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The Burn Model Systems Outcome Measures: A Content Analysis Using the International Classification of Functioning, Disability, and Health

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Abstract

Background—The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Burn Injury Model Systems (BMS) is a nationwide database that uses patient-reported outcome measures to collect data. Though the outcome measures demonstrate good psychometric properties; the question remains whether or not these measures collect data that encompass the entire experience of burn patients over time.

Methods—Each meaningful concept included in the BMS assessments was linked to the International Classification of Functioning, Disability and Health (ICF) in order to classify and describe the content of each measure. The linking was completed by two experienced coders. The perspective of each assessment was also determined.

Results—The body function component was most frequently addressed overall followed by the activities and participation component. The components body structures and environmental factors

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are not extensively covered in the BMS assessments. ICF chapter and category distribution varied greatly between assessments. The assessments were of the health status perspective.

Conclusion—This study suggests a need to revisit the item composition of the BMS assessments to more evenly distribute ICF topics and subtopics that are pertinent to burn injury which will ensure a broader but more precise understanding of burn injury recovery.

Keywords

ICF linking technique; burn injury; burn rehabilitation; burn assessments

In the past, 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.[1] In 1994 the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), formally known as the National Institute on Disability and Rehabilitation Research, committed to overcoming this problem by developing the Burn Model Systems (BMS) program in order to examine the effects of burn injury over time. Today, the multi-centered program collects data across a number of domains including physical and mental functioning, disability, distress, societal reintegration, injury complications and dispositions. [2]

The BMS program of assessments is comprised of items selected by a panel of burn injury experts from pre-established measures. The pre-established pediatric assessments include a combination of questions from the following assessments: Special Form (SF)12, SF10 Health Survey for Children, The Satisfaction with Appearance Scale, Community Integration Questionnaire, and The Satisfaction with Life Questionnaire. The adult assessment includes questions from Special Form (SF)12, the World Health Organization Disability Assessment Schedule (WHODAS), the Burn Specific Health Scale (BSHS), and the Patient Health Questionnaire 9 (Phq9). The BMS assessments are used to collect data 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. [2] As of 2007, the Burn Model Systems data have been collected from over 4,500 patients. [2] The goal of the program is to ensure high-quality research through the collection and management of robust and valid data in order to develop and hone clinical rehabilitation practices to best meet the needs of this population. [1]

Though the main outcome measures for the BMS dataset were meticulously devised and demonstrate good psychometric properties [2]; the question remains whether or not these measures collect data that comprehensively encompass the experiences of burn patients over time. Specifically, are there areas that are not being explored? Are there topics that would be better understood with more in-depth probing? One approach to address these questions would be to examine the extent to which the BMS data set would be inclusive of dimensions of human functioning defined by the universal references published by the World Health Organization, the International Classification of Functioning, Disability and Health (ICF) and the ICF Child and Youth (ICF CY).

The ICF and the ICF-CY are comprehensive taxonomies used to classify and describe health and health-related domains through the use of a universal language of codes. [3] The framework is composed of four distinct components that are further broken down into chapters and categories (figure 1). The framework was endorsed by the World Health Organization (WHO) in 2001 and its children and youth (CY) version in 2007. [3]

Following their respective publications, the ICF and ICF-CY have been applied around the world for policy development, economic analysis, research, patient evaluation, and treatment planning [4]. An increasing area of application has been studies of the extent to which content of existing measures correspond with the coverage of the ICF. In 2002, a standardized linking method was established which enabled the linking of health-related measures to the ICF. Through this linking process, researchers can evaluate and describe health-related assessment tools based on the ICF's comprehensive framework.[5]

Purpose of the study

Two objectives defined the purpose of the study. The first objective was to link, classify, and describe the concepts included in the BMS outcome measures through a standardized linking process based on the ICF/ICF-CY. By linking assessments to the ICF, determination could be made if information garnered from this large, multi-centered data collection effort provides researchers and clinicians with (a) comprehensive view of the nature and quality of life after burn injury, (b) what information is missing, and (c) where improvements the assessments were needed.

The second objective was to define the focus of each item included in the assessments in order to determine if it 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 the data it provides. The terms "health status" and "quality of life" cannot be interchanged, as they have very different meanings.[6–8] Quality of life is defined as an individual's perception of a specific situation based on his or her culture, value system, personal goals, standards and concerns [9]. Health status on the other hand is defined by biopsychosocial elements that pertain to health conditions, physical and emotional performance and social barriers or facilitators [8,10]. By defining the nature and focus of BMS assessments, users of the BMS could conduct studies that effectively differentiate outcomes based on quality of life and outcomes based on health status data.

Based on these objectives it was hypothesized (*Hypothesis 1*) ninety percent of the BMS outcome measure items would be linkable to the ICF; (*Hypothesis 2*) forty percent of the concepts in the BMS outcome measure would be linked to the ICF component 'activity and participation', thirty percent of the items would be linked to 'body structure', twenty percent of the items would be linked to 'environment', and ten percent of the items would be linked to 'body function' and; (*Hypothesis 3*) sixty percent of the items in the BMS outcome measures would be related to the health status perspective, thirty percent of the items would be related to the quality of life perspective, ten percent of the items would be related to

environment. The hypotheses were derived from a review of the assessments by an individual trained in the ICF linking technique.

Methods

To classify and describe the concepts within the BMS, all concepts within the assessments were examined for linkage to the ICF or the ICF-CY using Cieza and colleagues' standardized linking system [11]. The following instruments were linked: BMS initial questionnaire and follow-up age 0–4 years, BMS initial and follow-up 5–13, BMS initial and follow-up 14–18, and BMS adult follow-up. The BMS did not have an adult initial assessment at the time of this study. The pediatric (0 to 18 years) assessments were linked to the ICF-CY, and adult assessment were linked to the ICF. The BMS initial and follow-up assessments are comprised of selected items from several pre-established assessment tools. Items from those tools may be included in or excluded from each of the BMS assessments based on age appropriateness. Therefore, each assessment contains a different set of items from the same pre-established pool of assessment tools. Each item was linked to the ICF each time it appeared in order calculate the linking results for each separate assessment.

Linking Assessment Concepts to the ICF

The concepts within each assessment item (each assessment question and prefix is referred to as an item) were examined for linkage to the ICF classification system using the standardized linking rules listed below (table 1). A concept was defined as a single health aspect or an environmental factor with potential to impact health status [32]. Concepts that were too broad to link at the chapter level were linked at level one of the four components (body functions, body structures, activities and participation, environmental factors). Meaningful concepts that were not linkable to the ICF were labeled in accordance with the standardized linking rules in table 1 below. A coding example is as follows: the BMS adult assessment item, “rate the impact of your itching on your sleep over the last 2 weeks”, contains two meaningful concepts (1) itching and (2) sleep. “Itching” is linked to the Body Functions (b) component of the ICF, so the code for “itching” will begin with ‘b’. “Itching” is specifically linked to chapter 8, functions of the skin and related structures, of the Body Functions (b) component, thus the code will continue ‘b8’. “Itching” is further specified by the b8 category, 40, Sensations related to the skin. Therefore the final code for “itching” is ‘b840’. The same process would then be carried out for the concept “sleep”. Concepts that represented personal factors, medical interventions, or administrative inquiries were labeled as ‘no code’.

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”. Concepts within the prefixes were linked to ICF only once. They were not repeatedly linked with each item. Repeating the prefix concepts with each of the item concepts in the analysis would result in an inflated representation of the concept density for each item. Concept density is

the number of concepts found within each item. For example, in the item discussed above, the concept density is two, (1) itching and (2) sleep. Table 2 includes the number of prefixes included in each assessment and the total number of concepts that were identified within the prefixes.

All linking rules were implemented with one exception, personal factors were not linked and were labeled as ‘no code-pf’ as there is no taxonomy of codes for the ‘personal factor’ component [12]. Given the absence of codes for this component, there is no, standard universal language for personal factors as there is for the remaining four domains of the ICF/ICF-CY [12].

The linking flow chart below (figure 2) illustrates the process of application of the linking rules to each meaningful concept.

Coding for quality of life vs. health status

In addition to linking each concept to the ICF, the perspective or focus 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.[10] These definitions are based on the authors’ understanding of WHO terminology included in the WHOQOL-BREF and the ICF-CY standard classification documents. 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 Status (functioning):** functioning perspectives refer to the interaction or the individual components of body functions, activities, and participation
3. **Health Status (disability):** Disability perspectives refers to 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 [9 13 10]

The perspectives were identified on an item by item basis by one investigator. Health status items that were neutral in nature (did not inquire about function levels or disability levels) were identified as Health Status (general). Items that did not have a perspective were identified as “other”. An example of a “health status-general” item is, “When your child participated in leisure activities did he/she usually do this alone or with others?” An example of an “other” item is, “ “What was the geographical location of your injury?”

Linking 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 that

was created to store and analyze concepts in burn assessments and associated ICF codes. The meaningful concepts within each item were mutually agreed upon prior to linking. Items 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 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 International Classification of Disease (ICD) code.
2. Code all items deemed “personal factors” code as “no code-pf”
3. When the assessment refers to the patient’s “work/job” assign code of “remunerative employment” unless context clearly implies otherwise
4. Assign interventions (ie hydrotherapy, stretching, splinting, garments, casts etc) code as “no code-intervention”
5. For prefixes containing a phrase/concept referring to “activities”, do not code the word “activities” in the prefix, but code the specific activities defined in the question.
6. When a concept refers to an 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 [14]. 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. The perspective of each item was decided upon by one investigator. Therefore, inter-rater reliability was not established for item perspectives.

A quantitative and qualitative analysis

Once concepts from the BMS assessments were linked to the ICF, the linkage results were analyzed to determine:

1. The frequency with which concepts are linked to each ICF component/chapter/level
2. The nature of the concepts covered within each assessment
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 assessment
6. The concept 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

Results

Of the 121 concepts that were randomly extracted from the master database for coding by a second researcher, both researchers agreed on the linkability of a concept 82% of the time. A kappa coefficient was calculated to measure the inter-rater reliability of the coding process. A kappa value .67 indicated that coding agreement of concepts at the ICF chapter level was good. 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 items in all of the BMS assessments combined. A total of 61% (816 concepts) were linkable to the ICF or the ICF-CY. The results below are presented by ICF component representation. Figures 3–6 represent the number of concepts per ICF chapter for each age group. The initial and follow-up for each age group have been combined in the graphs. The graphs provide the reader with an overall visual impression of ICF areas that are well covered compared to those areas that lack representation within the BMS assessments. Significant differences between the assessments are described. For more specific information regarding frequency of ICF category representation organized by assessment, see the category frequency tables in the Appendix. An itemization of the BMS concepts unable to be linked to the ICF is included in table 2 below.

Body Functions

The *body functions (b)* component was the most frequently represented component among all of the assessments with the exception of the BMS adult follow-up assessment. The *body functions (b)* component represented 42% of total BMS concepts linked to the ICF, exceeding our hypothesis that 10% of linkable concepts would be linked to *body functions (b)*. As depicted above, mental functions (b1) (141/339 total body function concepts), sensory functions and pain (b2) (39/339 concepts), neuromusculoskeletal and movement-related functions (b7) (24/339 concepts), and functions of the skin and related structures (b8) (132/339 concepts) were heavily represented in the BMS 0–4 initial and follow-up, BMS 5–13 initial and follow-up, and the BMS 14–18 initial and follow-up. The mental functions chapter were heavily represented throughout the BMS assessments. The majority of the mental functions (b1) items were coded as emotional functions (b152) at the category level. This included specific mental functions related to the feeling and affective characteristics within the mental process. Unlike other component representation, there was little discrepancy between the initial and follow-up assessments for *body functions (b)* representation. The BMS adult follow-up differed from the other assessments in that genitourinary and reproductive functions (b6) were minimally represented by 3/339 concepts total while neuromusculoskeletal and movement-related functions (b7) were not represented at all. Although the *body functions (b)* component was most frequently addressed, only five of the eight body function (b) chapters are represented within the BMS assessments. *Body function (b)* chapters that were not addressed in any of the BMS data collection included

voice and speech functions (b3), functions of the cardiovascular, hematological, immunological and respiratory systems (b4), and functions of the digestive, metabolic and endocrine systems (b5).

Activity and Participation

The *activity and participation (d)* component was the second most frequently represented component among the assessments, represented by 34% of total linked concepts, similar to our hypothesis that 40% of linkable concepts would be linked to *activity and participation (d)*. Though it was the most frequently represented component in the BMS adult follow-up, and represented 3rd most frequently in the BMS 0–4 initial assessment. The *activity and participation (d)* component was the most thoroughly covered component among the assessments. All nine chapter topics were addressed across the collective BMS assessments. However, only the BMS adult follow-up addressed all nine topics within one assessment. Overall, the most frequently addressed chapter topic was community, social and civic life (d9); addressed a total of 65 times out of 275 activity and participation concepts.

The chapter topic, general tasks and demands (d2), was addressed in only the BMS adult follow-up assessment (5/275 concepts). No other assessment included this chapter. The chapter describes carrying out single or multiple tasks, organizing routines and handling stress. Therefore, only the BMS adult follow-up probed a person's ability to participate in the aforementioned areas. Communication (d3) was the second least addressed chapter topic (10/275 concepts) within the assessments, although it was addressed at least once in all of the BMS assessments. The chapter topic, self-care (d5), was addressed by 14/275 total activity and participation (d) concepts. Twelve of those 14 concepts were in the BMS adult follow-up. One self-care concept each was addressed in the BMS 5–13 initial and follow-up. No other BMS assessment addressed this component which includes washing and drying oneself, caring for body parts, eating and drinking and looking after one's own health.

Body Structure

The component *body structure (s)* was represented by 12% of the BMS concepts overall, though it was not represented at all in the BMS adult follow-up assessment. This differed from our hypothesis that 30% of concepts would be linked to *body structure (b)*. In the BMS 5–13 and 14–18 initial and follow-up assessments, two of the eight body structure (s) chapters were represented: structures related to movement (s7) and skin and related structures (s8). Only skin and related structures (s8) is represented in the 0–4 initial and follow-up. The *body structure (s)* component was most represented in the BMS initial assessments. The discrepancy between *body structure (s)* representations in initial assessments compared to follow-up assessments exists because the initial assessments asked many questions about burn and grafting location. In the follow-up assessment the burn and grafting questions were replaced with questions about types of burn injury treatment received after discharge from acute care. As evident in Figure 5, the chapters on structures in the ICF/ICF-CY not addressed in any of the BMS assessments included structures of the nervous system (s1), the eye, ear and related structures (s2), structures involved in voice and speech (s3), structures of cardiovascular, immunological, and respiratory systems (s4),

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

Environmental Factors

The *environmental factors (e)* component was represented by 13% of BMS assessment concepts overall, similar to our hypothesis that 20% of concepts would be linked to the *environmental factors (e)* component. The BMS 0–4 follow-up, BMS 5–13 initial and follow-up and the BMS 14–18 initial and follow-up assessments addressed three of the five *environmental factors (e)* chapters: products and technology (e1) (19/102 total environmental factors concepts), support and relationships (e3) (29/102 concepts), and services systems and policies (e5) 48/102 concepts). The BMS follow-up assessments, with the exception of the BMS adult follow-up, contained many questions about post-acute medical care which resulted in the strongest representation of chapter 5: services systems and policies (e5). The BMS adult follow-up assessment addressed *environmental factors (e)* chapters 1–4 at least once, but neglected to address services, systems and policies (e5).

Perspectives

Overall, the distribution of perspectives was the same for all of the BMS assessments with the exception of the BMS adult follow-up. The BMS adult follow-up will be discussed below. See Table 3 for perspective counts for each assessment. In the remainder of the assessments, the health status perspective was most frequently cited, 34–38% of the items in each assessment. Of the items labeled as health status, 89% were labeled as health status (disability) and the remainder was labeled as health status (functioning). 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. Forty-one percent of items were not appropriate for perspective coding.

In the adult follow-up assessment, the health status perspective was represented by 83% of the items. Only 2% of those items labeled as health status were identified as health status (functioning). The remainder of the items were labeled as health status (disability). Ten percent of the items were labeled as the quality of life perspective. The environmental (barriers) perspective was identified among 3% of the items. The environmental (facilitators) perspective was not represented in the adult follow-up assessment.

Discussion

The objectives of this study were to link, classify and describe the concepts used in the BMS assessments using the ICF framework. To this end, all meaningful concepts within the BMS assessments were extracted and coded using the ICF standardized linking technique. Overall, 61% of the concepts in the BMS assessments 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 concepts within the BMS assessments are linkable to the ICF and ICD frameworks combined. We hypothesized that 90% of the assessments would be linkable to ICF.

Linking: what's missing and what are the implications

Among all the BMS linkable concepts, the *body functions (b)* component was represented most frequently followed by the *activities and participation (d)* component. Although these components are important to our understanding of an individual's life after burn injury, their relative distribution may not reflect the representation of the components *body structures (s)* and *environmental factors (e)* that may also be important in defining that individual's experience following burn injury. 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 the 130 concepts represented the *environmental factors (e)* component. A similar distribution of counts was found in the other BMS assessments as well.

The disproportionate distribution of content is also evident in the representation of subtopics (or ICF chapters) within a component. In the BMS-initial 14–18, the *activity and participation (d)* component is the second most frequently represented component. However, within that component 10 concepts address the topic community, social and civic life (d9), while no concepts address the topic of self-care (d5). In the BMS 0–4 initial assessment, a total of 10 concepts address six different ICF categories under the chapter topic mobility (d4) while the chapters on communication (d3) and domestic life (d6) are represented by only one concept each. These findings on the uneven distribution of ICF chapters and specific chapter categories in the BMS raise the question of what distribution of ICF chapter and subtopics can best capture the entire experience of burn injury recovery. Answers to this question could then inform the further development of the BMS to include domains and subtopics pertinent to ensure a broader yet more precise understanding of burn injury recovery.

The component *body structures (s)* is represented by 12% of the BMS concepts overall, though it is not represented at all in the BMS adult follow-up assessment. 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. The *body structures (s)* component is most represented in the BMS initial assessments in a section that inquiries 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 are 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. In the future, the addition of assessment questions that address changes in body structure due to burn injury over time may improve understanding of not only the effects of burns on body structure but how those effects impact other areas of life.

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 13% of BMS assessment concepts overall. The BMS 0–4 follow-up, BMS 5–13 initial and follow-up and the BMS 14–18 initial and follow-up

assessments address three of the five *environmental factors (e)* chapters. Participation has been established as a key indicator of a person's health and well-being throughout the life span [15–17]. Environmental barriers and facilitators play a key role in a person's ability to participate in life activities. A recent review of 31 studies pertaining to the impact of environmental factors on children with disabilities revealed that all ICF environmental domains influence one's ability to participate in life activities. [20] 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.[18] Participation is a primary outcome of rehabilitation interventions [4] and is well covered in the BMS assessments. However, the environmental factors that impact the individual's ability to participate are not thoroughly examined in the BMS assessments and warrant more attention in the development of future measures in order to ensure a more thorough documentation of factors that impact the level of independence in participation in life activities post burn injury.

Concept density

The concept density of a question is the number of meaningful concepts identified within it. While the average concept density for the BMS assessments was 1.8, some questions were found to be very dense, containing 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 specifically determine which meaningful concept(s) the answerer 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 or 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 can only infer 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 the cause of the deficit. The density level of the question causes the question to lose much of its meaning. The second question mentioned above demonstrates the same issue with different concepts. In future editions of the BMS assessments, developers may consider deconstructing concept-dense questions into multiple items in order to capture more accurate information that will be useable in burn injury research.

The perspectives of the BMS assessments

The assessment questions in the BMS predominantly captured the health-status perspective. Few questions were attributed to the QOL perspective. Therefore, clinicians and researchers should be aware that outcomes produced from this data primarily demonstrate patients' status based on biopsychosocial elements that pertain to health conditions, physical and emotional functioning, and social barriers or facilitators [10,19]. The majority of the health status questions probe level of disability rather than level of function. Assessment of QOL and assessment of environmental barriers or facilitators that impact participation is very limited within the BMS assessments.

Questions of the health status perspective should not be used in QOL life research, measures in these respective areas should be kept separate. When a health status assessment is used to examine quality of life, results can be imprecise and misleading which can hinder or even misguide our understanding of life after burn injury [6]. 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 a variety of reasons. Furthermore, efforts made to improve one's health may diminish one's quality of life, such as in the management of diabetes.[7] Amalgamating data from health status items with QOL items can result in misleading outcomes that only serve to thwart progress towards understanding and improving the lives of burn patients following injury. [7] Also of note, is the large percentage of health status items that were categorized as "disability" rather than "functioning". It is common for both QOL assessments and health status assessment to emphasize negative aspects of a condition, as the clinical goal is to improve a person's functioning whether it be emotional, physical or behavioral. However, clinicians should be aware that problem-based questionnaires can have an effect on how children understand themselves and their condition. [10, 20] This may be an issue to address in future editions of the BMS or an issue that the clinician may want to discuss with child when the assessment is administered.

Study limitations

A limitation of this study was the potential for bias in the ICF linking procedure. Ideally, two coders would each link all of the items, 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. This potentially biases the results towards the linking outcomes of a single coder. A second potential limitation was the exhaustiveness of the ICF framework. Although a large number of ICF validity studies have been conducted worldwide, the ICF is a dynamic document that is subject to reviews, updates, and revisions. [4] The application of the ICF in this study did provide linkage to multiple dimensions of burn recovery; however, the BMS assessments also contained concepts that were not covered within the ICF.

Conclusion

By linking the BMS assessment to the ICF framework we determined that the majority of the concepts in the BMS were linked to the *body function (b)* and 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 may 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 in order to track structural deformation and/or developmental delay secondary to injury. Developers may also consider deconstructing questions with heavy concept density so as not to lose the overall meaning of the questions in the text. Researchers and clinicians currently using BMS data should be cognizant of the overall health status perspective of the assessments. As such, the BMS data provides complementary, but distinctly separate data from QOL outcomes within the burn population. Drawing on these conclusions, the findings of this study should serve as a call for the development of an ICF core set for burn injury [21]. Core set development is a multi-step standardized process that results in a comprehensive list of ICF categories that have been found to be pertinent to the overall understanding of a specific disease or condition. The core set can be used by clinicians, researchers and others to ensure that areas pertinent to specific patient populations have been assessed and addressed. The core set also serves to standardize data collection for specific diseases and conditions. Through the process of developing a burn injury core set, we can further refine burn injury assessments like the BMS and data collection procedures to ensure that we are capturing comprehensive data that will best serve patients with burn injuries and the health care providers and researchers committed to their recovery and well-being.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

ICF component breakdown. The ICF is composed of two main domains. Those domains are broken down into components. Components are then dissected into chapters and chapters are further classified into categories (smaller boxes). There are over 1400 categories in the ICF. [15]

Coding of a Meaningful Concept

Figure 2.
Coding of a meaningful concept

Figure 3.
Body functions (b) component by chapter. X axis represents the count

Figure 4.

Activity and participation (d) component by chapter. X axis represents count

Figure 5.

Body structures (s) component by chapter. X axis represents count

Environmental Factors

Figure 6.

Environmental factors (e) component by chapter. X axis represents count

Combined BMS assessment results: Linked Concepts

Figure 7.
Combined BMS results.

Table 1

Linking Rules as Described by Cieza et al [11,21,22]

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 “other specified” ICF categories, link at a broader level if unable to link at a specific level	E4 (Attitudes)
4	Do not use the “unspecified” ICF categories, link at a broader level if unable to link at a specific level	
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, nd-ph, nd-mh. 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 it should be assigned hc	hc diabetes, asthma

Abbreviations: nd-gh (not definable-general health); nd-ph (not definable-physical health); nd-mh (not definable-mental health); nd-qol (not definable-quality of life); pf (personal factor); nc (not covered); hc (health condition)

Table 2

Linking of the Burn Model Systems (BMS) concepts to the ICF.

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
Concept 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 (23%)	2 (2%)	29 (22%)	9 (8%)	29 (23%)	9 (7%)	0 (0%)
Body function	39 (41%)	39 (48%)	52 (40%)	52 (47%)	54 (44%)	56 (46%)	52 (34%)
Activities and Participation	28 (30%)	19 (23%)	40 (31%)	25 (23%)	32 (26%)	33 (27%)	95 (61%)
Environmental factors	5 (5%)	21 (26%)	9 (7%)	25 (23%)	9 (7%)	25 (20%)	8 (5%)
Total: linked concepts	94	81	130	111	124	123	155
Concepts unable to be linked							
Concepts considered health conditions (hc)	21 (28%)	7 (12%)	28 (29%)	13 (17%)	21 (28%)	15 (20%)	19 (36%)
Concepts not definable (nd)	9 (12%)	10 (17%)	9 (9%)	10 (13%)	9 (12%)	11 (14%)	19 (36%)
Concepts nd: general health	7 (9%)	4 (7%)	7 (7%)	4 (5%)	3 (4%)	4 (5%)	5 (9%)
Concepts nd: physical health	0 (0%)	0 (0%)	2 (2%)	1 (1%)	2 (3%)	2 (3%)	2 (4%)
concepts nd: quality of life	5 (7%)	2 (3%)	10 (11%)	7 (9%)	5 (7%)	5 (7%)	1 (2%)
Concepts nd: mental health	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Concepts not covered (nc)	7 (9%)	6 (10%)	9 (9%)	8 (11%)	9 (12%)	8 (11%)	4 (8%)
Concepts: no code	27 (36%)	31 (52%)	30 (32%)	32 (43%)	25 (34%)	31 (41%)	2 (4%)
Total: unlinked concepts	76	60	95	75	74	76	53

BMSI: Burn Model Systems, Initial; BMSF: Burn Model Systems, Follow-up. Percentage of linked and unlinked concepts for each assessment in parentheses.

Table 3

Perspective identification.

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

BMSF: Burn Model Systems Follow-up. Percentage of each assessment in parentheses.