] Quality of life is an individual's perception of a specific situation based on his or her culture, value system, personal goals, standards and concerns.[35] Whereas, health status is determined by biopsychosocial elements that pertain to health conditions, physical and emotional performance and social barriers or facilitators.[28,38] When a health status assessment is used to examine quality of life or vice versa, results can be imprecise and misleading which can hinder or even misguide our understanding of life after burn injury.

The standardized linking technique was used to link all relevant concepts within the BMS assessments to the ICF or ICF-CY to determine the following:

1. The frequency with which specific concepts were linked to each ICF component/chapter/level
2. The nature of the concepts covered within each instrument
3. The components/chapters/levels not covered by each assessment
4. The concepts in each assessment not covered by the ICF (nc)
5. The content density (concepts per item)
6. The similarities and differences in the concepts covered by each BMS instrument
7. Concepts unable to be linked to the ICF
8. The proportion of each instrument that examines each perspective: QOL, health status, or environmental factors

We hypothesized that *(Hypothesis 1)* ninety percent of the BMS outcome measure items would be linkable to the ICF; and that *(Hypothesis 2)* forty percent of the concepts in the measure would be linked to the ICF component 'activities and participation', thirty percent of the items would be linked to 'body structure', twenty percent of the items will be linked to 'environment', and ten percent of the items would be linked to 'body function'; and that *(Hypothesis 3)* sixty percent of the items in the Burn Model Systems outcome measures would be related to the health status perspective, thirty percent of the items would be related to the quality of life perspective, and ten percent of the items would be related to environment.

Methods

Materials

The following BMS assessments were linked and analyzed: BMS-initial 0-4, BMS follow-up 0-4, BMS-initial 5-13, BMS follow-up 5-13, BMS-initial 14-18, BMS follow-up 14-18, and BMS adult follow-up.

Analytic procedure

The linking methods are explained in detail in Chapter 3: Methods. This section will present a general description of the methods used to complete this study. All meaningful concepts within each of the question were extracted. Questions can contain more than one meaningful concept. The concepts were then

coded using the standardized linking technique explained in Chapter 3: Methods. Meaningful concepts that were linkable to the ICF were linked at the third and fourth level when possible. Meaningful concepts that were not linkable to the ICF were labeled in accordance with the standardized linking rules as 'nd' (not definable), 'nc' (not covered), 'hc' (health conditions), 'ndgh' (not definable-general health), 'ndmh' (not definable-mental health), 'ndph' (not definable-physical health), 'ndqol' (not definable-quality of life). Concepts that represented personal factors, medical interventions, or administrative inquiries were labeled as 'no code'.

The standardized linking technique suggests that concepts that represent personal factors such as gender, race, age, lifestyle, habits, education, and others should be labeled as 'pf' (personal factor). However, a recent call to refrain from using of the 'pf' (personal factor) label was issued on the grounds that the component does not contain chapter and/or category codes. Therefore, the label cannot be used to accurately classify and describe 'personal factor' concepts. Because the category has not been scientifically established, the consequences of using the 'personal factor' label are unknown. Supporters of abstaining from using the 'personal factor' label are calling for a systematic review and revision of the component to meet the standards to which the other ICF components have been held. [34] In this study, all personal factor concepts were labelled as 'no code' and were included among the 'unlinkable' concepts.

Many of the BMS assessment questions are initiated with a prefix. Several questions can fall under one prefix. For example, in the BMS-initial 0-4 a prefix states, "approximately how many times a month does your child usually participate (or accompany) in the following activities outside of your home?" The prefix is followed by five questions such as, "visiting friends or relatives" and "leisure activities such as movies, sports, restaurants". In the data analysis, the meaningful concepts within each of the prefixes were counted only once. Concepts within the prefixes were not repeated within the analysis. They are linked to the ICF only once. For example, in the prefix stated above the meaningful concept, 'participate in activities (outside of the home)' was linked to the ICF only once rather than

repeatedly linked with each of the five questions that follow that prefix. Table 7, located at the end of the Results section, shows the number of prefixes included in each assessment and the total number of concepts that were identified within the prefixes. Repeating the prefix concepts with each of the question concepts in the analysis would result in an inflated representation of the concept density for each question. See Table 6 for a description of the standardized linking rules.

Rule	Rule Description	Example
1	Acquiring knowledge of ICF(CY) chapters, domains, and categories	
2	Linking each meaningful concept to the most precise category	B28010 (pain in head and neck)
3	Do not use the so-called "other specified" ICF categories, additional information shall be documented	E4 (Attitudes)
4	Do not use the "unspecified" ICF categories, use lower level of category	
5	Designation not definable (nd) should be used when meaningful concept is not sufficient	If the concept refers to health, the designation should be nd-gh . If the concept refers to quality of life, the designation should be nd-qol
6	If a meaningful concept is clearly a personal factor defined by ICF (CY), this can be documented pf	pf gender, age This linking rule was not included in this study
7	If there is no evidence of a meaningful concept and no personal factors are identified, then assign the concept nc	nc
8	If a meaningful concept refers to health conditions or diagnosis if should be assigned hc	hc diabetes, asthma

Table 6. Linking Rules as Described by Cieza et al [11,15,31]
Abbreviations: nd-gh (not definable-general health), nd-qol (not definable-quality of life), pf (personal factor), nc (not covered), hc (health condition)

In addition to linking all meaningful concepts to the ICF, the perspective of each assessment question was also identified based on the WHO's definition of QOL, health status (functioning and disability) and environmental barrier or facilitator. The following perspective definitions were used to determine the perspective of each question included in all of the assessments:

1. **QOL**: QOL perspectives reflect individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns

2. **Health status (functioning):** functioning perspectives reflect the interaction or the individual components of body functions, activities, and participation

3. **Health status (disability):** Disability perspectives probe impairment, activity limitations, and/or participation restrictions

4. **Environmental (barriers)**: Barriers perspectives reflect environmental factors that hinder the functioning of an individual

5. **Environmental (facilitators):** Facilitators perspectives reflect environmental factors that promote or allow for the functioning of an individual[27 28 35]

Questions that probed an individual's perception of his or her health or situation were labeled as 'QOL' perspective. These questions often used terms such as "importance", "satisfaction", or "feelings about". Questions that asked about functional status, level of impairment or activity limitation were labeled as 'health status (functioning)' or health status (disability)'. Questions that referred to one's health or health-related status that did not specifically address functional ability or disability were labeled as 'health status (general)'. Lastly, questions that addressed environmental facilitators or barriers were labeled as 'environmental (barrier)' or 'environmental (facilitator)'.

Reliability

A second researcher with extensive ICF linking experience linked 10% of the questions included in a database that was created to store and analyzes burn assessment concepts and their ICF codes. To establish the level of agreement between the two coders both percentage agreement and Kappa statistics were used. A Kappa coefficient greater than .61 is considered good.[36] The meaningful concepts within each question were mutually agreed upon by the coders prior to linking. Once the linking was complete, a third researcher, trained in the ICF coding process, determined the final code(s) where coding differences occurred.

Results

Of the 121 concepts that were randomly extracted from the master database for coding by a second researcher, both researchers agreed on concept linkability 82% of the time. A kappa value of .67 indicated that agreement was good regarding the coding of concepts that were linkable to the ICF at the chapter level. A third coder was required 31 times (26%) to resolve differences.

Linking to the ICF

A total of 1,327 concepts were identified among 754 questions in all of the BIMS assessments. Many of the questions are repeated among the assessments. A total of 61% (816 concepts) were linkable to the ICF or the ICF CY. The results for the seven BMS assessments, initial and follow-up, are summarized in table 7 and described in detail below for each assessment. The distribution of each ICF component by chapter is displayed below.

BMS	BMSI0-4	BMSF0-4	BMSI5-13	BMSF5-13	BMSI14-18	BMSF14-18	BMSFA
Number of question	104	79	131	102	117	102	119

Number of prefixes	15	16	17	18	19	21	16
Number of question concepts	146	117	201	162	166	165	177
Number of prefix concepts	24	24	24	24	32	34	31
Total number of concepts	170	141	225	186	198	199	208
Content density (concepts per item)	1.6	1.8	1.7	1.8	1.7	2.0	1.7
Concepts linked to ICF							
Body structure	22	2	29	9	29	9	0
Body function	39	39	55	52	54	56	52
Activities and Participation	28	19	39	25	32	33	95
Environmental factors	5	21	9	25	9	25	8
Total: linked concepts	94	81	130	111	124	123	155
Concepts unable to be linked							
Concepts considered health conditions (hc)	21	7	28	13	21	15	19
Concepts not definable (nd)	9	10	9	10	9	11	19
Concepts nd:general health	7	4	7	4	3	4	5
Concepts nd: physical health	0	0	2	1	2	2	2
concepts nd: quality of life	5	2	10	7	5	5	1
Concepts nd: mental health	0	0	0	0	0	0	1
Concepts not covered (nc)	7	6	9	8	9	8	4
Concepts: no code	27	31	30	32	25	31	2
Total: unlinked concepts	76	60	95	75	74	76	53

Table 7. Linking of the Burn Model Systems concepts to the ICF

BMS 0-4 initial and follow-up assessments

Concepts linkable to the ICF

Of the 170 concepts identified in the BMS-initial 0-4, 94 concepts (55%) were linked to the ICF CY. Concepts were linked to all four ICF components. Eighty-one of the 141 concepts (57%) found in the BMS-follow up 0-4 were linkable to the ICF CY, and all four components were represented.

Of all linked concepts in both the BMS 0-4 initial and follow-up most were linked to the *body functions (b)* component with 39/170 concepts (41%) and 39/141 concepts (48%) respectively. Four of the eight *body functions (b)* component chapters were represented in both the initial and the follow up 0-4 assessments. They included: mental functions (b1) (initial: 8 out of 39 concepts, follow-up: 7 out of 39), sensory functions and pain (b2) (initial: 6 concepts, follow-up: 7 concepts), neuromusculoskeletal and movement-related functions (b7) (initial: 4 concepts, follow-up 4 concepts), and functions of the skin and related structures (b8) (initial: 21 concepts, follow-up 21 concepts). Categories most frequently represented in both the 0-4 initial and follow-up were protective functions of the skin (b810) and repair functions of the skin (b820).

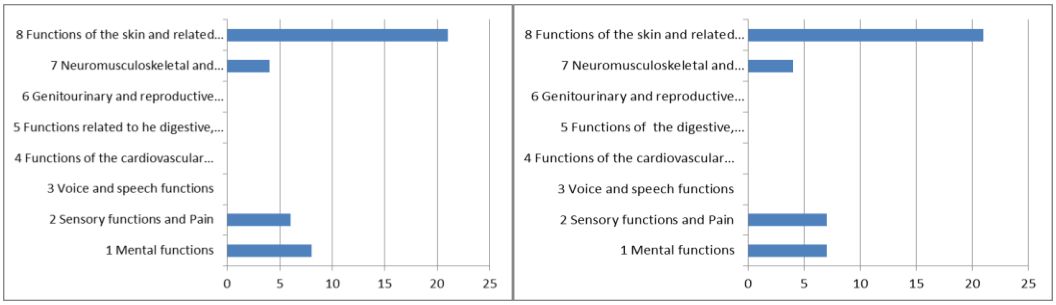

Figure 15. Burn Model Systems-initial 0-4 body functions (b) (left) and; Burn Model Systems-follow-up 0-4 body functions (b) (right).
X-axes represent the number of concepts

In the BMS-initial 0-4, the *body structure (s)* component was represented by 22/94 linked concepts (23%). Only 2/81 linked concepts (2%) in the BMS follow-up 0-4 represented the *body structure (s)* component. The discrepancy in *body structure (s)* representations between the assessments exists because the initial assessment asks many questions about burn and grafting location that are linked to chapters within the *body structure (s)* component. In the follow-up assessment the burn and grafting questions are replaced with questions about types of burn injury treatment received after discharge from acute care. One of the eight body structure chapters was represented in each assessment: skin and related structures (s8) (initial: 22 concepts, follow-up: 2 concept). Categories most often represented in the

BMS-initial 0-4 were skin of head and neck region (s8100), skin of upper extremity (s8102), and skin of lower extremity (s8104). The categories represented in the BMS follow-up 0-4 were skin of head and neck region (s8100) and skin and related structures (s8).

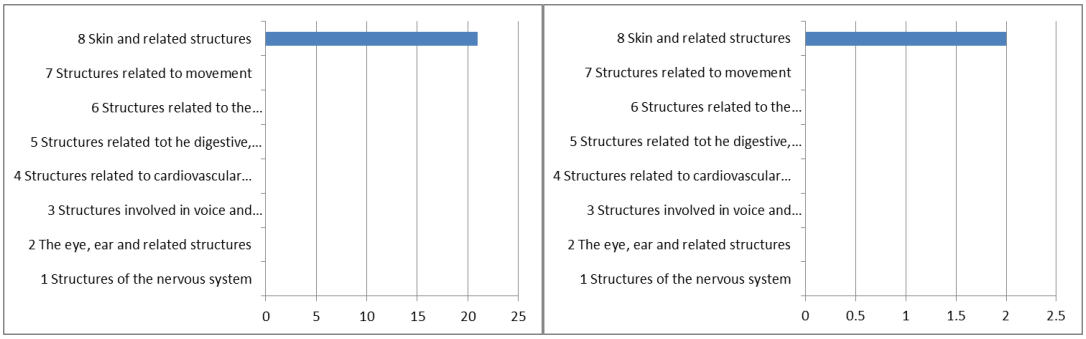

Figure 16. Burn Model Systems-initial 0-4 body structures (s) (left) and; and Burn Model Systems follow-up 0-4 body structures (b) (right).
X-axes represent the number of concepts

The *activities and participation (d)* component was represented in the BMS 0-4 initial and follow-up by 28/94 linked concepts (30%) and 19/81 linked concepts (23%) respectively. Six of the nine chapters were represented in the initial assessments, and seven of the nine chapters were represented in the follow up assessments. In a few cases concepts were considered too broad to be linked beyond the component level. This is displayed in the figure below (figure 16) as 'linked at level 1'. Five concepts out of 28 in the initial assessment and three concepts out of 19 in the follow-up were linked at the component level, *activities and participation (d). Activities and participation (d)* chapters represented in each assessment included: general task and demands (d2) (initial: 2 out of 28 concepts, follow-up: 1 out of 19 concepts), communication (d3) (initial: 2 concepts, follow-up 1 concept), mobility (d4) (initial: 10 concepts, follow-up: 5 concepts), domestic life (d6) (initial: 1 concept, follow-up: 1 concept), interpersonal interactions and relationships (d7) (initial: 3 concepts, follow-up: 2 concepts), and community, social and civic life (d9) (initial: 6 concepts, follow-up: 6 concepts). The category most frequently represented in both assessments was recreation and leisure (d920).

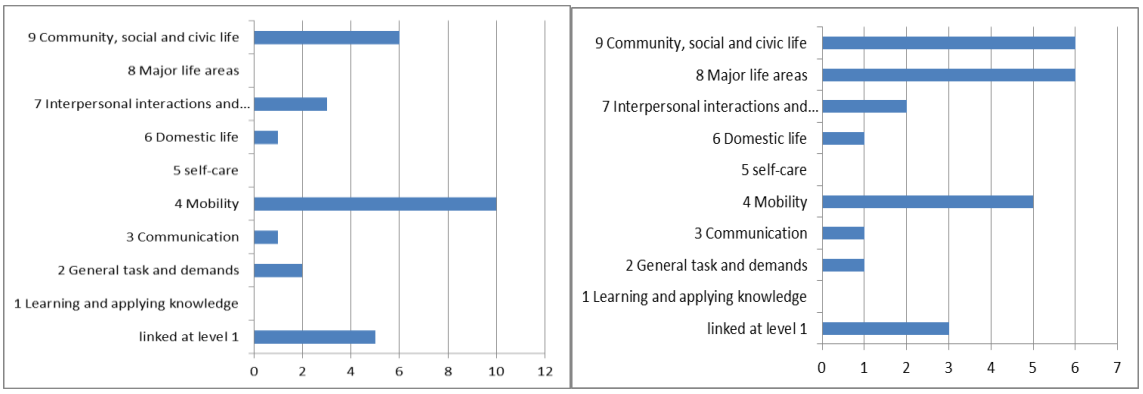

Figure 17. Burn Model Systems 0-4-initial activities and participation (d) (left) and; Burn Model Systems 0-4 follow-up activities and participation (d) (right).
X-axes represent the number of concepts

The *environmental factors (e)* component was represented by 5/94 linked concepts (5%) in the initial assessment and 21/81 linked concepts (26%) in the follow-up assessment. The discrepancy exists because the follow-up assessment contains many questions about post-acute medical care that were linked to the *environmental factors (e)* component. Two of the five environmental factors chapters were represented in the initial assessment. These chapters included: products and technology (e1) (3 concepts out of 5) and services, systems and policies (e5) (2 concepts). Three of the five chapters were represented in the follow-up assessment: products and technology (e1) (3 out of 21 concepts), support and relationships (e3) (4 concepts), and services, systems and policies (e5) (14 concepts). Categories most frequently represented in the initial assessment were general products and technology for personal use in daily living (e1150) and health services (e5800). Categories most often represented in the follow-up assessment included: health services (e5800) and health professionals (e355).

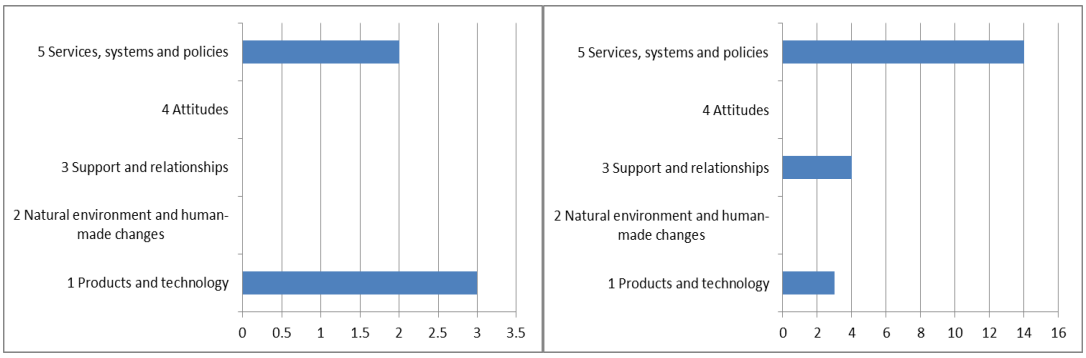

Figure 18. Burn Model Systems initial 0-4 environmental factors (e) (left) and; Burn Model Systems follow-up 0-4 environmental factors (e) (right).
X-axes represent the number of concepts

Concepts not linked to the ICF

Seventy-six out of 170 concepts (45%) of the BMS-initial 0-4 and 60/141 concepts (43%) of the BMS follow-up 0-4 were unlinkable to the ICF. In the 0-4 assessment, 21/76 unlinked concepts (28%) in the initial assessment and 7/60 unlinked concepts (12%) in the follow-up assessment were coded as 'hc' (health conditions). When a phrase such as "burn injury" or "diabetes" appears in the assessment, it is coded as a health condition. Health conditions are linked to the International Classification of Diseases (ICD), an international coding system used to classify diseases and other health issues and are therefore not linked to the ICF.[26,41,42] The WHO's ICF and ICD frameworks were created to be used in conjunction with one another to identify and explain the experience of a person with a disease, as function and disability can range from person to person with any given diagnosis.[26,41]

The next most frequent code represented among the unlinkable concepts was 'no code'. Twenty-seven out of 76 unlinkable concepts (36%) in the initial assessment and 31/60 unlinkable concepts (52%) in the follow-up assessment were coded as 'no code'. Concepts coded as 'no code' were personal factors, medical interventions, or administrative items. Concepts coded as 'nd' non-definable represented 9/76 unlinkable concepts (12%) in the initial assessment and 10/60 unlinkable concepts (16%) in the follow-up assessment. Not-definable concepts are concepts that are too broad or vague to be linked to the ICF. For example, a question

prefix in the BMS-initial 0-4 asks about "changes or effects (as a result of burn)". The phrase "changes or effects", in this case, was considered too vague to link to the ICF. An additional 12/76 unlinked concepts (16%) in the initial assessment and 6/60 unlinked concepts (10%) in the follow-up assessment were also coded as 'nd'. Although these concepts were considered too broad or vague to be linked to the ICF, their general subject matter was identifiable. Therefore, they were coded as 'ndgh' (not definable-general health), 'ndmh' (not definable-mental health) or 'ndqol' (not definable-quality of life). Finally, concepts that were clear and well-defined yet not covered by the ICF taxonomy were coded as 'nc' (not covered). Seven out of 76 unlinked concepts (9%) in the initial assessment and 6/60 unlinked concepts (10%) in the follow-up assessment were coded as 'nc' (not covered).

BMS 5-13 initial and follow-up assessments

Concepts linkable to the ICF

One hundred and thirty of the 225 concepts (58%) of in the BMS-initial 5-13 and 111/186 concepts (60%) in the BMS follow-up 5-13 were linkable to the ICF. All four ICF components were represented in both assessments. Like the BMS 0-4 assessments, the *body functions (b)* component was most frequently represented in the 5-13 assessments. Fifty-five out of 130 linkable concepts (40%) in the 5-13 initial and 52/111 linkable concepts (46%) in the 5-13 follow-up were linked to *body functions (b).* Four of the eight *body functions (b)* ICF chapters were represented in both assessments. Chapters most often coded in the 5-13 initial assessment included: mental functions (b1) (initial: 21 out of 52 concepts, follow-up: 19 out of 51 concepts) and functions of the skin and related structures (b8) (initial: 21 concepts, follow-up: 21 concepts). The other *body function (b)* chapters represented included: sensory function and pain (b2) and neuromusculoskeletal and movement-related functions (b7). Categories most often coded in both assessments included: experience of self and time functions (b180) and protective functions of the skin (b 810). Repair function of the skin (b820) was also frequently represented in the 5-13 follow-up assessment.

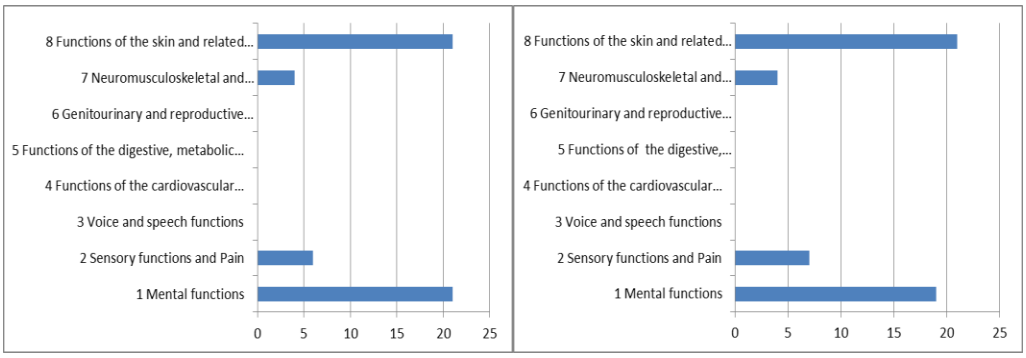

Figure 19. Burn Model Systems initial 5-13 body functions (b) (left) and; Burn Model Systems follow-up 5-13 body functions (b) (right).
X-axes represent the number of concepts

The component, *activities and participation (d),* was the next most frequent component represented in both assessments. Thirty-nine out of 130 linked concepts (30%) in the initial assessment linked and 25/111 linked concepts (25%) in the follow-up were representative of the *activities and participation* component. Eight of the nine *activities and participation (d)* chapters were represented in both 5-13 initial and follow-up assessments. In both assessments the chapters, community, social and civic life (d9) (initial: 10 out of 40 concepts, follow-up: 8 out of 26concepts) and mobility (d4) (initial: 10 concepts, follow-up: 5 concepts) were most often represented. *Activities and participation (d)* categories most frequently coded in the 5-13 initial included: socializing (d9205), school education (d820), and managing one's own behavior (d250). Categories most frequently coded in the follow-up 5-13 were: socializing (d9205) and recreation and leisure (d920).

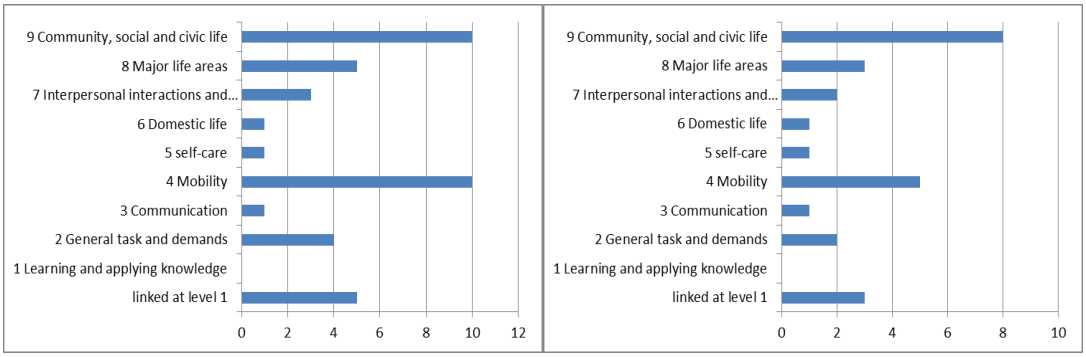

Figure 20. Burn Model Systems initial 5-13 activities and participation (d) (left) and; Burn Model Systems follow-up 5-13 activities and participation (d) (right). The X-axes represents the number of concepts

The *body structures (s)* component was represented by 29/130 linked concepts (22%) in the 5-13 initial and 9/111 linked concepts (8%) in the 5-13 follow-up. Two of eight *body structures (s)* chapters were represented in both assessments: structures related to movement (s7) (initial: 6 concepts out of 29, follow-up: 6 concepts out of 9), skin and related structures (s8) (initial: 23 concepts, follow-up: 3 concepts). Categories most frequently represented in the initial 5-13 included: skin of head and neck region (s8100), skin of upper extremity (s8102), and skin of lower extremity (s8104). The category most often coded in the follow-up 5-13 was structure of head and neck region (s710).

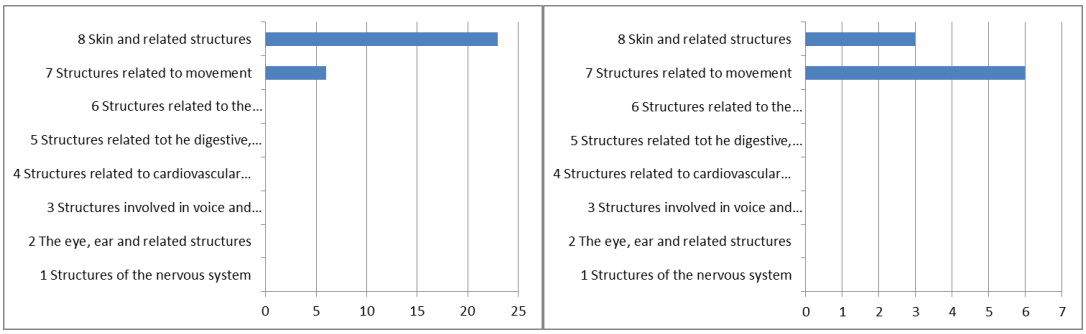

Figure 21. Burn Model Systems initial 5-13 body structures (s) (left) and; Burn Model Systems follow-up 5-13 body structures (b) (right).
X-axes represent the number of concepts

The component, *environmental factors (e),* was represented by 9/13 linked concepts (14%) in the 5-13 initial and 25/111 linked concepts (23%) in the 5-13 follow-up. Three of five environmental factors (e) chapters were represented in both assessments: products and technology (e1) (initial: 3 out of 9 concepts, follow-up: 3 out 25 concepts), support and relationship (e3) (initial: 4 concepts, follow-up: 8 concepts), and services, systems and policies (e5) (initial: 2 concepts, follow-up: 14 concepts). Categories most often represented in the initial 5-13 included: general products and technology for personal use in daily living (e1150), friends (e320), and health services (e5800). Categories most often represented in the follow-up 5-13 were: health services (e5800) and health professions (e355).

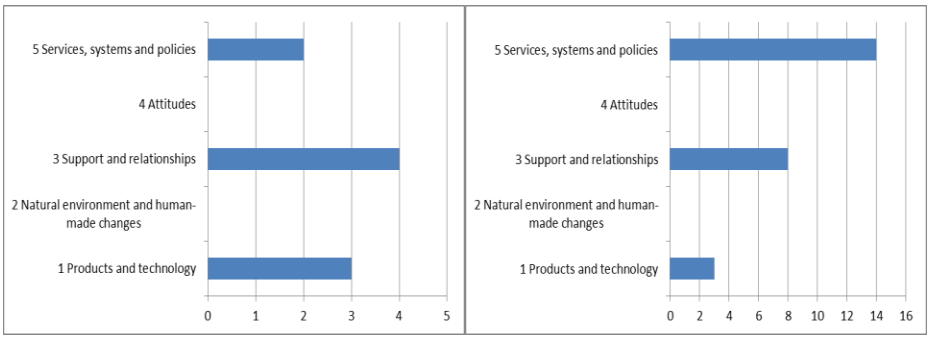

Figure 22. Burn Model Systems initial 5-13 environmental factors (e) (left) and; Burn Model Systems follow-up 5-13 environmental factors (e) (right).
X-axes represent the number of concepts

Concepts not linkable to the ICF

Ninety-five out of 225 (42%) concepts (42%) identified in the 5-13 initial and 75/186 concepts in the 5-13 follow-up were unlinkable to the ICF. Thirty out of 95 unlinked concepts (32%) in the initial 5-13 and 32/75 unlinked concepts (43%) in the follow-up 5-13 were coded as 'no code'. Twenty-eight out of 95 unlinked concepts (29%) in the initial 5-13 and 13/75 unlinked concepts (17%) of the follow-up 5-13 were coded as 'hc' (health condition). Nine out of 95 unlinked concepts (9%) and 10/75 unlinked concepts (13%) of the 5-13 initial and follow-up assessments respectively were coded as 'nd' (not definable). An additional 19/95 unlinked concepts (20%) in the initial 5-13 and12/75 unlinked concepts (16%) in the follow-up 5-13 assessment were coded as 'nd' (not definable) with additional qualifiers (general health, physical health, quality of life). Concepts coded as 'nc' (not covered) represented 9/95 unlinked concepts (9%) in the 5-13initial and 8/75 unlinked concepts (11%) in the 5-13 follow-up.

BMS 14-18 initial and follow-up assessments

Concepts linkable to the ICF

One hundred and twenty-four out of 198 concepts (63%) in the BMS 14-18 initial and 123/199 concepts (62%) of the BMS 14-18 follow-up were linkable to the ICF. All four ICF components were represented in both assessments.

The *body functions (b)* component was represented by 54/124 linked concepts (42%) identified in the 14-18 initial and 56/123 linked concepts (45%) in the 14-18 follow-up assessment. Four of the eight body functions (b) chapters were represented in both assessments. Chapters represented most frequently included: mental functions (b1) (initial: 23 out of 53 concepts, follow-up: 23 out of 55 concepts) and functions of the skin and related structures (b8) (initial: 21 concepts, follow-up: 21 concepts). Categories most often coded in both of the assessments were: experience of self and time function (b180) and protective functions of the skin (b810). Repair functions of the skin (b820) also appeared frequently in the 14-18 initial assessment.

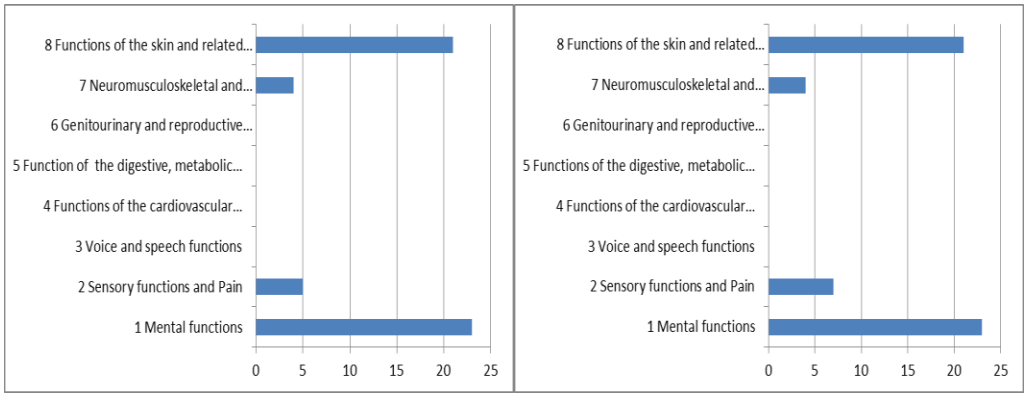

Figure 23. Burn Model Systems-initial 14-18 body functions (b) (left) and; Burn Model Systems follow-up 14-18 body functions (b) (right).
X-axes represents the number of concepts

Thirty-two out of 124 linked concepts (27%) in the14-18 initial and 33/123 linked concepts (28%) in the14-18 follow-up were representative of the component, *activities and participation (d).* Seven out of nine chapters were represented in both assessments. Chapters coded most often included: major life areas (d8) (initial: 10 out of 33 concepts, follow-up: 10 out of 34 concepts) and community, social and civic life (d9) (initial: 10 concepts, follow-up: 10 concepts). Categories coded most often were the same in both assessments: carrying out daily routine (d230), remunerative employment (d850), recreation and leisure (d920), and socializing (d9205).

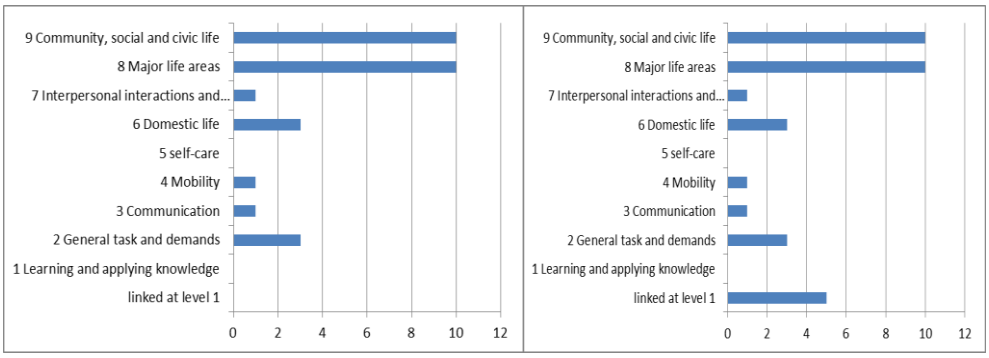

Figure 24. Burn Model Systems initial 14-18 activities and participation (d) (left) and; Burn Model Systems follow-up 14-18 activities and participation (d) (right).
X-axes represent the number of concepts

Twenty-nine out of 124 linked concepts (23%) in the14-18 initial and 9/123 linked concepts (7%) in the 14-18 follow-up were representative of the *body structures (s)* component. Two of eight *body structures (s)* chapters were represented in both assessments: structures related to movement (s7) (initial: 6 out of 29 concepts, follow-up: 6 out of 9 concepts) and skin and related structures (s8) (initial: 23 concepts, follow-up: 3 concepts). ICF categories most frequently represented in the initial 14-18 included: skin of head and neck region (s8100), skin of upper extremity (s8102), and skin of lower extremity (s8104). The category most often coded in the follow-up 14-18 was structures of head and neck region (s710).

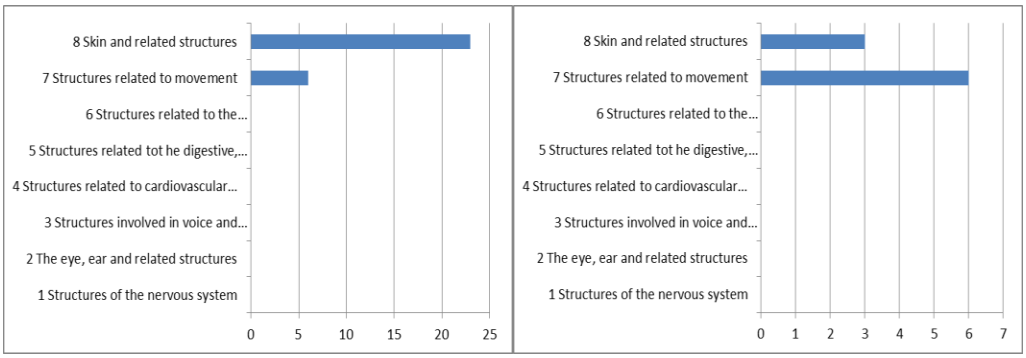

Figure 25. Burn Model Systems initial 14-18 body structures (s) (left) and; Burn Model Systems follow-up 14-18 body structures (s) (right).
X-axes represent number of concepts

The component, *environmental factors* (e), was represented by 9/124 (7%) and 25/123 (20%) of linked concepts in the 14-18 initial and follow-up assessments respectively. Three of the five *environmental factor (e)* chapters are represented in the assessments: products and technology (e1) (initial: 3 out of 9 concepts, follow-up: 3 out of 25 concepts), support and relationships (e3) (initial: 6 concepts, follow-up: 8 concepts) and services, systems and policies (e5) (initial: 2 concepts, follow-up: 14 concepts). Environmental factors (e) categories most frequently represented in the 14-18 initial included: general products and technology for personal use in daily living (e1150) and friends (e320). The category most often coded in the 14-18 follow-up was health professional (e355).

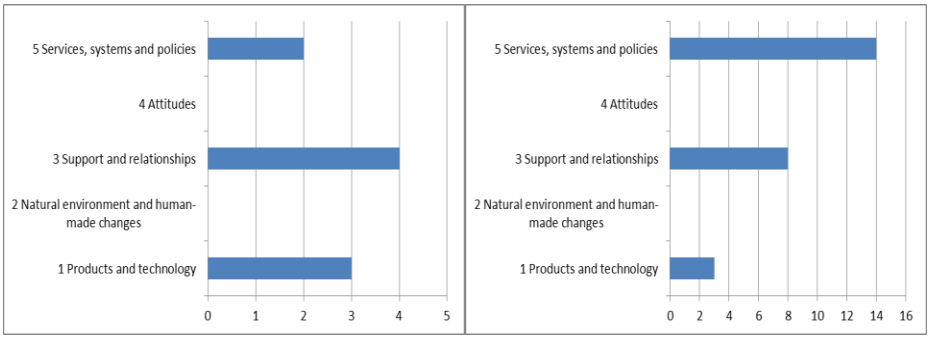

Figure 26. Burn Model Systems initial 14-18 environmental factors (e) (left) and; Burn Model Systems follow-up 14-18 environmental factors (e) (right).
X-axes represent the number of concepts

Concepts not linkable to the ICF

Seventy-four out of 198 concepts (37%)in the 14-18 initial assessment and 76/199 concepts (38%) in the 14-18 follow-up assessment were unlinkable to the ICF. Concepts coded as 'no code' represented 25/74 unlinked concepts (34%) in the initial 14-18 and 31/76 unlinked concepts (41%) of unlinked concepts in the 14-18 follow-up. Twenty-one of 74 unlinked concepts (28%) in the 14-18 initial and 15/76 unlinked concepts (20%) in the 14-18 follow-up assessment were coded as 'hc' (health condition). Concepts considered 'nd' (not definable) represented 9/74 (12%) and 11/76 (14%) unlinked concepts in the initial and follow-up assessments respectively. Ten out of 74 unlinked concepts (14%) in the 14-18 initial and 11/76 unlinked concepts (14%) in the 14-18 follow-up were coded as 'ndgh' (not definable-general health), 'ndph' (not definable-physical health), or 'ndqol' (not

definable-quality of life). Nine out of 74 unlinked concepts (12%) in the 14-18 initial and 8/76 unlinked concepts (11%) in the 14-18 follow-up were 'nc' (not covered) by the ICF.

BMS adult follow-up assessment

The BMS adult follow-up is administered to patients 16 years and older at 5, 10, 15 and 20 years post-burn. One hundred and fifty-five out 208 concepts (74%) in the adult follow-up were linked to the ICF. Three of the four ICF components were represented in the assessment.

Fifty-two out of 155 of linked concepts (33%) in the assessment were linked to the *body functions (b)* component. Four out of eight body functions (b) chapters were represented: mental functions (b1) (42 out of 52 concepts), sensory functions and pain (b2) (1 concept), genitourinary and reproductive functions (b6) (3 concepts) and functions of the skin and related structures (b8) (6 concepts). The category, emotional functions (b152) was most frequently coded.

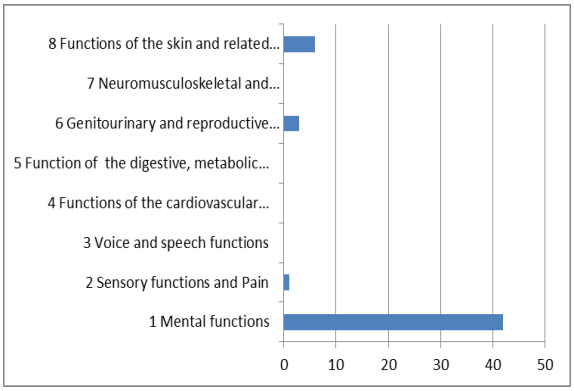

Figure 27. Burn Model Systems adult follow-up body functions (b). X-axis represents the number of concepts

Ninety-five out of 155 linked concepts (61%) were linked to the *activities and participation (d)* component. Eight of the nine *activities and participation (d)* chapters were represented in the assessment. Those chapters most often linked included: self-care (d5) (12 concepts out of 95), major life areas (d8) (18 concepts), and community, social and civil life (d9) (15 concepts). Categories most frequently

coded were: carrying out daily routines (d230) and remunerative employment (d850).

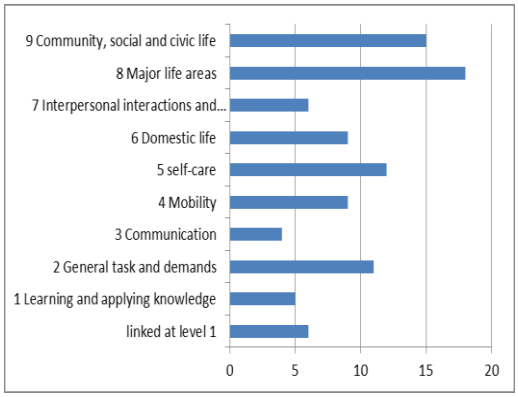

Figure 28. Burn Model Systems adult follow-up activities and participation (d). X-axis represents the number of concepts

Eight out of 155 linked concepts (5%) in the adult follow-up were linked to the *environmental factors (e)* component. Four of the five chapters were represented. The chapter most frequently linked was natural environment and human-made changes to the environment (e2) (4 concepts). The category most often coded was temperature (e2250).

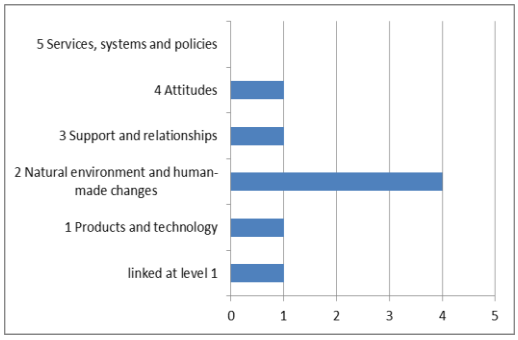

Figure 29. Burn Model Systems adult follow-up environmental factors (e). X-axis represents the number of concepts

The component, *body structures (s),* was not represented in the adult follow-up assessment.

Concepts not linkable to the ICF

Fifty-three out of 208 concepts (26%) in the adult follow-up were unlinkable. Two out of 53 unlinked concepts (4%) were coded as 'no code'. Nineteen out of 53 unlinked concepts (35%) were 'hc' (health conditions), and nineteen out of 53 unlinked concepts 35% were considered 'nd' (not definable). Nine out of 53 (16%) were coded as 'ndgh' (not definable-general health), 'ndph' (not definable-physical health), 'ndqol' (not definable-quality of life), or 'ndmh' (not definable-mental health). Lastly, four out of 53 unlinked concepts (8%) were considered 'nc' (not covered) by the ICF.

Perspectives

Overall, the perspectives distribution was the same for all of the BMS assessment with exception of the BMS adult follow-up, which will be discussed separately. The health status perspective was most frequently cited, 40-46% of items in each assessment. The health status (disability) was most often attributed. Of the items labeled as health status, only 8-14% were labeled as health status (functioning). Health status (other) was attributed 4-9%. The quality of life perspective was assigned to 16-27% of items. Three of the assessments contained one concept that addressed the environmental (facilitators) perspective. The perspective, environmental (barriers), was not included in any of the assessments.

In the adult follow-up assessment, the health status perspective was overwhelmingly represented by 84% of the items. Only 2% of those items labeled as health status were identified as health status (functioning). Eight percent were labeled as health status (disability). Ten percent of the items were labeled as the quality of life perspective. The environmental (barriers) perspective and health status (general) was identified among 2- 3% of the items. The environmental (facilitators) perspective was not represented in the adult follow-up assessment.

Perspectives	BMSI0-4	BMSF0-4	BMSI5-13	BMSF5-13	BMSI14-18	BMSF14-18	BMSFA
Environmental (barriers)	0	0	0	0	0	0	4 (3%)
Environmental (facilitators)	0	0	1 (.8%)	0	1 (.9%)	1 (1%)	0
Health Status (disability)	35 (34%)	25 (32%)	44 (34%)	30 (29%)	40 (34%)	33 (32%)	97 (82%)
Health Status (functioning)	3 (3%)	3 (4%)	4 (3%)	5 (5%)	5 (4%)	5 (5%)	2 (2%)
Health Status (general)	10 (10%)	5 (6%)	7 (5%)	6 (6%)	5 (4%)	5 (5%)	2 (2%)
Other	41 (40%)	38 (48%)	45 (34%)	33 (32%)	40 (34%)	32 (31%)	2 (2%)
Quality of Life	15 (14%)	13 (16%)	30 (23%)	28 (27%)	26 (22%)	26 (25%)	12 (10%)
Total number of items	**104**	**79**	**131**	**102**	**117**	**102**	**119**

Table 8. Perspectives represented by Burn Model Systems
Numbers represent counts.

Discussion

The goal of this study was to link, classify and describe the concepts used in the BMS outcome measures using the ICF framework. To this end, all meaningful concepts within the BMS assessments were extracted and coded using the ICF standardized linking technique. We hypothesized that 90% of the concepts in the BMS would be linked to the ICF. Overall, 61% of the concepts in the BMS measures were found to be linkable to the ICF. Concepts labeled 'hc'(health condition) are presumed to be linked to the ICD framework, the ICF's partner document. Therefore 70% of the BMS assessments are linkable to the ICF and ICD frameworks.

Linking: what's missing and what are the implications

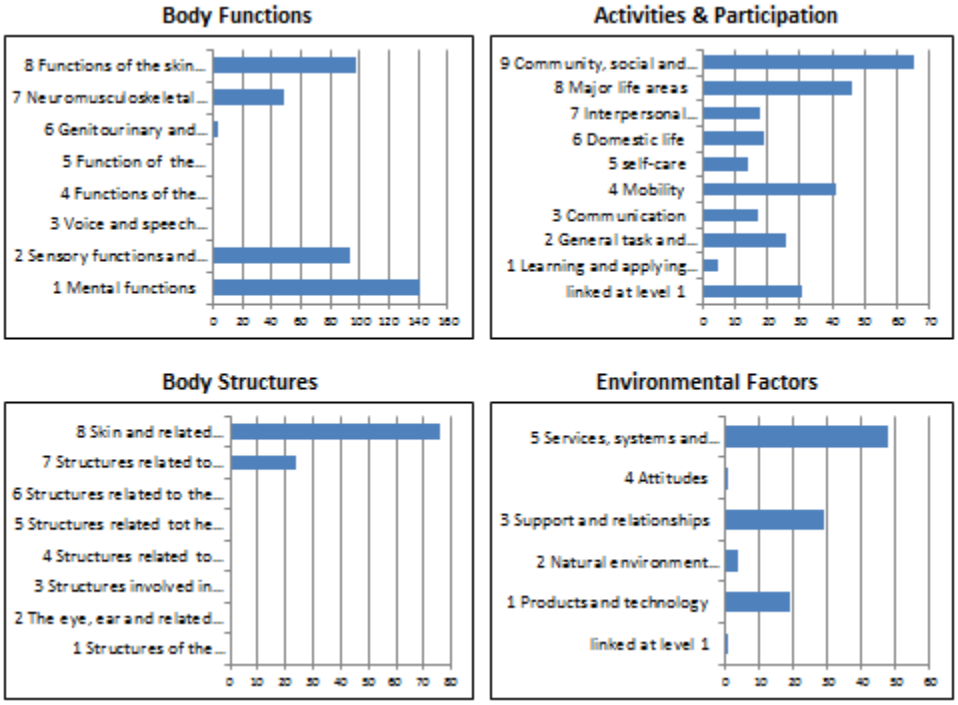

Figure 30. Linkable concepts by chapter for all Burn Model Systems assessments. X-axes represent the number of concepts

Among all the BMS linkable concepts, the *body functions (b)* component is represented most frequently at 42%, a much larger amount than our hypothesis of 10%. Four out of eight body functions (b) chapters were represented in the BMS 0-4, 5-13, and 14-18 initial and follow-up assessments. ICF topics that were not addressed included: voice and speech function (b3), functions of the cardiovascular, hematological, immunological and respiratory systems (b4), functions of the digestive, metabolic and endocrine systems (b5), genitourinary and reproductive functions (b6), and functions of the skin and related structures. The BMS adult follow-up assessment omitted the same chapters as above with one exception; the adult follow-up assessment did include genitourinary and reproductive functions (b6) but did not include neuromusculoskeletal and movement-related functions (b7).

The next most commonly linked ICF component *was activities and participation (d)*, representing 34% of all linkable BMS concepts, similar to our

hypothesis of 40% for *activities and participation* representation. The BMS adult follow-up assessment included all nine of the *activities and participation (d)* chapters. None of the remaining BMS assessments included concepts related to chapter 1, learning and applying knowledge (d1). The BMS 0-4 and 14-18 initial and follow-up did not include content related to chapter 5, self-care (d5). The BMS 0-4 initial and follow-up assessments did not include chapter 8, major life areas (d8) as well.

While the components, *body functions (b)* and *activities and participation (d),* are well represented within the BMS assessments, this appears to be at the expense of other components such *body structures (s)* and *environmental factors (e).* For example, in the BMS-initial 5-13 there were 130 linkable concepts. Of those 130 concepts, 52 were *body functions (b)* concepts and 40 were *activities and participation (d).* Only nine of those concepts represented the *environmental factors (e)* component. Similar counts occur in the other BMS assessments. In the BMS 0-4 initial, 16 concepts address the *body functions (b)* topics, protective functions of the skin (b810) and repair functions of the skin (b820), while the environmental factors (e) topic of support and relationships (e3) is not addressed at all.

It should also be noted that although the components *body function (b)* and *activities and participation (d)* are frequently represented within the assessments, the distribution of specific chapter categories is uneven. For example in the BMS 0-4initial assessment, a total of 10 concepts address six different categories under the chapter topic mobility (d4) while the chapter topics of communication (d3) and domestic life (d6) are represented by one concept each. In the BMS 5-13 initial, six categories that fall under the chapter topic mobility (d4) and four categories that fall under the chapter topic community, social and civic life (d9) are represented in the assessment. Meanwhile, only one category under the chapter of self-care (d5) is represented once in the assessment. Identifying ICF components and chapters included and excluded in the BMS assessments raises the question, which ICF components and chapters should be addressed in these assessments and of those chapters that should be addressed, to what depth? The answer to this question is

beyond the scope of this study, but should be considered prior to the development of an ICF Core Set for burn injury as the appropriate chapters/categories would likely vary based on developmental stage within a pediatric population.

The component *body structure (s)* is represented by 12% of the BMS concepts overall, though it is not represented at all in the BMS adult follow-up assessment. We hypothesized that 30% of BMS concepts would be linked to the body structure component. In the BMS 0-4, 5-13 and 14-18 initial and follow-up assessments, two of the eight body structure (s) chapters were represented. Topics not included consisted of: structures of the nervous system (s1), the eye, ear and related structures (s2), structures involved in voice and speech (s3), structures of the cardiovascular, immunological and respiratory systems (s4), structures related to the digestive, metabolic and endocrine systems (s5), structures related to the genitourinary and reproductive systems (s6). In addition, the BMS 0-4 initial and follow-up assessments do not include the topic structures related to movement (s7). The *body structure (s)* component is most represented in the BMS initial assessments in a section that inquires about location of burn and location of grafting post injury. While answers to these questions provide researchers with information regarding which body structures were affected by burn injury; the level of deformation, level of functional ability or deficit, and presence of development lag secondary to injury is not addressed. The follow-up assessments do not inquire into the state of healing of the structures previously addressed in the initial assessments. The assessments ask what type of outpatient treatment is being sought, but do not address the impact that the treatment has or has not had on the injured structure.

The addition of questions in the assessments that address changes in body structure due to burn injury over time may improve understanding of not only the effects of burn on body structure but how those effects impact other areas of life. Furthermore, addition of these questions would increase the applicability of the ICF to the BMS through the use of the ICF qualifier scale. The scale is designed to indicate the extent or magnitude of impairment and specify the nature of a change to a particular structure.[27] Through the addition of assessment questions that

address body structure (s), specifically magnitude of impairment and structural changes over time, researchers can conduct more focused studies that will hone clinical understanding of patient recovery from burn injury and thus result in improved rehabilitation efforts and outcomes.

Similar to the representation of the *body structure (s)* component, the *environmental factors (e)* component is also under-represented in the BMS assessments. The *environmental factors (e)* component is represented by only 13% of BMS assessment concepts overall. We hypothesized that 10% of concepts would be representative of the *environmental factors* component. The BMS 0-4 follow-up, BMS 5-13 initial and follow-up and the BMS 14-18 initial and follow-up assessments address content in three of the five environmental factors (e) chapters. However the content of two chapters, natural environment and human-made changes to environment (e2), and attitudes (e4), was not included in those assessments. The BMS-initial 0-4 excludes three chapter topics: natural environment and human-made changes to environment (e2), support and relationships (e3), and attitudes (e4). The BMS adult follow-up addresses all chapter topics except: services, systems and policies (e5).

Participation has been established as a key indicator of a person's health and well-being throughout the life span. [44-46] Environmental barriers and facilitators play a key role in a person's ability to participate in life activities. [57] A recent review of 31 studies pertaining to the impact of environmental factors on children with disabilities revealed that all ICF environmental domains influence the child's ability to participate in life activities. The most common facilitators were social support, family and friends and geographical location. The most common barriers were negative attitudes, physical accessibility of the environment, and lack of support from staff and service providers.[57] Participation is a primary outcome of rehabilitation interventions[33] and is well covered in the BMS assessments. However, the environmental factors that impact one's ability to participate are not thoroughly examined in the BMS assessments and warrant more attention in future editions to

establish a more thorough understanding of the factors that impact the level of independence in participation in life activities post burn injury.

One-third to one-half of the BMS 0-4, 5-13 and 14-18 assessments were unlinkable to the ICF, and a quarter of the BMS adult follow-up was not linkable. Overall, all BMS concepts could not be linked to the ICF, those labeled 'no code' represented 35%. Most of the 'no code' concepts in the BMS were medical interventions (i.e. splinting, casting or scar massage) or 'personal factors' as defined by the ICF. Twenty-four percent of all BMS unlinked concepts were labeled 'hc' (health conditions) and would therefore be linked to the ICD rather than the ICF. Thirty-one percent of the unlinked concepts were labeled as 'nd' (not definable). These concepts were considered too broad or vague to be linked to the ICF. For example, a prefix taken from BMS follow-up 14-18 states," These questions are about how you feel and how things were with you during the 4 weeks before your burn". The phrase "how things were with you" is a meaningful concept probing for the individual's understanding of how he or she was handling life in general. However, the concept's meaning is suggestive and not manifest; therefore it is considered unlinkable to the ICF. This demonstrates how some meaning in the assessments is lost through the coding process. Similar 'nd' (not definable) concept count results were attained by other studies that linked assessments to the ICF.[11,17,48] Ten percent of the unlinked concepts were labeled as 'nc' (not covered). Concepts coded as 'nc' (not covered) are not covered by the ICF. For example, in BMS follow-up 5-13 the question asks, "if your child has stopped his/her burn occupational or physical rehabilitation therapy since his/her last follow-up, whose decision was it to discontinue?" The meaning of the concept "whose decision was it to discontinue" is not linkable to the ICF, as there is no code for the concept. Overall, similar percentages of unlinked concepts within pediatric assessments have been documented in the literature.[28]

Concept density

Concept density is the number of meaningful concepts identified per question. While the average concept density for the BMS assessments was 1.8, some

questions were found to be very dense with seven concepts or more. For example, in the BMS-initial 0-4 a question asks, "During the past 7 days or since your child was burned if less than 7 days ago: was your child limited in the kind of schoolwork or activities with friends he/she could do because of emotional or behavioral problems?" This question contains five meaningful concepts. A question in the BMS-initial 14-18 reads, "During the 4 weeks before your burn how much of the time did your physical health or emotional problems interfere with your social activities like visiting friends, relatives, etc?" This question has six meaningful concepts. The patient's or proxy's answer to these questions and other concept-dense questions within the BMS assessments do not contribute to the understanding of the experience of patients post burn injury because an assessor cannot determine which meaningful concept the patient or proxy is addressing in his or her answer. The first aforementioned question asks about ability to perform school work or activities with friends. These are two separate topics that require very different sets of skills and abilities. These skills and abilities are impacted in different ways by emotional problems vs. behavioral problems. While emotional problems and behavioral problems are often associated, this is not always the case. If the patient or proxy answers 'yes' to this question we only determine that the patient's ability to do school work or activities with friends is limited by emotional problems or behavior problems or both. We cannot isolate in which area the deficit lies or define the cause of the deficit. The density level of the question causes the question to lose its meaning altogether. The second question mentioned above, demonstrates the same issue with different concepts. In future editions of the BMS assessments, developers should consider deconstructing concept-dense questions into multiple items to capture more accurate information that will be useable in burn injury research.

The perspectives of the BMS assessments

As we hypothesized, the BMS assessment questions were predominantly defined within the health-status perspective. Few questions were attributed the QOL perspective. Therefore, clinicians and researchers should be aware that outcomes produced from the BMS data primarily demonstrate patients' status based

on biopsychosocial elements that pertain to health conditions, physical and emotional performance, and social barriers or facilitators.[28,39] The majority of the health status questions probe level of disability rather than level of function. QOL data (personal perception of a situation based on culture, value system, personal goals, and standards and concerns[35]) and data that describes environmental barriers or facilitators that impact participation is very limited within the BMS database. Questions of the health status perspective should not be used in QOL life research and vice versa. Misinterpreting the health status items as QOL items can result in misleading outcomes that only serve to thwart progress towards understanding and improving the lives of burn patients post injury. [30]

Study limitations

This study was limited by the potential for bias in the ICF linking results. Ideally, two coders trained in the ICF linking technique would code all of the questions, and a kappa score would be computed to determine their level of agreement. However, in this study one trained coder linked all of the items within each of the assessments, and a second trained coder linked ten percent of the items in the database that included linking outcomes for all BMS assessments as well as linking outcomes for a second set of burn injury assessments. This potentially biases the results towards the linking outcomes of a single coder. Another potential limitation was the exhaustiveness of the ICF framework. Although a vast number of ICF validity studies have been conducted worldwide, the ICF is a living document that is subject to reviews, updates, and revisions. The BMS assessments contained concepts that were not covered by the ICF. The meaning of these concepts, therefore, could not be coded and were lost due to the linking process. A final limitation was lack of clearly defined concepts within the BMS assessments. BMS concepts with meanings that were suggestive rather than manifestly stated were coded as “not definable”, as a result those meaningful units were not captured through the linking process.

Conclusion

By linking the BMS assessments to the ICF framework we determined that the majority of the concepts were linked to the *body function (b)* or the *activities and participation (d)* components. Although these components are represented often within the BMS, the distribution of chapter and category representation within the components is uneven. Developers of future editions of the BMS assessments should consider the addition of concepts regarding the impact of environmental factors on participation as well the addition of body structure concepts within the follow-up assessments to track structural deformation and or developmental delay secondary to injury. Developers should also consider deconstructing questions with heavy concept density so as not to lose the overall meaning of the questions in the text. Both researchers and clinicians currently using BMS data should be cognizant of the overall health status perspective of the assessments. Generally speaking, this data should not be used to examine QOL outcomes within the burn population.

Chapter 6 Preliminary Burn Injury Core Set Categories

Introductions

In 2001 the World Health Organization (WHO) endorsed the International Classification of Functioning, Disability and Health (ICF) and in 2007 its Children and Youth version (ICF-CY).[26] The ICF is an integrative framework based on a model of functioning and disability containing four main components: body functions, body structures, activities and participation, and environmental factors. Each component contains five to nine chapters. The chapters are further broken down into 1,424 categories (see figure 30 below). The purpose of the framework is to provide a unified and standardized language that can be used worldwide to classify and describe health and health-related domains.

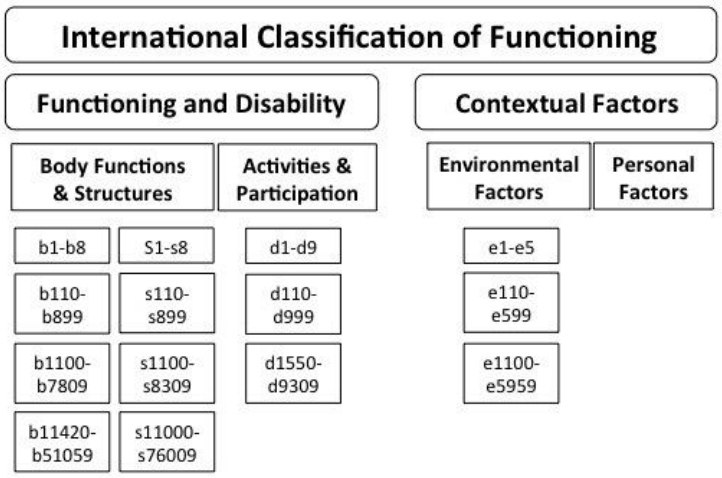

Figure 31. ICF component breakdown[27]

A number of validity studies have found the ICF categories to be both exhaustive and precise, suggesting that the framework encompasses the range of the human

experience.[26] In addition, the ICF provides a standardized language that can be used worldwide to describe and classify health and health-related domains.[26]

Medical workers, patients, families, researchers, and policy makers are able to describe and discuss disability and functioning using this universal language. The ICF framework affords the opportunity to understand the impact of disability worldwide on both individual and societal levels through global information exchange and the ability to pool and compare data collected around the world. [28]

In 2002, the Classification Assessment Surveys and Terminology Team of the WHO and the ICF Research Branch initiated the development of the Core Set project. The objective of this project was to create internationally agreed upon condition- or disease-specific ICF Comprehensive Core Sets and Brief Core Sets.[15] These Core Sets are developed through a standardized methodology established to scientifically determine the ICF categories most pertinent to the assessment of an individual with a specific condition or disease.[58] A Comprehensive Core Set provides a basic international standard of what aspects should be measured to best describe, in a comprehensive and multidisciplinary assessment, the functioning and disability of an individual diagnosed with a specified disease or condition. A Brief Core Set is comprised of as few ICF categories from the Comprehensive Core Set as possible to be practical, but as many as deemed necessary to comprehensively describe the typical spectrum of functioning and disability of patients with a specific condition. The Brief Core Set is intended to serve as the minimum data to be reported in all clinical studies of a condition and as such the data can be used to compare and describe the burden of disease across studies and around the world.[15]

The development of an ICF Core Set is a standardized process endorsed by the WHO.[59] The preparatory phase consists of four parts; a systematic review of the literature to comprehensively describe the aspects of functioning related to a specific health condition, a survey of international experts that obtains the health professionals' perspectives regarding which aspects of functioning are most relevant for assessment, a qualitative study consisting of interviews of individuals

with the specified health condition and their care takers, and finally a prospective study of clinical encounters to identify relevant areas of functioning assessed by interdisciplinary clinical teams. The integration of evidence gathered during the four steps of the preparatory phase provides the basis for developing a preliminary list of ICF category candidates for possible inclusion within a Comprehensive Core Set. Once the preliminary list is established, a sample of international experts from all pertinent fields gathers for ICF training and participates in a consensus meeting where all evidence is reviewed, and ICF categories are selected from the preliminary ICF category list through an iterative decision-making process. Brief Core Sets are then developed out of the Comprehensive Core Set through the same iterative process by the same expert panel.

Since 2002, ICF Core Sets have been developed for 34 health conditions. [60] At present, no Core Set exists in the area of burn injury. A call for the development of a Core Set for burn injury was published in 2006[16], however very little progress towards this goal has been made. At present, no call has yet been put forth for the development of a Core Set for burn injury in the pediatric population. Because burn injury occurs most often among children (0-18 years)[61] and the impact of burn injury may differ throughout the pediatric developmental stages, a separate Core Set for pediatric burn injury should be developed to comprehensively address the factors unique to a pediatric population.

Until recently, no pediatric Core Sets existed for any pediatric condition. The first one was devised using the Core Set standardized methodology in 2014 for children with cerebral palsy.[62] A Comprehensive Core Set was developed to address aspects of functioning in children from birth to18 years of age. Derived from the Comprehensive Core Set, Brief Core Sets were developed based on the experience of a child with cerebral palsy at specific developmental stages, birth to 6 years, 6-14 years, and 14 -18 years.[62] A pediatric ICF Core Set (birth to 18 years) for burn injury will provide an international standard for the assessment and reporting of disability and functioning among pediatric patients who have sustained burns. The Core Set

would not only serve as a guide to ensure a comprehensive clinical assessment, but would also broaden and improve clinical research outcomes through the standardization of the assessment of pertinent ICF categories among all pediatric patients with burn injury.

Since the call for the development of a Core Set for adult burn injury in 2006, two additional publications have emphasized the importance of a burn injury Core Set and provided initial steps towards its development. A systematic review compiled the most frequently used adult generic and burn-specific assessments in burn rehabilitation.[17] The content of those assessments was then linked to the ICF to determine which ICF categories are most frequently assessed in patients with burn injury. The results revealed that 46% of concepts were linked to *body functions (b),* and 20% were linked to *activities and participation (d)* with the few remaining concepts linked to health condition, *body structures (s)* and personal or *environmental factors (e).*[17] In a subsequent publication, seven "core domains" were preselected by the authors.[6] Six of these were derived from the ICF. The domains included skin, neuromuscular function, sensory and pain, psychological functions, community participation and perceived quality of life. The authors then searched the burn injury literature to determine the most frequently used and gold standard measures for each of the domains.

Determining the most efficient and precise way to measure pertinent outcomes typically follows (as opposed to precedes) the development of a Core Set.[62] However, the present study provides preliminary insight into what outcome measures exist for different areas of burn injury assessment and which are most appropriate with consideration given to time and financial burden.[6] The original paper that called for the development of a Core Set for burn injury explored functional outcomes after burn injury where "functional outcomes" was defined as "all consequences, both short term and long term, following burn injury."[16] The investigators examined burn literature for the most frequently used assessments in pediatric, adult, and elderly populations. The content of those assessments was then

linked to the ICF at the chapter level to determine the ICF chapter topics most frequently assessed in burn rehabilitation. Only three studies addressed burn injury outcomes among an elderly population. The measures included in these studies focused mostly on the ICF chapters of self-care, domestic life, and support and relationships. Twenty-eight studies examined burn injury outcomes among adults. These assessments most often addressed the following ICF chapters: mental functions (b1), mobility (d4), self-care (d5), domestic life (d6), interpersonal interactions and relationships (d7), major life areas (d8), and community, social, and civic life (d9). Sixteen studies explored burn injury outcomes in pediatric populations in which the most common ICF chapter topics assessed included: mental functions (b1), sensory function and pain (b2), mobility (d4), and self-care (d5).

One of the objectives of this study was to generate a preliminary list of Core Set categories that is pertinent to pediatric burn injury. This list will serve as a foundation for developing a pediatric burn injury ICF Core Set. Similar to other Core Sets, the development of a pediatric burn injury Core Set is intended to result in a global effort to collect more robust burn injury data that can be used to develop and hone acute care management and rehabilitation practices and ultimately, increase the long-term functional independence of patients post burn injury.

Methods

The first step in the standardized procedure for developing a Core Set is a systematic review of the literature on a disease or condition. Based on the literature, reviewers determine the most frequently used assessment tools for a specific condition or diagnosis. Those assessments are then linked to the ICF to determine the ICF categories most often assessed for a particular health condition. This initiates the development of a list of ICF categories candidates for inclusion in a disease- or health condition- specific Core Set. This study will contribute to the first step in the development of a pediatric Core Set for burn injury.

Literature search

A structured literature search was conducted in the fall of 2014 to determine if any preliminary work towards the development of an ICF Core Set for pediatric burn injury existed. Inclusion criteria included any articles that applied the ICF standardized linking technique to assessment tools used in a pediatric population with burn injury. The PubMed and Cochrane Library databases were searched using the keywords "ICF", "International Classification of functioning, disability and health", "ICF CY", "International Classification of functioning, disability and health-Child and Youth", "burn", "burn injury", "burn rehabilitation", pediatric burn injury", "pediatric burn rehabilitation", "child", "children", "core set", "ICF core set". The search revealed five publications that integrated the ICF into burn injury rehabilitation outcomes.[6,16,17,63,64] Two of these papers applied the ICF standardized linking technique in an effort to develop a Core Set for burn injury.[16,17] One was a systematic review that linked pediatric burn injury assessments to the ICF.[16] The results of this study were used in conjunction with the Burn Models System (BMS) and Burn Outcomes Questionnaire (BOQ) assessment linking results to develop a preliminary ICF Comprehensive Core Set for pediatric burn injury. The systematic review of pediatric burn injury literature is described below.

The authors conducted a systematic review of pediatric burn injury literature and linked the assessment tools used in each of the studies to the chapter level of the ICF.[16] The authors searched the literature in Medline (1966-November 2003) for all publications presenting empirical data relating to the functional consequences of burn injury. Functional consequences of burn injury were defined as "all consequences, both short and long term, following injury."[16] The reference lists of each article were then hand searched for additional pertinent publications. Publications that merely described the consequences of burns in a specific body region and case reports were excluded. Only publications in English, French, German, and Dutch were included. Their search revealed a total of 50 studies meeting the inclusion criteria. Sixteen of those studies were conducted in a pediatric burn population. The assessment items used to determine burn consequences in

each of those studies were then linked to the ICF at the chapter level to determine the percentage of publications that addressed specific ICF chapter topics. Half of the studies investigated burn injury consequences among a severely burned pediatric population and six of those studies focused on patients with massive burns (>70% total burn surface area).

The ICF linking results from this systematic review of pediatric burn injury literature combined with the linking results from two nationwide burn injury database assessment tools (described below) will provide the basis for the development of an initial list of ICF category candidates for a pediatric Comprehensive Core Set for burn injury.

The use of linking results from two nationwide database assessment tools

Using previously described methods (see chapter 3), the assessments used to collect data in two multi-center nationwide burn injury databases were linked to the ICF at the most detailed levels possible to determine the ICF categorical composition of each of the assessments. The first database is known as the Multi-Center Benchmarking Study. Initiated in 2001, a consensus panel of experts from the American Burn Association (ABA) and Shriners Hospitals for Children burn hospitals developed the Burn Outcomes Questionnaire (BOQ). The BOQ has since proven reliable, valid, and responsive to change in a burn population over time.[23] As of 2012 the Multi-Center Benchmarking Study had collected data from over 1,100 severely burned patients.[18] The second database is known as the Burn Injury Model Systems program. In 1994, the National Institute on Disability and Rehabilitation Research (NIDRR) developed the Burn Injury Model Systems outcome assessment. The majority of the questions were selected by a panel of experts from the following pre-established instruments: Special Form (SF)12, SF10 Health Survey for Children, The Satisfaction with Appearance Scale, Community Integration Questionnaire, and The Satisfaction with Life Questionnaire. As of 2007, Burn Injury Model Systems data have been collected from over 4,500 patients.[19]

Results

The representation of each ICF chapter in the BMS and BOQ assessments and the frequency with which each pediatric burn injury publication addresses each ICF chapter

Table 9 shows the frequency with which each ICF chapter was represented in each of the assessments for both the BMS database and the BOQ database as well as the percentage of pediatric burn injury publications that contained outcome measures that addressed each ICF chapter as reported by Van Baar and colleagues in 2006[16].

ICF Chapters	**%** of publications that address the chapter topic (total number of publication: 16)	**Number** of concepts within the BMS assessments that address the chapter topic (total number of concepts: 663)	**Number** of concepts within the BOQ assessments that address the chapter topic (total number of concepts: 230)
Body functions (b)			
1 Mental functions	75	101	38
2 Sensory functions and Pain	50	38	15
3 Voice and speech functions	6		
4 Functions of the cardiovascular, hematological, immunological and respiratory systems	19		2
5 Function of the digestive, metabolic and endocrine systems	6		
6 Genitourinary and reproductive functions			
7 Neuromusculoskeletal and movement-related functions	31	24	2
8 Functions of the skin and related structures	38	126	12
Activities and Participation (d)			
1 Learning and applying knowledge	31		1
2 General task and demands	13	15	12
3 Communication	38	6	3
4 Mobility	56	32	35
5 self-care	56	2	22
6 Domestic life	25	10	6

7 Interpersonal interactions and relationships		12	3
8 Major life areas	44	28	20
9 Community, social and civic life	44	50	26
Body structures (s)			
1 Structures of the nervous system			
2 The eye, ear and related structures			
3 Structures involved in voice and speech			
4 Structures related to cardiovascular, hematological, immunological and respiratory systems			
5 Structures related to the digestive, metabolic and endocrine systems			
6 Structures related to the genitourinary and reproductive systems			
7 Structures related to movement	13	24	
8 Skin and related structures		70	
Environmental factors (e)			
1 Products and technology		18	4
2 Natural environment and human-made changes			
3 Support and relationships	38	28	6
4 Attitudes	31		5
5 Services, systems and policies		48	14

Table 9. ICF chapter frequency in pediatric burn literature and the BMS and BOQ assessments. The second column is percent of publications (systematic review results). The third and fourth columns are the count of concepts (BMS and BOQ)

The BMS assessments and the BOQ assessments included 663 and 230 linkable concepts respectively. Four of the eight *body functions (b)* chapters were represented by all three sources. Those chapters included mental functions (b1), sensory functions and pain (b2), neuromusculoskeletal and movement-related functions (b7), and functions of the skin and related structures (b8). Chapter one, mental functions (b1), was most heavily represented among the pediatric burn injury publications (75%) and among the BOQ assessments (38 concepts). It was addressed second most frequently among the BMS assessments(101), outnumbered by only one chapter, functions of the skin and related structures (b8) (126 concepts). The chapter, functions of the cardiovascular, hematological, immunological and respiratory systems (b4), was represented in two of the three

sources. It was addressed in 19% of pediatric burn injury publications but was represented by only two concepts among the BOQ assessments and was not addressed among the BMS assessments. The chapters, voice and speech function (b3) and functions of the digestive, metabolic and endocrine system (b5), were addressed in only 6% of pediatric burn injury publications and were not addressed by either the BMS or the BOQ assessments. The chapter, Genitourinary and reproductive functions (b6), was not included in any of the sources.

Seven of the nine *activities and participation (d)* chapters were represented by all three reports. Those chapters included: general tasks and demands (d2), communication (d3), mobility (d4), self-care (d5), domestic life (d6), major life areas (d8), and community, social and civic life (d9). Mobility (d4) and self-care (d5) were most frequently represented among the pediatric burn injury assessments (56%). Mobility (d4) was also the most frequently addressed *activities and participation (d)* topic among concepts included in the BOQ assessments (35 concepts) and the second most frequently addressed *activities and participation (d)* topic among BMS assessments (32 concepts), second only to community, social and civic life (d9) (50 concepts). Learning and applying knowledge (d1) and interpersonal interactions and relationships (d7) were addressed by two of the three reports.

None of the eight body structure (s) chapters were addressed by all three sources. Two of the three addressed the chapter, structures related to movement (s7). Thirteen percent of pediatric burn injury publications addressed structures related to movement (s7), and 24 concepts among the BMS assessments addressed the topic. The chapter was not addressed among the BOQ assessments. Skin and related structures (s8) was frequently addressed (70 concepts) among the BMS assessments. None of the BOQ assessments and no pediatric burn injury publications covered the content of the chapter. The remaining *body structure (s)* chapters were not addressed by any of the sources: structures of the nervous system (s1), the eye, ear and related structures (s2), structures involved in voice and speech (s3), structures related to cardiovascular, hematological, immunological

and respiratory systems (s4), structure related to the digestive, metabolic, and endocrine systems (s5), and structures related to the genitourinary and reproductive systems (s6).

Four of the five environmental factors (e) chapters were represented by at least two of the sources. Chapter three, support and relationships (e3), was the only chapter represented by all three sources. It was the most addressed *environmental factors (e)* topic among the pediatric burn injury publications (38%) and the second most frequently addressed *environmental factors (e)* topic in the BMS and BOQ assessments. Services, systems and policies (e5) was most frequently addressed by the BMS (48 concepts) and BOQ (14 concepts) assessments, but was not addressed in any of the pediatric burn injury publications. Products and technology (e1) was represented by both the BMS and BOQ assessments, but did not appear in any of the pediatric burn injury assessments. Attitudes (e4) was addressed in 31% of pediatric burn injury assessments and by five concepts among the BOQ assessments but was not addressed in the BMS assessments. No reports addressed natural environment and human-made changes (e2).

Preliminary list of ICF category candidates for an ICF Core Set for burn injury

The table below (Table 10) is a list of 117 preliminary ICF category candidates for a Comprehensive Core Set for pediatric burn injury derived from the linking results of the BMS and BOQ national databases. All linkable ICF categories from both databases were combined to form the list of candidates. The table indicates the specific assessment(s) and age group(s) that covered each category as well as the frequency with which each category was identified within each assessment. This is a preliminary Comprehensive Core Set list; however, the division by age group provides insight into which categories may be important to include within separate age-based pediatric Brief Core Sets. The final column demonstrates the frequency with which each category appeared among all nine assessments within both nationwide databases. The BMS initial and follow-up assessments for each age group were collapsed in the table. This is not an exhaustive list of category candidates; the assessments used in Van Baar and colleagues' systematic review[16]

require linking beyond the chapter level to determine the frequency with which specific ICF categories are being assessed in the pediatric burn population. Additional category suggestions are also included in the Discussion section below. This list is a preliminary step towards the four-part preparatory phase in the standardized process for developing an ICF Core Set.

Preliminary list of ICF categories for a pediatric burn injury Core Set	**BOQ0-4**	**BOQ11-18**	**BOQ5-18**	**BMS5-13**	**BMS14-18**	**BMS0-4**	**Grand Total**
b1 Temperament And Personality Functions	1						1
b1180 Body Image				2	2		4
b125 Disposition And Intra-personal Functions				2	2		4
b126 Temperament And Personality Functions	1						1
b1266 Confidence		1	1				2
b130 Energy And Drive Functions					4		4
b134 Sleep Functions	3	1	1	6	6	6	23
b1340 Amount Of Sleep		1	1				2
b1343 Quality Of Sleep		1	1				2
b140 Attention Functions	1	1	1				3
b152 Emotional Functions	6	5	5	10	12	7	45
b16710 Expression Of Spoken Language	1						1
b180 Experience of self and time functions				16	16	2	34
b1801 Body Image	1	2	2	4	4		13
b2700 Sensitivity To Temperature				4	4	4	12
b280 Sensation Of Pain	5	5	5	9	8	9	41
b455 Exercise Tolerance Function		1	1				2
b710 Mobility Of Joint Function				1	1	1	3
b7101 Mobility Of Several Joints		1	1				2
b7102 Mobility Of Joints Generalized				5	5	5	15
b730 Muscle Power Functions				2	2	2	6
b810 Protective Function				1	1	1	3

Of The Skin							
b810 Protective Functions Of The Skin				16	16	16	48
b820 Repair Functions Of The Skin				2	2	2	6
b820 Repair Functions Of The Skin				13	13	13	39
b840 Sensation Related To Skin	1						1
b840 Sensation Related To The Skin	4	3	3	10	10	10	40
b860 Functions Of Nails	1						1
d A&p	2	1	1	8	9	8	29
d130 Copying	1						1
d220 Undertaking Multiple Tasks		1	1				2
d230 Carrying Out Daily Routine		1	1		6		8
d250 Managing One's Own Behavior	2	3	3	6		3	17
d330 Speaking	3						3
d3350 Producing Body Language				2	2	2	6
d410 Changing Basic Body Position				2		2	4
d4100 Lying Down		1	1				2
d4103 Sitting		1	1				2
d4104 Standing	1						1
d4105 Bending		1	1	3		3	8
d4300 Lifting				3		3	6
d4301 Carrying In The Hands	1						1
d440 Fine Hand Use		1	1				2
d4400 Picking Up		1	1				2
d4410 Changing Basic Body Positions				1		1	2
d445 Hand And Arm Use		2	2				4
d4450 Crawling	1						1
d450 Walking	2	1	1				4
d4500 Walking Short Distances		1	1				2
d455 Moving Around	1	1	1				3
d4551 Climbing	2	2	2		2		8
d4552 Running		1	1				2
d4555 Scooting And Rolling	1						1
d465 Moving Around Using Equipment				3		3	6

d4750 Driving Human-powered Transportation				3		3	6
d520 Caring For Body Parts				2			2
d5202 Caring For Hair		1	1				2
d540 Dressing	1						1
d5400 Putting On Clothes	1	1	1				3
d5401 Taking Off Clothes	1						1
d5501 Carrying Out Eating Appropriately	2	1	1				4
d560 Drinking	3						3
d57020 Managing Medications And Following Health Advice		1	1				2
d6 Household Tasks (d630-649)	1	1	1				3
d6200 Shopping	1	1	1	2	2	2	9
d640 Doing Housework					2		2
d6403 Using Household Appliances					2		2
d7 Interpersonal Interactions And Relationships	1						1
d7 Interpersonal Interactions And Relationships		1	1	2	2	2	8
d7500 Informal Relationships With Friends				3		3	6
d8 Work And Employment (d840-859)					4		4
d820 School Education		2	2	6			10
d8201 Maintaining Educational Program		2	2				4
d8202 Progressing In Educational Program		1	1				2
d845 Acquiring, Keeping And Terminating A Job					2		2
d850 Remunerative Employment					2		2
d850 Remunerative Employment	1	1	1		4		7
d860 Basic Economic Transaction					2		2
d865 Complex Economic Transactions					2		2
d870 Economic Self-sufficiency				2	2		4
d8700 Personal Economic Resources					2		2

d880 Engagement In Play	4	1	1				6
d8803 Shared Cooperative Play	1						1
d920 Recreation And Leisure		5	5	6	6	6	28
d9200 Play					2		2
d9201 Sports		4	4	2	4	2	16
d9202 Arts And Culture		1	1	2	2	2	8
d9205 Socializing	2	2	2	8	6	2	22
e110 Drugs	1						1
e1150 General Products And Technology For Personal Use In Daily Living				4	4	4	12
e1151 Assistive Products And Technology For Personal Use In Daily Living	3			2	2	2	9
e3 Support And Relationships		1	1				2
e310 Immediate Family				2	2		4
e320 Friends				4	4		8
e355 Health Professionals	2	1	1	4	4	4	16
e4 Attitudes	1						1
e425 Individual Attitudes Of Acquaintances, Peers, Colleagues, Neighbors And Community Members		1	1				2
e430 Individual Attitudes Of People In Positions Of Authority		1	1				2
e565 Economic Services, systems and policies				1	1	1	3
e5650 Economic Services				1	1	1	3
e5700 Social Security Services				1	1	1	3
e5800 Health Services	4	2	2	13	13	13	47
e5850 Education And Training Services		1	1				2
e5853 Special Education And Training Services		2	2				4
s710 Structure Of Head And Neck Region				4	4		8
s730 Structure Of Upper Extremity				2	2		4
s7302 Structure Of Hand				2	2		4
s750 Skin Of Lower				2	2		4

Extremity							
s760 Structure Of The Trunk				2	2		4
s8 Skin And Related Structures				4	4	4	12
s8100 Skin Of Head And Neck Region				8	8	6	22
s8102 Skin Of Upper Extremity				4	4	4	12
s8103 Skin Of Pelvic Region				2	2	2	6
s8104 Skin Of Lower Extremity				4	4	4	12
s8105 Skin Of Trunk And Back				2	2	2	6
s810 Structure Of Areas Of Skin Area				2	2	2	6
Grand Total	72	79	79	239	245	175	889

Table 10. The preliminary list of ICF Core Set category candidates
Numbers represent the frequency of categorical representation within each assessment; initial and discharge BMS assessments were combined by age group

Discussion

The preliminary ICF Core Set for pediatric burn injury: What's missing?

The preliminary list of category candidates was derived from nine age-based burn injury assessments that were meticulously developed by panels of experts in the field of pediatric burn injury. These assessments have been found to have good psychometric properties and have been used for over a decade. [18,19] However, the linking results described in chapters 4 and 5 indicate that these assessments may not cover all pertinent topics and may emphasize some areas while neglecting others. When the concepts of each were linked to the ICF, the results indicated that the ICF components, *activities and participation (d)* and *body functions (b),* were heavily represented, while *body structures (s) and environmental factors (e)* were scarcely addressed. Therefore, the list of Core Set category candidates derived from the linking of these assessments should be considered as a preliminary starting point for the development of a Core Set for pediatric burn injury.

When the BMS and BOQ linking results were combined with the pediatric burn injury publication results, all but eight of the 30 ICF chapters were not covered by at least one report. The majority of chapters not covered were of the *body*

structure (s) ICF component. Only 13% of pediatric burn injury studies included in van Baar and colleagues' review[16] addressed *body structures (s).* Of those publications, only one chapter, structure related to movement (s7), was addressed. This would indicate that objective data regarding skin and related structures (s8) as well as other affected body structures is not being routinely collected.

Body structure (s) chapters included in the preliminary list of category candidates were structures related to movement (s7) and skin and related structures (s8). While these chapters are likely the most pertinent *body structure (s)* topics in the area of burn injury recovery and rehabilitation; the chapter topic, structures of the cardiovascular, immunological and respiratory systems (s4) should also be considered for inclusion in the Comprehensive Core Set. Inhalation injury is considered one of the most critical injuries resulting from exposure to smoke.[65] Patients can present with hyper-reactive airways for at least six months post injury. Some longer term studies indicate that patients may develop obstructive and restrictive respiratory patterns and may never regain normal lung function. [66-68] A pediatric burn cohort study demonstrated no difference in exercise tolerance among patients who had sustained an inhalation injury compared to those who had not.[68] However, those with an inhalation injury demonstrated a significantly higher respiratory rate and had an increased incidence of abnormal lung function.[68] Thus, the inclusion of ICF categories that address structures related to the respiratory system should be considered for a pediatric Comprehensive Core Set. Damage to the larynx secondary to exposure to smoke toxins can also result in persistent hoarseness or dysphonia. [65] Similar to laryngeal damage, other long term internal structural damage may result from burn injury. It is important to note that a Comprehensive Core Set is a list of the representative categories for a specific health condition that may require assessment; however an individual should be evaluated on a case-by-case basis. ICF categories that are not included in a Core Set but may impact an individual should also be considered.

Environmental factors (e) categories were also relatively underrepresented among the BMS and BOQ assessments. Among pediatric burn injury publications,

only two *environmental factors (e)* chapters were represented. Thirty-eight percent of publications addressed support and relationships (e3) and 31% addressed attitudes (e4).[16] However, when the BMS and BOQ linking outcomes were combined to create the preliminary Core Set list, *environmental factors (e)* chapter representation improved (4 out of 5 chapters). Although chapter representation improved, categorical representation within those chapters was not diverse. Additional *environmental factors (e)* categories should be considered for the final Core Set. A comprehensive understanding of the overall health and well-being of a child with a burn injury requires the assessment of environmental factors that impact disability and ability to function. Parents of children with disabilities reported less environmental support within their communities, frequently reporting that the availability and adequacy of public transportation, programs and services, information, equipment and supplies, and time and money are "usually not available or adequate".[43] Therefore, environmental barriers and facilitators that impact participation in daily activity such as physical layout, sensory quality, physical demands of activity, cognitive demands of activity, social demands of activity, relations with peers, attitudes, weather conditions and safety[43,47] should be considered for inclusion in the future pediatric Core Set for burn injury.

Future steps

The preliminary list of Core Set categories derived in this study provides a starting point for the development of a Comprehensive Core Set for pediatric burn injury that will ensure that patients receive a comprehensive rehabilitation evaluation. It will provide more robust data for long-term research in the field of burn recovery and will also be available for teaching and administrative purposes. To ensure that all pertinent ICF categories have been included in the preliminary list of Core Set categories, the assessments that were linked to the ICF chapter levels by van Baar and colleagues[16] should be further linked to the most detailed possible level, similar to the linking of the BMS and BOQ assessments. This will more precisely define the ICF categories required to describe the experience of a person with burn injury. Van Baar and colleagues[16] also did not include studies that

explored outcomes related to specific body regions. The assessments used in body-part specific studies should be considered in the future development of a Comprehensive Core Set as severe burn injury to specific areas of the body such as hands, face, genitalia, and across joints can result in serious long-term functional consequences that may have a more critical impact upon daily function than burns to other bodily areas. Inclusion of body part-specific categories in the Comprehensive Core Set may contribute to a more detailed description of the effects of burn injury over time. Upon completion of the ICF Comprehensive Core Set for pediatric burn injury, age-specific Brief Core Sets should be derived from the Comprehensive Core Set in order address the effects of burn injury on functioning and disability at different developmental stages.

Conclusion

This preliminary list of Core Set category candidates for pediatric burn injury is the first of its kind in the field. It was *developed* in order that medical workers and researchers who specialize in pediatric burn injury will unite with the WHO in a mission to finalize the Comprehensive and Brief Core Sets, so that we may better serve our patients, collect more robust data to conduct sound research, and teach and communicate more effectively using a global language. May this serve as a call to action for all who specialize in pediatric burn injury around the world.

Chapter 7 Summary and Conclusions

The two central goals of this study were: 1) to assess the comprehensiveness of the main outcome measures in two widely used national pediatric burn databases: the Burn Injury Model Systems (BMS) and the Multi-Center Benchmarking Study (BOQ) using the ICF and the ICF-Child and Youth (ICF-CY) version frameworks; and 2) to contribute to the preliminary identification of ICF categories for the development of an ICF Core Set for pediatric burn patients. The study also identified the overall perspective (health status versus QOL versus environmental) of the BMS and BOQ assessments. The results of this study provide an analysis of the extent to which the experiences of children with burn injury are being systematically and comprehensively examined by researchers and understood by clinicians. The findings suggest that some areas are well covered, others are perhaps overemphasized, and some areas are neglected.

Approximately half of the identified concepts in the BOQ assessments were linked to the ICF. BOQ concepts were most frequently linked to the *activities and participation (d)* component followed by the *body functions (b)* component. Approximately 60% of the BMS was linkable to ICF. The *body functions (b)* component was most frequently represented in the BMS assessments followed by *activities and participation (d).* The BOQ does not address any of the topics related to the component *body structures (s)*. Thus, pediatric structural developmental delays and/or lags secondary to injury cannot be assessed or followed over time using these assessments. *Body structure (s)* is represented by 12% of BMS concepts overall, and is not represented at all in the BMS adult follow-up assessment. *Environmental factors (e)* are rarely addressed in either the BOQ or BMS assessment, with exception of the BMS adult follow-up assessment. However, many environmental factors have a significant impact on functioning and the ability to participate in activity and should be more comprehensively represented by these assessment tools. The varied distribution of ICF categorical representation within and among ICF components represented in the BOQ and BMS assessments suggests that some frequently represented topics could be more concisely represented which

would allow for increased representation of pertinent categories from poorly represented areas without increasing the overall burden of the assessment.

Researchers and clinicians should be cognizant of the perspectives of the BOQ and BMS measures. The majority of the BOQ and BMS assessment items represented the health status perspective. The validity of studies that used the data collected from these assessments to determine quality of life should therefore be questioned. These data answer questions regarding the health status over time of persons with burn injury. Very few items address quality of life issues. A separate assessment tool should be used to determine quality of life outcomes in this population.

The majority of BOQ and BMS concepts that were not linked to the ICF were labeled as health conditions and therefore potentially classifiable to the International Classification of Disease, or labeled as 'no code', a category in which the majority was clinical interventions or personal factors. Remaining unlinked concepts were either not covered by the ICF or not defined clearly enough to be linked. When a concept meaning is latent, or suggestive of a meaning, it cannot be linked to the ICF. While these latent concepts may be an important part of the assessment measure, they cannot be classified through the ICF linking process.

The BOQ and BMS linking results were compiled to develop a preliminary list of 117 ICF category candidates for a pediatric burn injury Core Set. The results described above suggest that when the categories represented in both the BOQ and BMS were combined to create the preliminary list, ICF chapters were more completely represented. Twenty out of 30 chapters were represented in the list of category candidates. The list can serve as a preliminary starting point for the development of a Comprehensive Core Set for pediatric burn injury. The assessments included in a systematic review of pediatric burn literature[16] that were linked to the ICF at the chapter level should be further linked to the highest possible ICF level to more precisely define the categories required to describe the experience of a child with burn injury. The category list derived from this linking should be

added to the preliminary list of Core Set categories devised in the third paper. This will further contribute to the first step in the development process of a standardized Core Set for pediatric burn injury.

The study described in the preceding three chapters provides important insight into comprehensiveness of 11 assessments used to collect data for two nationwide multi-center pediatric burn injury databases. Through this research, we have defined the distribution of ICF categories and identified pertinent areas that are underrepresented or completely omitted in the assessments. These results should be considered when preparing future editions of the BOQ and BMS assessments to ensure a comprehensive assessment of a person's experience of life after burn injury.

The preliminary list of Core Set category candidates developed through the compilation of categories identified in the BOQ and BMS assessments is the first of its kind in the field of burn injury. The Core Sets developed from this work can be applied in clinical and educational settings as well as in research around the world. The global language of the ICF and the standardization of assessment areas in burn rehabilitation will serve to guide clinicians and researchers in assessing function, disability and health in clinical studies, clinical encounters and multi-disciplinary patient evaluation.

This study marks the initial integration of the ICF into the field of pediatric burn injury. The linking results can contribute information to the development of sound and comprehensive assessments that can improve the data collected in two widely used burn injury databases. The preliminary list of Core Set category candidates for pediatric burn injury was developed as a contribution to the first step of the standardized ICF Core Set development process and serves as a call to all burn injury specialists to develop Comprehensive and Brief Core Sets for burn injury for universal use.

Appendix A: BOQ Assessment Questions

Assessment Report

Burn Outcomes Questionnaire Ages: 0-4 Type:

(no prefix)

1 In general, would you say that this child's health is excellent, very good, good, fair, or poor?

The following are descriptions of children. Please fill in the circle that best describes this child in the past month because of burn
injury. Please answer every item as best you can.

2 Shows awareness and interest in others

3 Initiates a familiar play routine

4 Takes turns in simple play

5 Attempts to imitate adults' previous action during a play activity

6 During play, child may suggest new things or responds to adult suggestion with another idea

For each item, please fill in the circle that best describes your child in the past month because of burn injury.

7 Uses single word with meaning

8 Finger feeds

9 Scoops with a spoon and brings to mouth

10 Holds bottle or spout cup

11 Lifts open cup securely with 2 hands

12 Assists such as pushing arms through shirt

13 Rolls, scoots, crawls or creeps on floor

14 Walks up entire flight with no difficulty

For each item, please fill in the circle that best describes this child in the past month because of the burn injury.

15 Walks holding onto people or furniture

16 Walks without support

17 Carries objects that can be held in one hand

18 Pulls to a stand

19 Climbs onto an adult chair

If this child is under two year of age, skip to question 25. If this child is two year or older, please fill in the circle that best
describes your child in the past month because of burn injury.

20 Uses two words together with meaning

21 Uses 4-5 word sentences

22 Connects two or more thoughts to tell a simple story

23 Puts on T-shirt

24 Puts on and removes front opening shirt including fasteners

The following are descriptions of children's mood states. Please fill in the circle that best describes this child's mood in the past
month because of the burn injury.

25 Angry mood

26 Temper tantrums or hot temper

27 Destroys own things

28 Unhappy, sad or depressed

29 Seems unresponsive to affection

30 Withdrawn, doesn't get involved with others

31 Stubborn, sullen or irritable

32 Too fearful or anxious

33 nightmares and other sleep disruptions

For each item, please fill in the circle that best describes this child in the past month because of the burn injury. Over the past
month, how often has this child's health or behavior…

34 interrupted family meals

35 limited parents' ability to have time for themselves or time with friends

36 made shopping or household chores more difficult or stressful

37 limited parents' ability to work

38 limited family's ability to spend time with others

During the past month, how often has this child…

39 had pain from the burn injury

40 had itching from the burn injury

During the past month, how much of the time has this child…

41 been scratching

42 required medicine for pain/itch

43 awakened because of itching

During the past month, how severe has this child's

44 pain from the burn injury been?

45 itching from the burn injury been?

For each item, please fill in the circle that best describes this child in the past month because of the burn injury. Do you agree or
disagree with the following statements? Because of this child's burn injury…

46 your child is unattractive to others

47 changes in this child's appearance have interfered with his/her relationships

48 you are uncomfortable taking your child in public because of his/her appearance

Since the burn injury, how statisfied are you now with this child's…

49 symptom relief (pain and itch)

50 apearance

51 sleep

52 function (ability to play and have fun)

53 overall medical care

Over the past month, how much worry or concern have you had about…

54 child's recovery from the effects of the burn injury

55 child's amount of pain and suffering

56 child's future health

(no prefix)

57 The burn team answered my questions about possible future surgery…

58 Compared to before the burn, how would you rate this child's current overall health?

Before the burn injury, did a doctor, nurse, or other health professional say that this child has any of the following conditions? If
yes, please tell us if this child gets treatment, and if this child's activities are limited by the condition.

59 asthma

60 attention or behavioral problems

61 chronic allergies or sinus trouble

62 developmental delays

63 mental retardation

64 diabetes

65 epilepsy

66 hearing problems

67 heart problems

68 learning problems

69 sleep problems

70 speech problems

71 vision problems

72 depression

73 other chronic medical problems(specify)

(no prefix)

74 Has this child had surgery for the burn injury in the past 6 months (number of operations?)

Has this child begun any new treatment for the burn injury in the past 6 months? (indicate no or yes for each item)

76 wearing splints?

77 wearing jobst garment

78 using distractor devices

79 Physical therapy

80 Occupational therapy

81 no new treatment in the past 6 months

(no prefix)

82 What is the child's date of birth?

83 Is this child male or female?

84 What is this child's race?

85 What is the highest level of education achieved by this child's mother (or stepmother, if that is with whom he/she is
living)

86 What is the highest level of education achieved by this child's father (or stepfather, if that is with whom he/she is
living)?

87 Is this child's mother (or stepmother, if that is with whom he/she is living) employed?

88 Is this child's father (or stepfather, if that is with whom he/she is living) employed? List occupation.

89 Who does this child live with now?

90 Is there a change in the child's living situation because of the burn?

91 Who is filling out this questionnaire?

Assessment Report

Burn Outcomes Questionnaire Ages: 5-18 Type:

(no prefix)

1 In general, would you say that this child's health is excellent, very good, good, fair, or poor?

2 Compared to before the burn, how would you rate this child's current overall health?

Before the burn injury, did a doctor, nurse, or other health professional say that this child has any of the following conditions? If
yes, please tell us if this child gets treatment, and if this child's activities are limited by the condition.

3 asthma

4 attention or behavioral problems

5 chronic allergies or sinus trouble

6 developmental delays

7 mental retardation

8 diabetes

9 epilepsy

10 hearing problems

11 heart problems

12 learning problems

13 sleep problems

14 speech problems

15 vision problems

16 depression

17 drug problem

18 alcohol problem

19 other chronic medical problems(specify)

(no prefix)

20 During the past week, how often have you had pain from the burn injury?

21 During the past week, how bad has your pain from the burn injury been?

22 During the past week, how much of the time have you had itching from the burn injury?

23 During the past week, how bad has your itching from the burn injury been?

24 Can this child take part in recreational activities with other kids the same age (for example, dancing, bicycling, skating,
hiking, jogging)?

25 If recreational activities are hard or this child can't do them at all, is he/she limited by: pain, doctor or parent
instruction, dislike of recreational activity, too young, general health, fear the other kids won't like him/her, activity
not in season

During the last week, has it been easy or hard for this child to:

26 bicycle?

27 climb three flights of stairs?

28 climb one flight of stairs?

29 Run short distances?

30 Walk three blocks?

31 Get on or off a bus?

(no prefix)

32 How often does this child need help from another person for walking or climbing?

During the last week, has it been easy or hard for this child to:

33 Pour a half gallon of milk?

34 Use fork or spoon?

35 Comb his/her hair?

36 button buttons?

37 Pull on a shirt or sweater over his/her head?

38 Turn his/her neck to look back over his/her shoulder

39 Get on and off toilet or chair?

40 Get in and out of bed?

41 Turn door knobs?

42 Bend over from a standing position and pick up something off the floor?

How often has this child been able to follow the burn team instructions in…

43 doing exercises?

44 doing wound care?

45 Wearing dressings?

46 Wearing garments?

47 Keeping appointments?

The following questions ask about this child's appearance.

48 This child feels that the burn is unattractive to others

49 This child thinks people would not want to touch him or her.

50 This child feels unsure of himself/herself among strangers

51 changes in my appearance have interfered with my relationships.

For each item, please fill in the circle that best describes this child in the past month because of the burn injury. Over the past
month, how often has this child's health or behavior…

52 limited parents' ability to have time for themselves or time with friends

During the last month, how often has this child's health or behavior…

53 Interrupted simple family activities like meals?

For each item, please fill in the circle that best describes this child in the past month because of the burn injury. Over the past
month, how often has this child's health or behavior…

54 made shopping or household chores more difficult or stressful

55 limited parents' ability to work

During the last month, how often has this child's health or behavior…

56 Limited his/her family's ability to spend time with other families?

Over the past month, how much worry or concern have you had about…

57 child's recovery from the effects of the burn injury

58 child's amount of pain and suffering

59 child's future health

How well does each of the following statements describe this child?

60 This child has more nightmares.

61 This child feels angry.

62 This child feels depressed and talks about death.

63 This child feels upset.

(no prefix)

64 Compared to before the burn, are this child's grades:

65 Was this child in a special class before the burn injury?

66 Is this child in a special class or special school now?

Following this child's return to school after the burn injury, how would you rate his/her:

67 Acceptance by classmates?

68 Acceptance by teachers?

69 Ability to perform school work?

How satisfied is this child now with his/her:

70 pain relief?

71 Itch relief?

72 Amount and quality of sleep?

73 Ability to do chores?

74 Ability to do school work?

75 Ability to play and have fun?

76 Overall medical care?

(no prefix)

77 Was this child satisfied with school re-entry services received?

78 how well were your questions answered about future surgery?

79 What is the child's date of birth?

80 Is this child male or female?

81 What is this child's race?

82 If this child is not in school, what is the reason? Too young? Burn injury? Other?

83 What is the highest grade in school this child has completed?

84 What is the highest level of education achieved by this child's mother (or stepmother, if that is with whom he/she is
living)

85 What is the highest level of education achieved by this child's father (or stepfather, if that is with whom he/she is
living)?

86 Is this child's mother (or stepmother, if that is with whom he/she is living) employed?

87 Is this child's father (or stepfather, if that is with whom he/she is living) employed? List occupation.

88 Before the burn injury, who did this child live with?

89 Who does this child live with now?

90 Is there a change in the child's living situation because of the burn?

91 Who is filling out this questionnaire?

Burn Outcomes Questionnaire Ages: 11-18 Type:

(no prefix)

1 In general, would you say that this child's health is excellent, very good, good, fair, or poor?

2 Compared to before the burn, how would you rate this child's current overall health?

Before the burn injury, did a doctor, nurse, or other health professional say that this child has any of the following conditions? If
yes, please tell us if this child gets treatment, and if this child's activities are limited by the condition.

3 asthma

4 attention or behavioral problems

5 chronic allergies or sinus trouble

6 developmental delays

7 mental retardation

8 diabetes

9 epilepsy

10 hearing problems

11 heart problems

12 learning problems

13 sleep problems

14 speech problems

15 vision problems

16 depression

17 drug problem

18 alcohol problem

19 other chronic medical problems(specify)

(no prefix)

20 During the past week, how often have you had pain from the burn injury?

21 During the past week, how bad has your pain from the burn injury been?

22 During the past week, how much of the time have you had itching from the burn injury?

23 During the past week, how bad has your itching from the burn injury been?

24 Can this child take part in recreational activities with other kids the same age (for example, dancing, bicycling, skating,
hiking, jogging)?

25 If recreational activities are hard or this child can't do them at all, is he/she limited by: pain, doctor or parent
instruction, dislike of recreational activity, too young, general health, fear the other kids won't like him/her, activity
not in season

During the last week, has it been easy or hard for this child to:

26 bicycle?

27 climb three flights of stairs?

28 climb one flight of stairs?

29 Run short distances?

30 Walk three blocks?

31 Get on or off a bus?

(no prefix)

32 How often does this child need help from another person for walking or climbing?

During the last week, has it been easy or hard for this child to:

33 Pour a half gallon of milk?

34 Use fork or spoon?

35 Comb his/her hair?

36 button buttons?

37 Pull on a shirt or sweater over his/her head?

38 Turn his/her neck to look back over his/her shoulder

39 Get on and off toilet or chair?

40 Get in and out of bed?

41 Turn door knobs?

42 Bend over from a standing position and pick up something off the floor?

How often has this child been able to follow the burn team instructions in…

43 doing exercises?

44 doing wound care?

45 Wearing dressings?

46 Wearing garments?

47 Keeping appointments?

The following questions ask about this child's appearance.

48 This child feels that the burn is unattractive to others

49 This child thinks people would not want to touch him or her.

50 This child feels unsure of himself/herself among strangers

51 changes in my appearance have interfered with my relationships.

For each item, please fill in the circle that best describes this child in the past month because of the burn injury. Over the past
month, how often has this child's health or behavior…

52 limited parents' ability to have time for themselves or time with friends

During the last month, how often has this child's health or behavior…

53 Interrupted simple family activities like meals?

For each item, please fill in the circle that best describes this child in the past month because of the burn injury. Over the past
month, how often has this child's health or behavior…

54 made shopping or household chores more difficult or stressful

55 limited parents' ability to work

During the last month, how often has this child's health or behavior…

56 Limited his/her family's ability to spend time with other families?

Over the past month, how much worry or concern have you had about…

57 child's recovery from the effects of the burn injury

58 child's amount of pain and suffering

59 child's future health

How well does each of the following statements describe this child?

60 This child has more nightmares.

61 This child feels angry.

62 This child feels depressed and talks about death.

63 This child feels upset.

(no prefix)

64 Compared to before the burn, are this child's grades:

65 Was this child in a special class before the burn injury?

66 Is this child in a special class or special school now?

Following this child's return to school after the burn injury, how would you rate his/her:

67 Acceptance by classmates?

68 Acceptance by teachers?

69 Ability to perform school work?

How satisfied is this child now with his/her:

70 pain relief?

71 Itch relief?

72 Amount and quality of sleep?

73 Ability to do chores?

74 Ability to do school work?

75 Ability to play and have fun?

76 Overall medical care?

(no prefix)

77 Was this child satisfied with school re-entry services received?

78 how well were your questions answered about future surgery?

79 What is the child's date of birth?

80 Is this child male or female?

81 What is this child's race?

82 If this child is not in school, what is the reason? Too young? Burn injury? Other?

83 What is the highest grade in school this child has completed?

84 What is the highest level of education achieved by this child's mother (or stepmother, if that is with whom he/she is
living)

85 What is the highest level of education achieved by this child's father (or stepfather, if that is with whom he/she is
living)?

86 Is this child's mother (or stepmother, if that is with whom he/she is living) employed?

87 Is this child's father (or stepfather, if that is with whom he/she is living) employed? List occupation.

88 Before the burn injury, who did this child live with?

89 Who does this child live with now?

90 Is there a change in the child's living situation because of the burn?

Assessment Report

Burn Outcomes Questionnaire Ages: young adult-short form Type:

(no prefix)

1 Compared to before the burn, how would you rate this child's current overall health?

2 During the past week, how often have you had pain from the burn injury?

3 During the past week, how bad has your pain from the burn injury been?

4 During the past week, how much of the time have you had itching from the burn injury?

5 During the past week, how bad has your itching from the burn injury been?

During the last week, has it been easy or hard for this child to:

6 climb three flights of stairs?

7 climb one flight of stairs?

8 Walk three blocks?

9 Use fork or spoon?

10 Get in and out of bed?

11 Bend over from a standing position and pick up something off the floor?

(no prefix)

12 Can this child take part in recreational activities with other kids the same age (for example, dancing, bicycling, skating, hiking, jogging)?

Does your physical function limit your social activities in any of the following ways?

13 Going out to parties/social gatherings

14 Going out with friend or partner?

15 Attending community gathering

16 Being active in general

The following questions ask about this child's appearance.

17 This child feels that the burn is unattractive to others

18 This child thinks people would not want to touch him or her.

19 This child feels unsure of himself/herself among strangers

Does your appearance limit your social activities in any of the following ways?

20 Going out to parties/social gatherings

21 Going out with friends or partner

22 Attending community gathering

23 Being active in general

(no prefix)

24 I feel frustrated because I cannot be sexually aroused as well as before the burn injury

25 Since my burn I am simply not interested in sex anymore

How much of a problem was each of the following during the past 4 weeks because of the burn injury?

26 Lack of sexual interest

27 Having difficulty in becoming sexually aroused

29 Having difficulty in having an orgasm

How well does each of the following statements describe you?

30 I feel angry since my burn injury

31 I feel sad since my burn injury

over the past month, how often has your burn injury

32 limited your family's ability to have time for themselves or time with friends

33 interrupted simple family activities like meals

34 limited your ability to spend time with other family members

Over the past month, how much worry or concern have you had about…

35 child's recovery from the effects of the burn injury

36 child's amount of pain and suffering

37 child's future health

How satisfied is this child now with his/her:

38 pain relief?

39 Itch relief?

40 Amount and quality of sleep?

41 Ability to do chores?

42 school work/job

43 Ability to play and have fun?

Following your return to job or school after the burn injury, how would you rate your…

44 acceptance by peers

45 acceptance by teachers/boss

46 ability to perform

The following questions concern your spiritual or religious beliefs and experiences. There are not right or wrong answers. For
each question, circle the number of the answer that is most true for you.

47 How much is religion (and/or God), a source of strength and comfort to you?

48 How strongly religious (or spiritually oriented) do you consider yourself to be?

People have many different definitions of the "higher power" that we often call "God". Please use your definition of God when
answering the following questions.

49 How close to do you feel to God?

The following questions concern your spiritual or religious beliefs and experiences. There are not right or wrong answers. For
each question, circle the number of the answer that is most true for you.

50 Indicate whether you agree of disagree with this statement: "God dwells within you".

(no prefix)

51 What is the child's date of birth?

52 Is this child male or female?

53 What is this child's race?

54 If you are not in school or working outside of the home, what is the reason? A: burn injury or other?

55 What is the highest grade in school this child has completed?

56 What is your total household income?

57 What is your current marital status?

58 Are you currently working outside of the home?

59 If you are working, what is your job title?

60 Is this the same job you had before your burn injury?

61 What health insurance coverage(s) do you presently have?

Before the burn injury, did a doctor, nurse, or other health professional say that this child has any of the following conditions? If
yes, please tell us if this child gets treatment, and if this child's activities are limited by the condition.

62 asthma

63 Attention deficit hyperactivity disorder (ADHD)

64 chronic allergies or sinus trouble
65 diabetes
66 epilepsy
67 hearing problems
68 heart problems
69 learning problems
70 sleep problems
71 speech problems
72 vision problems
73 depression
74 drug problem
75 alcohol problem
76 smoking habit
77 pregnancy
78 anemia
79 high blood pressure
80 stomach problems (ulcer)
81 liver problems
82 kidney problems
83 other chronic medical problems(specify)

Appendix B: BMS Assessment Questions

Assessment Report

Burn Model Systems | Ages: 0-4 | Type: initial

(no prefix)

3 Ethnicity

QUESTIONS 4-13 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

15 Shopping

16 Leisure activities such as movies, sports, restaurants

17 Visiting friends or relatives

During the 4 weeks before the burn

18 When your child participated in leisure activities did he/she usually do this alone or with others?

(no prefix)

25 Residence at time of burn

26 state of residence

27 living with at time of burn

28 school status at time of burn?

30 If not working or going to school, best description of reason

31 concomitant medical problems

32 pre-existing physical disabilities

33 Patient received psychiatric/psychological treatment in last year

36 Educational achievement of father, paternal guardian

37 Educational achievement of mother, materal guardian

38 number of children living in home

39 Child Protection involved with the family in year prior to burn?

40 Height at time of Admission

41 Weight at time of admission

42 Primary etiology of injury

43 Geographical location of injury

44 Circumstance of injury

45 Total number of days on inpatient rehab unit (separate from ICU and burn service days)

46 Inhalation injury?

47 other injuries (excluding inhalation)?

Part of the body burned:

48 head/neck

49 trunk

50 Perineum

51 Arm

52 Hand

53 leg

54 Foot

Part of the body grafted:

55 Head/neck

56 Trunk

57 Perineum

58 Arm

59 Hand

60 Leg

61 Foot

(no prefix)

62 Total body surface area burned (percent).

63 Total body surface area grafted (percent)

64 Days on ventilator

65 number of trips to OR (burn or non-burned related)

66 Active range of motion deficits

67 Amputation due to burn (including amputation after d/c)

68 heterotopic ossification at d/c

69 Disposition

70 living with at hospital d/c

71 primary sponsor of care at d/c from hospital

72 height at d/c

73 weight at d/c

Does your child have any of the following problems due to his/her burn?

74 Exposed bone

75 Exposed tendons

(no prefix)

76 Does your child have scars as a result of his/her burn injury?

77 Does your child avoid situations where his/her burn scars can be seen?

78 If your child were to dress as he/she did before the burn, would his/her burn scars be visible?

79 Does your child wear clothing, other than his/her usual clothes, to hide his/her burn scars?

80 Does your child use cosmetics, wigs, etc to hide his/her burn scars?

Does your child have any of the following skin related problems due to his/her burn?

81 chronic open wounds

82 fragile skin (skin tears,blisters)

83 Dry skin

84 skin tightness that interferes with function

85 Loss of skin sensation

86 Increased skin sensitivity

The next questions ask you to rate the amount of pain your child may have had in the last week. Using a scale of 0-10, where 0=no
pain and 10=unbearable, excruciating pain, please reate your child's general level of pain:

87 Your level of pain in the last week

The following question asks you to rate the amount of itching your child may have experienced in the last week. Using a scale of
0-10,…,please rate the itch your child has experienced on the burned or grafted areas of his/her body:

88 Your amount of itching the last week:

The following question asks you to rate the amount of sleep difficulty your child may have had in the last week. Using a scale 1-
10,…, please rate the sleeping difficulty your child has experienced:

89 Your difficulty sleeping in the last week:

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

90 raised or thick scar

91 Scar lighter or darker than other skin

92 Scar that restricts range of motion at any joint

Following is a list of changes or effects that can result from a burn. At this time, has your child eperienced any of these changes or
effects due to his/her burn?

93 Facial expression

94 Mouth scarring

95 Hand functioning

96 Foot functioning

This is a list of 12 items that may be causing your child distress. On a scale of 0-10,…, please rate each of the following issues with
respect to the amount of distress each one now causes your child.

97 Pain

98 Decreased range of motion

99 Itching

100 Sleep disturbance

101 Temperature changes

102 Decreased strength

103 Dislike appearance

104 uncomfortable scars

105 changes in skin color

107 Long recovery time

108 pressure garments

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

120 changes in my child's appearance have interfered with his/her relationships

122 My child doesn't think people would want to touch him/her

QUESTIONS 123-132 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

(no prefix)

133 Space/place of injury

QUESTIONS 6-15 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

17 Shopping

18 Leisure activities such as movies, sports, restaurants

19 Visiting friends or relatives

During the 4 weeks before the burn

20 When your child participated in leisure activities did he/she usually do this alone or with others?

This is a list of 12 items that may be causing your child distress. On a scale of 0-10,…, please rate each of the following issues with
respect to the amount of distress each one now causes your child.

27 Pain

28 Decreased range of motion

29 Itching

30 Sleep disturbance

31 Temperature changes

32 Decreased strength

33 Dislike appearance

34 uncomfortable scars

35 changes in skin color

37 Long recovery time

38 pressure garments

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

50 changes in my child's appearance have interfered with his/her relationships

52 My child doesn't think people would want to touch him/her

(no prefix)

53 Does your child have scars as a result of his/her burn injury?

54 Does your child avoid situations where his/her burn scars can be seen?

55 If your child were to dress as he/she did before the burn, would his/her burn scars be visible?

56 Does your child wear clothing, other than his/her usual clothes, to hide his/her burn scars?

57 Does your child use cosmetics, wigs, etc to hide his/her burn scars?

Does your child have any of the following skin related problems due to his/her burn?

58 chronic open wounds

59 fragile skin (skin tears ,blisters)

60 Dry skin

61 skin tightness that interferes with function

62 Loss of skin sensation

63 Increased skin sensitivity

The next questions ask you to rate the amount of pain your child may have had in the last week. Using a scale of 0-10, where 0=no
pain and 10=unbearable, excruciating pain, please reate your child's general level of pain:

64 Your level of pain in the last week

The following question asks you to rate the amount of itching your child may have experienced in the last week. Using a scale of
0-10,…,please rate the itch your child has experienced on the burned or grafted areas of his/her body:

65 Your amout of itching the last week:

The following question asks you to rate the amount of sleep difficulty your child may have had in the last week. Using a scale 1-
10,…, please rate the sleeping difficulty your child has experienced:

66 Your difficulty sleeping in the last week:

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

67 raised or thick scar

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

68 Scar lighter or darker than other skin

69 Scar that restricts range of motion at any joint

Following is a list of changes or effects that can result from a burn. At this time, has your child experienced any of these changes or
effects due to his/her burn?

70 Facial expression

71 Mouth scarring

72 Hand functioning

73 Foot functioning

(no prefix)

74 height at follow-up

75 weight at follow up

76 What is your child's current school status?

78 If your child is not working or going school, what is the best description of the reason?

79 Is your child on disability insurance at this follow-up?

80 Since your child's last follow-up, has he/she received occupational or physical therapy for his/her burn?

81 if now stopped, what is the date the occupational or physical therapy was stopped? Fill in the blank

(Skip this section if no OT/PT therapy was received) Below is a list of therapies that your child may have received for his/her
burn injury. Since your child's last follow-up, which of the following treatments did he/she receive to treat his/her burn?

82 hydrotherapy

83 Stretching

84 Paraffin (wax treatments)

85 Strengthening program

86 conditioning program

87 compression garments

88 splinting

89 casting

90 scar massage

(Skip this section if no OT/PT therapy was received) Burn patients may receive their therapies at different places. Since your
child's last follow up, where did he/she receive his/her outpatient occupational or physical burn therapy?

91 Burn center

92 other facility

93 If your child has stopped his/her burn occupational or physical therapy since his/her last follow up, what is the primary
reason he/she stopped?

94 If your child has stopped his/her burn occupational or physical rehabilitation therapy since his/her last follow up, whose
decision was it to discontinue?

(no prefix)

95 Since your child's last follow up, has he/she received psychological or peer support therapy for his/her burn?

96 If now stopped, what is the date psychological or peer support therapy was stopped?

(Skip this section if no psych or peer support therapy was received) Burn patients may receive their therapies at different places.
Since your child's last follow-up, where did he/she receive his/her psychological or peer support burn therapy?

97 Burn Center

98 other facility

99 If your child has stopped his/her burn psychological or peer support therapy since his/her last follow-up, what is the
primary reason?

100 If your child has stopped his/her burn psychological or peer support therapy since his/her last follow-up, whose
decision was it to discontinue?

Burn patients may have burn related surgeries after they leave the hospital for their primary burn care.

101 since your child's last follow up, has he/she had any burn related surgeries?

102 If yes, was the surgery for open wounds?

103 If yes, was the surgery for joint contracture?

104 If yes, was surgery for scar management?

Does your child have any of the following skin related problems due to his/her burn?

105 Heat sensitivity or intolerance?

106 Cold sensitivity or intolerance

(no prefix)

200 First date returned to work/school since injury (fill in the blank)

(no prefix)

3 Ethnicity

QUESTIONS 4-13 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

14 Did your child take responsibility for personal grooming when asked?

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

15 Shopping

16 Leisure activities such as movies, sports, restaurants

17 Visiting friends or relatives

During the 4 weeks before the burn

18 When your child participated in leisure activities did he/she usually do this alone or with others?

19 Did your child have a best friend with whom he/she confided?

Here are 5 statements with which your child may agree or disagree. Using a scale 1-7,…, indicate your child's agreement with
each item by the appropriate choice (as it was 4 weeks prior to the burn).

20 (In the 4 weeks before my burn), in most ways my life was close to what I think it should be.

21 (In the weeks before my burn), the conditions of my life were excellent.

22 (In the 4 weeks before my burn), I was satisfied with my life.

23 (In the 4 weeks before my burn), I had gotten the important things I wanted in life.

24 (In the 4 weeks before my burn), if I could have lived my life over, I would have changed almost nothing.

(no prefix)

25 Residence at time of burn

26 state of residence

27 living with at time of burn

28 school status at time of burn?

29 Employment status at time of burn

30 If not working or going to school, best description of reason

31 concomitant medical problems

32 pre-existing physical disabilities

33 Patient received psychiatric/psychological treatment in last year

34 Patient's history of alcohol abuse in the last year

35 Patient's history of drug abuse in the last year.

36 Educational achievement of father, paternal guardian

37 Educational achievement of mother, materal guardian

38 number of children living in home

39 Child Protection involved with the family in year prior to burn?

40 Height at time of Admission

41 Weight at time of admission
42 Primary etiology of injury
43 Space/place of injury
44 Geographical location of injury
45 Circumstance of injury
46 Total number of days on inpatient rehab unit (separate from ICU and burn service days)
47 Inhalation injury?
48 other injuries (excluding inhalation)?

Part of the body burned:

49 head/neck
50 trunk
51 Perineum
52 Arm
53 Hand
54 leg
55 Foot

Part of the body grafted:

56 Head/neck
57 Trunk
58 Perineum
59 Arm
60 Hand
61 Leg
62 Foot

(no prefix)

63 Total body surface area burned (percent).
64 Total body surface area grafted (percent)
65 Days on ventilator
66 number of trips to OR (burn or non-burned related)
67 Active range of motion deficits
68 Amputation due to burn (including amputation after d/c)
69 heterotopic ossification at d/c
70 Disposition
71 living with at hospital d/c
72 primary sponsor of care at d/c from hospital
73 height at d/c
74 weight at d/c

Does your child have any of the following problems due to his/her burn?

75 Exposed bone
76 Exposed tendons

(no prefix)

77 Does your child have scars as a result of his/her burn injury?
78 Does your child avoid situations where his/her burn scars can be seen?

79 If your child were to dress as he/she did before the burn, would his/her burn scars be visible?

80 Does your child wear clothing, other than his/her usual clothes, to hide his/her burn scars?

81 Does your child use cosmetics, wigs, etc to hide his/her burn scars?

Does your child have any of the following skin related problems due to his/her burn?

82 chronic open wounds

83 fragile skin (skin tears,blisters)

84 Dry skin

85 skin tightness that interferes with function

86 Loss of skin sensation

87 Increased skin sensitivity

The next questions ask you to rate the amount of pain your child may have had in the last week. Using a scale of 0-10, where 0=no
pain and 10=unbearable, excruciating pain, please reate your child's general level of pain:

88 Your level of pain in the last week

The following question asks you to rate the amount of itching your child may have experienced in the last week. Using a scale of
0-10,…,please rate the itch your child has experienced on the burned or grafted areas of his/her body:

89 Your amount of itching the last week:

The following question asks you to rate the amount of sleep difficulty your child may have had in the last week. Using a scale 1-
10,…, please rate the sleeping difficulty your child has experienced:

90 Your difficulty sleeping in the last week:

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

91 raised or thick scar

92 Scar lighter or darker than other skin

93 Scar that restricts range of motion at any joint

Following is a list of changes or effects that can result from a burn. At this time, has your child eperienced any of these changes or
effects due to his/her burn?

94 Facial expression

95 Mouth scarring

96 Hand functioning

97 Foot functioning

This is a list of 12 items that may be causing your child distress. On a scale of 0-10,…, please rate each of the following issues with
respect to the amount of distress each one now causes your child.

98 Pain

99 Decreased range of motion

100 Itching

101 Sleep disturbance

102 Temperature changes

103 Decreased strength

104 Dislike appearance

105 uncomfortable scars

106 changes in skin color

107 financial concerns

108 Long recovery time

109 pressure garments

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

110 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of family.

111 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of friends

112 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of
strangers.

113 My child is satisfied with his/her overall appearance

114 My child is satisfied with the appearance of his/her scalp

115 My child is satisfied with the appearance of his/her face.

116 My child is satisfied with the appearance of his/her neck.

117 My child is satisfied with the appearance of his/her hands.

118 My child is satisfied with the appearance of his/her arms.

119 My child is satisfied with the appearance of his/her legs.

120 My child is satisfied with the appearance of his/her chest.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

121 changes in my child's appearance have interfered with his/her relationships

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

122 My child feels his/her burn is unattractive to others.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

123 My child doesn't think people would want to touch him/her

QUESTIONS 124-133 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

QUESTIONS 6-15 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

16 Did your child take responsibility for personal grooming when asked?

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

17 Shopping

18 Leisure activities such as movies, sports, restaurants

19 Visiting friends or relatives

During the 4 weeks before the burn

20 When your child participated in leisure activities did he/she usually do this alone or with others?

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

21 does your child have a best friend with whom he/she confides?

Here are 5 statements with which your child may agree or disagree. Using a scale 1-7,…, indicate your child's agreement with
each item by the appropriate choice (as it was 4 weeks prior to the burn).

22 (In the 4 weeks before my burn), in most ways my life was close to what I think it should be.

23 (In the weeks before my burn), the conditions of my life were excellent.

24 (In the 4 weeks before my burn), I was satisfied with my life.

25 (In the 4 weeks before my burn), I had gotten the important things I wanted in life.

26 (In the 4 weeks before my burn), if I could have lived my life over, I would have changed almost nothing.

This is a list of 12 items that may be causing your child distress. On a scale of 0-10,…, please rate each of the following issues with
respect to the amount of distress each one now causes your child.

27 Pain

28 Decreased range of motion

29 Itching

30 Sleep disturbance

31 Temperature changes

32 Decreased strength

33 Dislike appearance

34 uncomfortable scars

35 changes in skin color

36 financial concerns

37 Long recovery time

38 pressure garments

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

39 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of family.

40 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of friends

41 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of
strangers.

42 My child is satisfied with his/her overall appearance

43 My child is satisfied with the appearance of his/her scalp

44 My child is satisfied with the appearance of his/her face.

45 My child is satisfied with the appearance of his/her neck.

46 My child is satisfied with the appearance of his/her hands.

47 My child is satisfied with the appearance of his/her arms.

48 My child is satisfied with the appearance of his/her legs.

49 My child is satisfied with the appearance of his/her chest.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

50 changes in my child's appearance have interfered with his/her relationships

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

51 My child feels his/her burn is unattractive to others.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

52 My child doesn't think people would want to touch him/her

(no prefix)

53 Does your child have scars as a result of his/her burn injury?

54 Does your child avoid situations where his/her burn scars can be seen?

55 If your child were to dress as he/she did before the burn, would his/her burn scars be visible?

56 Does your child wear clothing, other than his/her usual clothes, to hide his/her burn scars?

57 Does your child use cosmetics, wigs, etc to hide his/her burn scars?

Does your child have any of the following skin related problems due to his/her burn?

58 chronic open wounds

59 fragile skin (skin tears,blisters)

60 Dry skin

61 skin tightness that interferes with function

62 Loss of skin sensation

63 Increased skin sensitivity

The next questions ask you to rate the amount of pain your child may have had in the last week. Using a scale of 0-10, where 0=no
pain and 10=unbearable, excruciating pain, please rate your child's general level of pain:

64 Your level of pain in the last week

The following question asks you to rate the amount of itching your child may have experienced in the last week. Using a scale of
0-10,…,please rate the itch your child has experienced on the burned or grafted areas of his/her body:

65 Your amount of itching the last week:

The following question asks you to rate the amount of sleep difficulty your child may have had in the last week. Using a scale 1-
10,…, please rate the sleeping difficulty your child has experienced:

66 Your difficulty sleeping in the last week:

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

67 raised or thick scar

68 Scar lighter or darker than other skin

69 Scar that restricts range of motion at any joint

Following is a list of changes or effects that can result from a burn. At this time, has your child experienced any of these changes or
effects due to his/her burn?

70 Facial expression

71 Mouth scarring

72 Hand functioning

73 Foot functioning

(no prefix)

74 height at follow-up

75 weight at follow up

76 What is your child's current school status?

77 What is your child's current employment status?

78 If your child is not working or going school, what is the best description of the reason?

79 Is your child on disability insurance at this follow-up?

80 Since your child's last follow-up, has he/she received occupational or physical therapy for his/her burn?

81 if now stopped, what is the date the occupational or physical therapy was stopped? Fill in the blank

(Skip this section if no OT/PT therapy was received) Below is a list of therapies that your child may have received for his/her
burn injury. Since your child's last follow-up, which of the following treatments did he/she receive to treat his/her burn?

82 hydrotherapy

83 Stretching

84 Paraffin (wax treatments)

85 Strengthening program

86 conditioning program

87 compression garments

88 splinting

89 casting

90 scar massage

(Skip this section if no OT/PT therapy was received) Burn patients may receive their therapies at different places. Since your
child's last follow up, where did he/she receive his/her outpatient occupational or physical burn therapy?

91 Burn center

92 other facility

93 If your child has stopped his/her burn occupational or physical therapy since his/her last follow up, what is the primary
reason he/she stopped?

94 If your child has stopped his/her burn occupational or physical rehabilitation therapy since his/her last follow up, whose
decision was it to discontinue?

(no prefix)

95 Since your child's last follow up, has he/she received psychological or peer support therapy for his/her burn?

96 If now stopped, what is the date psychological or peer support therapy was stopped?

(Skip this section if no psych or peer support therapy was received) Burn patients may receive their therapies at different places.
Since your child's last follow-up, where did he/she receive his/her psychological or peer support burn therapy?

97 Burn Center

98 other facility

99 If your child has stopped his/her burn psychological or peer support therapy since his/her last follow-up, what is the
primary reason?

100 If your child has stopped his/her burn psychological or peer support therapy since his/her last follow-up, whose
decision was it to discontinue?

Burn patients may have burn related surgeries after they leave the hospital for their primary burn care.

101 since your child's last follow up, has he/she had any burn related surgeries?

102 If yes, was the surgery for open wounds?

103 If yes, was the surgery for joint contracture?

104 If yes, was surgery for scar management?

Does your child have any of the following skin related problems due to his/her burn?

105 Heat sensitivity or intolerance?

106 Cold sensitivity or intolerance

(no prefix)

200 First date returned to work/school since injury (fill in the blank)

(no prefix)

3 Ethnicity

QUESTIONS 4-15 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

During the 4 weeks before the burn

16 Who was looking after your personal finances, such as banking or paying bills?

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

17 Shopping

18 Leisure activities such as movies, sports, restaurants

19 Visiting friends or relatives

During the 4 weeks before the burn

20 When your child participated in leisure activities did he/she usually do this alone or with others?

21 Did your child have a best friend with whom he/she confided?

Here are 5 statements with which your child may agree or disagree. Using a scale 1-7,…, indicate your child's agreement with
each item by the apporpriate choice (as it was 4 weeks prior to the burn).

22 In the 4 weeks before my burn, in most ways my life was close to my ideal

23 (In the weeks before my burn), the conditions of my life were excellent.

24 (In the 4 weeks before my burn), I was satisfied with my life.

25 (In the 4 weeks before my burn), I had gotten the important things I wanted in life.

26 (In the 4 weeks before my burn), if I could have lived my life over, I would have changed almost nothing.

(no prefix)

27 Residence at time of burn

28 state of residence

29 living with at time of burn

30 school status at time of burn?

31 Employment status at time of burn

32 If not working or going to school, best description of reason

33 concomitant medical problems

34 pre-existing physical disabilities

35 Patient received psychiatric/psychological treatment in last year

36 Patient's history of alcohol abuse in the last year

37 Patient's history of drug abuse in the last year.

38 Primary etiology of injury

39 Space/place of injury

40 Geographical location of injury

41 Circumstance of injury

42 Total number of days on inpatient rehab unit (separate from ICU and burn service days)

43 Inhalation injury?

44 other injuries (excluding inhalation)?

Part of the body burned:

45 head/neck

46 trunk

47 Perineum

48 Arm

49 Hand

50 leg

51 Foot

Part of the body grafted:

52 Head/neck

53 Trunk

54 Perineum

55 Arm

56 Hand

57 Leg

58 Foot

(no prefix)

59 Total body surface area burned (percent).

60 Total body surface area grafted (percent)

61 Days on ventilator

62 number of trips to OR (burn or non-burned related)

63 Active range of motion deficits

64 Amputation due to burn (including amputation after d/c)

65 heterotopic ossification at d/c

66 Disposition

67 living with at hospital d/c

68 primary sponsor of care at d/c from hospital

69 height at d/c

70 weight at d/c

Does your child have any of the following problems due to his/her burn?

71 Exposed bone

72 Exposed tendons

(no prefix)

73 Does your child have scars as a result of his/her burn injury?

74 Does your child avoid situations where his/her burn scars can be seen?

75 If your child were to dress as he/she did before the burn, would his/her burn scars be visible?

76 Does your child wear clothing, other than his/her usual clothes, to hide his/her burn scars?

77 Does your child use cosmetics, wigs, etc to hide his/her burn scars?

Does your child have any of the following skin related problems due to his/her burn?

78 chronic open wounds

79 fragile skin (skin tears,blisters)

80 Dry skin

81 skin tightness that interferes with function

82 Loss of skin sensation

83 Increased skin sensitivity

The next questions ask you to rate the amount of pain your child may have had in the last week. Using a scale of 0-10, where 0=no
pain and 10=unbearable, excruciating pain, please rate your child's general level of pain:

84 Your level of pain in the last week

The following question asks you to rate the amount of itching your child may have experienced in the last week. Using a scale of
0-10,…,please rate the itch your child has experienced on the burned or grafted areas of his/her body:

85 Your amount of itching the last week:

The following question asks you to rate the amount of sleep difficulty your child may have had in the last week. Using a scale 1-
10,…, please rate the sleeping difficulty your child has experienced:

86 Your difficulty sleeping in the last week:

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

87 raised or thick scar

88 Scar lighter or darker than other skin

89 Scar that restricts range of motion at any joint

Following is a list of changes or effects that can result from a burn. At this time, has your child experienced any of these changes or
effects due to his/her burn?

90 Facial expression

91 Mouth scarring

92 Hand functioning

93 Foot functioning

This is a list of 12 items that may be causing your child distress. On a scale of 0-10,…, please rate each of the following issues with
respect to the amount of distress each one now causes your child.

94 Pain

95 Decreased range of motion

96 Itching

97 Sleep disturbance

98 Temperature changes

99 Decreased strength

100 Dislike appearance

101 uncomfortable scars

102 changes in skin color

103 financial concerns

104 Long recovery time

105 pressure garments

In each of the following statements, mark the most correct response for your child according to the

following scale, 1-7

106 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of family.

107 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of friends

108 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of
strangers.

109 My child is satisfied with his/her overall appearance

110 My child is satisfied with the appearance of his/her scalp

111 My child is satisfied with the appearance of his/her face.

112 My child is satisfied with the appearance of his/her neck.

113 My child is satisfied with the appearance of his/her hands.

114 My child is satisfied with the appearance of his/her arms.

115 My child is satisfied with the appearance of his/her legs.

116 My child is satisfied with the appearance of his/her chest.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

117 changes in my child's appearance have interfered with his/her relationships

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

118 My child feels his/her burn is unattractive to others.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

119 My child doesn't think people would want to touch him/her

Assessment Report

Burn Model Systems Ages: 14-18 Type: follow up

QUESTIONS 6-17 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

18 Who was looking after your personal finances, such as banking or paying bills?

Approximately how many times a month during the 4 weeks before the burn did your child usually participate (or accompany) in
the following activities outside of your home?

19 Shopping

20 Leisure activities such as movies, sports, restaurants

21 Visiting friends or relatives

During the 4 weeks before the burn

22 When your child participated in leisure activities did he/she usually do this alone or with others?

23 Did your child have a best friend with whom he/she confided?

Here are 5 statements with which your child may agree or disagree. Using a scale 1-7,…, indicate your child's agreement with
each item by the appropriate choice (as it was 4 weeks prior to the burn).

24 In the 4 weeks before my burn, in most ways my life was close to my ideal

25 (In the weeks before my burn), the conditions of my life were excellent.

26 (In the 4 weeks before my burn), I was satisfied with my life.

27 (In the 4 weeks before my burn), I had gotten the important things I wanted in life.

28 (In the 4 weeks before my burn), if I could have lived my life over, I would have changed almost nothing.

This is a list of 12 items that may be causing your child distress. On a scale of 0-10,…, please rate each of the following issues with
respect to the amount of distress each one now causes your child.

29 Pain

30 Decreased range of motion

31 Itching

32 Sleep disturbance

33 Temperature changes

34 Decreased strength

35 Dislike appearance

36 uncomfortable scars

37 changes in skin color

38 financial concerns

39 Long recovery time

40 pressure garments

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

41 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of family.

42 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of friends

43 Because of changes in my child's appearance caused by his/her burn, he/she is uncomfortable in the presence of
strangers.

44 My child is satisfied with his/her overall appearance

45 My child is satisfied with the appearance of his/her scalp

46 My child is satisfied with the appearance of his/her face.

47 My child is satisfied with the appearance of his/her neck.

48 My child is satisfied with the appearance of his/her hands.

49 My child is satisfied with the appearance of his/her arms.

50 My child is satisfied with the appearance of his/her legs.

51 My child is satisfied with the appearance of his/her chest.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

52 changes in my child's appearance have interfered with his/her relationships

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7

53 My child feels his/her burn is unattractive to others.

In each of the following statements, mark the most correct response for your child according to the following scale, 1-7, strongly
disagree to strongly agree

54 My child doesn't think people would want to touch him/her

(no prefix)

55 Does your child have scars as a result of his/her burn injury?

56 Does your child avoid situations where his/her burn scars can be seen?

57 If your child were to dress as he/she did before the burn, would his/her burn scars be visible?

58 Does your child wear clothing, other than his/her usual clothes, to hide his/her burn scars?

59 Does your child use cosmetics, wigs, etc to hide his/her burn scars?

Does your child have any of the following skin related problems due to his/her burn?

60 chronic open wounds

61 fragile skin (skin tears,blisters)

62 Dry skin

63 skin tightness that interferes with function

64 Loss of skin sensation

65 Increased skin sensitivity

The next questions ask you to rate the amount of pain your child may have had in the last week. Using a scale of 0-10, where 0=no
pain and 10=unbearable, excruciating pain, please rate your child's general level of pain:

66 Your level of pain in the last week

The following question asks you to rate the amount of itching your child may have experienced in the last week. Using a scale of
0-10,…,please rate the itch your child has experienced on the burned or grafted areas of his/her body:

67 Your amount of itching the last week:

The following question asks you to rate the amount of sleep difficulty your child may have had in the last week. Using a scale 1-
10,…, please rate the sleeping difficulty your child has experienced:

68 Your difficulty sleeping in the last week:

Next is a list of scarring problems that may result from a burn injury. Does your child have any of the following scarring problems
dues to his/her burn?

69 raised or thick scar

70 Scar lighter or darker than other skin

71 Scar that restricts range of motion at any joint

Following is a list of changes or effects that can result from a burn. At this time, has your child experienced any of these changes or
effects due to his/her burn?

72 Facial expression

73 Mouth scarring

74 Hand functioning

75 Foot functioning

(no prefix)

76 What is your child's current school status?

77 What is your child's current employment status?

78 If your child is not working or going school, what is the best description of the reason?

79 Is your child on disability insurance at this follow-up?

80 Since your child's last follow-up, has he/she received occupational or physical therapy for his/her burn?

81 if now stopped, what is the date the occupational or physical therapy was stopped? Fill in the blank

(Skip this section if no OT/PT therapy was received) Below is a list of therapies that your child may have received for his/her
burn injury. Since your child's last follow-up, which of the following treatments did he/she receive to treat his/her burn?

82 hydrotherapy

83 Stretching

84 Paraffin (wax treatments)

85 Strengthening program

86 conditioning program

87 compression garments

88 splinting

89 casting

90 scar massage

(Skip this section if no OT/PT therapy was received) Burn patients may receive their therapies at different places. Since your
child's last follow up, where did he/she receive his/her outpatient occupational or physical burn therapy?

91 Burn center

92 other facility

93 If your child has stopped his/her burn occupational or physical therapy since his/her last follow up, what is the primary
reason he/she stopped?

94 If your child has stopped his/her burn occupational or physical rehabilitation therapy since his/her last follow up, whose
decision was it to discontinue?

(no prefix)

95 Since your child's last follow up, has he/she received psychological or peer support therapy for his/her burn?

96 If now stopped, what is the date psychological or peer support therapy was stopped?

(Skip this section if no psych or peer support therapy was received) Burn patients may receive their therapies at different places.
Since your child's last follow-up, where did he/she receive his/her psychological or peer support burn therapy?

97 Burn Center

98 other facility

99 If your child has stopped his/her burn psychological or peer support therapy since his/her last follow-up, what is the
primary reason?

100 If your child has stopped his/her burn psychological or peer support therapy since his/her last

follow-up, whose
decision was it to discontinue?

Burn patients may have burn related surgeries after they leave the hospital for their primary burn care.

101 since your child's last follow up, has he/she had any burn related surgeries?

102 If yes, was the surgery for open wounds?

103 If yes, was the surgery for joint contracture?

104 If yes, was surgery for scar management?

Does your child have any of the following skin related problems due to his/her burn?

105 Heat sensitivity or intolerance?

106 Cold sensitivity or intolerance

(no prefix)

200 First date returned to work/school since injury (fill in the blank)

Assessment Report

Burn Model Systems Ages: adult Type: follow up

QUESTIONS 5-16 HAVE BEEN OMITTED FOR COPYRIGHT PURPOSES. YOU CAN ACCESS A COPY OF THE SF12 SF10 QUESTIONS FROM OPTUM AT https://www.optum.com/optum-outcomes/survey-request-form.html

(no prefix)

17 How do you rate your overall health in the past 30 days?

The next 40 questions ask about difficulties due to health conditions…(over the last 30 days) How much difficulty you had doing
the following activities.::: Understanding and communicating in the last 30 days, how much difficulty did you have in:

18 Concentrating on doing something for 10 minutes?

19 Remembering to do important things?

20 Analyzing and finding solutions to problems in day to day life?

21 Learning a new task, for example, learning how to get to a new place?

22 Generally understanding what people say?

23 Starting and maintaining a conversation?

The next 40 questions ask about difficulties due to health conditions…(over the last 30 days) How much difficulty you had doing
the following activities.::: Self Care. In the last 30 days how much difficulty did you have in:

24 Standing for long periods, such as 30 min?

25 Standing up from sitting down?

26 Moving around inside your home?

27 Getting out of your home?

28 Walking a long distance such as a kilometer (or equivalent)?

29 Washing your whole body?

30 Getting dressed?

31 Eating?

32 Staying by yourself for a few days?

The next 40 questions ask about difficulties due to health conditions…(over the last 30 days) How much difficulty you had doing
the following activities.::: Getting alone with people. In the last 30 days, how much difficulty did you have

in:

33 Dealing with people you do not know?

34 Maintaining a friendship?

35 Getting along with people who are close to you?

36 Making new friends?

37 Sexual activity?

The next 40 questions ask about difficulties due to health conditions…(over the last 30 days) How much difficulty you had doing
the following activities.::: Life activities. In the last 30 days, how much difficulty did you have in:

38 Taking care of your household responsibilities?

39 Doing most important household tasks well?

40 Getting all household work done that you needed to do?

41 Getting your household work done as quickly as needed?

42 Do you work (paid, non paid, self-employed) or go to school? Yes or no

The next 40 questions ask about difficulties due to health conditions…(over the last 30 days) How much difficulty you had doing
the following activities.::: In the last 30 days, how much difficulty did you have in:

43 Your day to day work/school?

44 Doing your most important work/school task well?

45 Getting all the work done that you need to do?

46 Getting your work done as quickly as needed?

The next 40 questions ask about difficulties due to health conditions…(over the last 30 days) How much difficulty you had doing
the following activities.::: Participation in society. In the last 30 days:

47 How much of a problem did you have in joining in community activities (for example, festivities, religious or other
activities) in the same way as anyone else can?

48 How much of a problem did you have because of barriers or hindrances in the world around you?

49 How much of a problem did you have living with dignity because of the attitudes and actions of others?

50 How much time did you spend on your health condition, or its consequences?

51 How much have you been emotionally affected by your health condition?

52 How much has your health been a drain on the financial resources of you or your family?

53 How much of a problem did your family have because of your health problems?

54 how much of a problem did you have in doing things by yourself for relaxation or pleasure?

55 Overall, how much did these difficulties interfere with your life?

56 Overall, in the past 30 days, how many days were these difficulties present? Fill in the blank

57 In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any
health conditions?

58 In the past 30 days, not counting the days that your were totally unable, for how many days did you cut back or reduce
your usual activities or work because of any health conditions?

BSHS: How much difficulty do you have:

59 bathing independently?

60 dressing by yourself?
61 getting in and out of a chair?
62 signing your name?
63 eating with utensils?
64 Tying shoes laces, bows, etc?
65 picking up coins from a flat surface?
66 turning a door knob?
67 working in your old job performing your old duties?

To what extent does each of the following statements describe you?

68 I am troubled by feelings of loneliness.
69 I often feel sad or blue.
70 At times, I think I have had an emotional problem.
71 I am not interested in doing things with my friends.
72 I do not enjoy visiting people.
73 I have no one to talk to about my problems.
74 I have feelings of being trapped or caught.
75 My injury has put me further away from my family.
76 I would rather be alone than with my family.
77 I do not like the way my family acts around me.
78 My family would be better off without me.
79 I feel frustrated because I cannot be sexually aroused as well as I used to.
80 I am simply not interested in sex anymore.
81 I no longer hug, hold or kiss
82 Sometimes, I would like to forget that my appearance has changed.
83 I feel that my burn is unattractive to others.
84 My general appearance really bothers me.
85 The appearance of my scars bothers me.
86 Being out in the sun bothers me.
87 Hot weather bothers me.
88 I cannot get out and do things in hot weather.
89 It bothers me that I cannot get out in the sun.
90 My skin is more sensitive than before.
91 Taking care of my skin is a bother.
92 There are things that I have been told to do for my burn that I dislike doing.
93 I wish that I did not have to do so many things to take care of my burn.
94 I have a hard time doing all the things I have been told to take care of my burn.
95 Taking care of my burn makes it hard to do other things that are important to me.
96 My burn interferes with my work.
97 being burned has affected my ability to work.
98 My burn has caused problems with my working.

Over the last 2 weeks, how often have you been bothered by any of the following problems?

99 Little interest or pleasure in doing things
100 Feeling down, depressed or hopeless

101 Trouble falling asleep or staying asleep, or sleeping too much.

102 Feeling tired or having little energy.

103 poor appetite or overeating.

104 Feeling bad about yourself-or that you are a failure or have let yourself or your family down.

105 Trouble concentrating on things, such as reading the newspaper or watching television.

106 Moving or speaking so slowly that other people could have noticed. Or the opposite-being so fidgety or restless that you have been moving around a lot more than usual.

107 Thoughts that you would be better off dead, or of hurting yourself in some way.

108 If you checked off any problems (above) how difficult have these problems made it for you to do your work, take care of thing at home, or get along with other people?

Rate the impact of your itching on the following activities over the last 2 weeks

109 During the last 2 weeks, have you had any itching in the area of the burn, skin grafts or donor sites?

110 During the last 2 weeks, how many hours a day have you been itching?

111 Please rate the intensity of your itching over the past 2 weeks.

112 Over the past 2 weeks has your itching gotten better or worse compared to the previous month?

113 sleep

114 leisure/social

115 housework/errands

116 work/school

Please rate the current, within last 2 weeks, SEVERITY of your insomnia problem(s)

118 difficulty falling asleep

119 Difficulty staying asleep

120 Problem waking up too early

121 To what extent do you consider your sleep problem to INTERFERE with your daily functioning (eg daytime fatigue, ability to function at work/daily chores, concentration, memory, mood, etc)

122 How SATISFIED/DISSATISFIED are you with your current sleep pattern

123 How NOTICEABLE to others do you think your sleeping problem is in terms of impairing the quality of your life?

124 How WORRIED/distressed are you about your current sleep problems?

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Vita

Candice Lee Osborne was born on July 31, 1979 in Dallas, TX to John and Dawn Osborne. Candice graduated from Lake Highlands High School in Dallas, TX in 1997. She attended Hendrix College where she earned her Bachelor of Arts degree in 2001. Candice attended Texas Woman's University where she graduated with a Master of Occupational Therapy degree in 2007. During her time at TWU, she was selected for the U.S Army Occupational Therapy Fieldwork Internship. She joined the U.S Army as an active duty occupational therapist intern and occupational therapist from 2006-2009 working in the areas of upper extremity orthopedic rehabilitation and inpatient psychosocial rehabilitation. In 2009 she returned to Dallas and worked as an occupational therapist at the Centre for Neuro Skills, a sub-acute neurological rehabilitation facility through the summer of 2011. In the fall of 2011, Candice enrolled at University of Texas Medical Branch in the Rehabilitation Science PhD program and the Masters of Public Health program. During her time at UTMB Candice has been affiliated with Shriners Hospital for Children where she has participated in several projects. She also works part-time as an inpatient occupational therapist at UTMB's John Sealy Hospital from 2013 to present.

Abstracts and Presentations

- *Introduction to the International Classification of Functioning, Disability, and Health*; Introduction to Rehabilitation Science course, UTMB, November 2014

  Effect of a six week supervised exercise program on lower extremity functional parameters in burned children; presented at the 46th Annual Meeting of the American Burn Association, Boston, MA, March 2014

- *The effects of upper extremity prostheses types on functional activity*; *a pilot study;* presented at the American Occupational Therapy Association National Meeting, Houston, TX, June 2009

- *Universal Design: Constructs and Strategies for Health;* presented at the Texas Occupational Therapy Association conference, San Antonio, TX, November 2005

Publications

- **Osborne CL.** Is transcutaneous electrical nerve stimulation effective as a modality to reduce pain and pruritus in patients with burn injuries? *Occupational Therapy Critically Appraised Topics*. Published online May 2013.

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