VALIDATION OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH CORE SETS FOR TRAUMATIC BRAIN INJURY FROM AUSTRALIAN COMMUNITY PATIENT PERSPECTIVES

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Objective: To examine the validity of the Comprehensive and Brief International Classification of Functioning, Disability and Health (ICF) Core Sets for Traumatic Brain Injury for patients with traumatic brain injury living in the community in Australia.

Design: Qualitative methodology using focus groups and individual interviews.

Patients: Community-dwelling adult persons with traumatic brain injury.

Methods: Patients sustaining traumatic brain injury with post-traumatic amnesia between September 2009 and August 2013, selected from the Royal Melbourne Hospital Trauma Registry, were invited to participate in the study. Participants were asked structured questions based on the ICF framework. Digital recordings of the discussions were transcribed in full for linking to the ICF categories.

Results: Saturation of data was reached after 5 groups involving 21 participants. Participants identified as relevant 77.7% (n = 108/139) and 100% (n = 23/23) of the Comprehensive and Brief ICF Core Sets for traumatic brain injury, respectively. Additional ICF categories identified in 2 or more groups were: b180 "experience of self and time functions"; b250 "taste function"; b265 "touch function"; b530 "weight maintenance function"; b780 "sensation related to muscles and movement"; and d650 "carrying for household objects".

Conclusion: The study found additional ICF categories to consider and supports the use of the ICF Core Sets for traumatic brain injury in Australian adults in the community.

Key words: brain injury; traumatic; rehabilitation; qualitative research; focus groups; self-report.

Accepted Jul 2, 2021; Epub ahead of print Jul 9, 2021
J Rehabil Med 2021; 53: jrm00218

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Traumatic brain injury (TBI) is a significant cause of death and disability in all age groups. TBI affects approximately 69 million individuals per year worldwide (1). In Australia, the incidence of TBI is estimated to be 99.1–107 per 100,000 person-years (2, 3). Multidisciplinary rehabilitation for TBI optimizes modifiable biopsychosocial factors to improve personal and social functioning through compensatory and remedial mechanisms. Researchers and clinicians should seek to understand the lived experience of patients with TBI, in order to provide person-centred rehabilitation programmes of relevance to the patient.

Qualitative studies using open-ended questions encourage participants to focus on issues of interest and related concepts considered relevant by the participant. However, these studies are labour intensive and challenging to conduct. Cognitive problems can affect the validity of self-reports in TBI, but research in other diseases affecting cognition, such as Alzheimer’s disease, identified the importance of incorporating patient perspectives in understanding psychological and social contributors to behaviours and effects of treatment (4).

The World Health Organization (WHO) recommends using the International Classification of Functioning, Disability and Health (ICF) to describe physiological, personal and social functioning in disability (5). The ICF uses a nested alphanumeric classification system to present a relational understanding of functioning and disability for ICF components of Body Functions, Body Structures, Activities and Participation, and Environmental Factors (5). For example, a TBI survivor may experience difficulties at work due to problems with multitasking. The disability (d8451 “maintaining a job” in Participation) relates to the activity limitations (d220 “undertaking multiple tasks” in Activities) and the impairments (b164 “higher-level cognitive functions” in Body Functions), which are also related to:
• other cognitive, psychological, sensory and physical problems;
• other activity limitations and participation restrictions;
• physical, social and attitudinal environment; and
• age, sex, resilience, self-efficacy, comorbidities and other health conditions.

Thus, the ICF framework presents the relationship between the relevant components of disability.

ICF Core Sets are collections of ICF categories of relevance to a health condition or a healthcare context (6). In 2010, the Comprehensive and Brief ICF Core Sets for TBI were developed through an international, multi-stage decision-making and consensus process involving patients, caregivers, health professionals and researchers (7).

The Comprehensive ICF Core Set for TBI lists 139 ICF categories for multidisciplinary assessment of TBI, while the Brief ICF Core Set for TBI lists 23 ICF categories for epidemiological studies or clinical encounters (8, 9).

The ICF Core Sets for TBI represent the spectrum of TBI severities and the continuum of care following TBI (7). Validation studies ensure the relevance of ICF Core Sets and identify any missed concepts through focus groups or individual interviews. Validation studies for ICF Core Sets for other health conditions include rheumatoid arthritis, fibromyalgia and stroke (10–13). In TBI, validation studies were conducted in patients with mild TBI in Norway (14), and patients and caregivers for all TBI severities in Italy (15). The objective of the current study is to examine the validity of the ICF Core Sets for TBI for patients with TBI living in the community in Australia.

METHODS

A qualitative methodology was used to interview persons with TBI through focus groups and individual interviews. The study was approved by the Melbourne Health Research Ethics Committee (HREC 2013.224) in 2013. The study was completed in 2015.

Participants

The Royal Melbourne Hospital (RMH) is a Level 1 trauma centre in Victoria, Australia. The RMH Trauma Registry was searched to identify adult patients who sustained a major trauma (as defined by death; admission to intensive care unit for more than 24 hours requiring a period of mechanical ventilation; injury to 2 or more body systems and Injury Severity Score over 12; or urgent surgery for an intracranial, intrathoracic or intra-abdominal injury, or pelvic or spinal fractures). From the surviving patients with major trauma, patients with a documented period of post-traumatic amnesia (PTA) with TBI, who were admitted between 1 September 2009 and 30 August 2013, were identified. The registry contributes to the state-wide trauma registry according to the Victorian State Trauma Registry Patient inclusion criteria. It was possible to search for PTA in the registry because PTA was a coded complication of trauma. All identified persons were invited by post and provided with a written consent form. From respondents, potential participants were selected using a maximum variation strategy based on age, sex, time since injury, and place of residence for remoteness (16). All participants were contacted by phone before their participation in the study to discuss the nature of the research and to confirm the informed consent. Participants expressing difficulty with attending focus groups at the RMH at Royal Park Campus, due to travel or scheduling reasons, were offered individual interviews in person or via phone. There was no monetary reimbursement for time or travel.

Sample size

Each group consisted of 3–6 participants. Saturation of data was required to determine the sample size (17). Saturation was anticipated at 5 groups, based on a previous validation study using a comparable methodology (11).

Data collection

Pre-injury demographic (age, sex, postcode) and injury details (admission date, cause and mechanism of injury, Glasgow Coma Scores, and injuries sustained), and acute hospitalization data (length of stay, discharge outcomes) were available in the RMH Trauma Registry. All additional pre- and post-injury outcomes were self-reported by the participants. Participants were asked about living arrangements, marital status, educational level, employment status, alcohol and substance use, and psychiatric diagnoses. The information was collected from the participants when confirming consent by phone before the focus group to ensure confidentiality. All focus groups were conducted by the same moderator (PC), who is a medical doctor with training in qualitative research methodologies and research among vulnerable populations. Accompanying caregivers were asked to wait at another venue. Exceptions were made if it was considered that the participant would feel vulnerable without the caregiver. Caregivers were permitted to observe the session and discouraged from making any comments. All groups began with an introduction in non-technical English language to outline the session. Attendees were asked to maintain confidentiality and to refrain from discussing injury details, in order to minimize psychological distress. Rest breaks were offered. The concept of ICF was introduced with the visual aid of a Microsoft PowerPoint 2010 presentation. The ICF-based approach was used for open-ended questions (11). The moderator verbally presented the questions in sequence for all ICF chapters covered by the Comprehensive ICF Core Set for TBI. The wording of the questions was replicated from previous validation studies (11, 12).

• [Body Functions] If you think about the {insert chapter heading} of your body and mind, what does not work the way it is supposed to?
• [Body Structures] If you think about the {insert chapter heading} of your body, in what parts are your problems?
• [Activities and Participation] If you think about {insert chapter heading} of your daily life, what are your problems in this area?
• [Environmental Factors] If you think about {insert chapter heading} of your environment and your living conditions
  ◦ What do you find helpful or supportive?
  ◦ What barriers do you experience?

At the end, the moderator summarized the discussion and presented the Comprehensive ICF Core Set for TBI to the participants. Participants were invited to verify and amend the findings and add comments, as prompted by the presentation of the Comprehensive ICF Core Set for TBI. Individual interviews

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were conducted at the hospital or on the phone. All procedures for personal interviews were as for the focus groups, with no visual aid for phone interviews.

Focus group discussions and individual interviews were digitally recorded with a Philips LFH0895 Voice Tracer Meeting Recorder, (Philips, Australia) and transcribed verbatim. All potential identifiers (name, age, places, and dates), individual injury descriptions, and comments by the moderator or caregivers were not transcribed with notation made to the effect on the transcript. Personal interviews were pooled into the allocated groups and reordered according to ICF chapter headings at the point of transcription to prevent individual re-identifications. Meaning condensation procedure was applied to divide the data into meaning units, which is a standard process in the validation of ICF Core Sets (11, 12). Each statement containing 1 meaning unit was assigned 1 unique identification number for reference purposes.

**Qualitative analysis**

The qualitative analysis involved the identification of meaning units for inclusion and exclusion. Meaning units were excluded from ICF linking if the change following TBI was neither problematic nor beneficial from the patient perspective (e.g. “I made new friends after losing my old friends”). Some meaning units could not be linked to an ICF category because they referred to Personal Factors or because the concepts not covered or not defined within the ICF. Meaning units were also excluded from ICF linking if other injuries or pre-existing health conditions caused a problem. Unclear statements (e.g. “I have that problem too”, “I can’t do that”, “My friends thinks I’m okay”) were also excluded.

**Linking to ICF**

Each concept was linked to the most precise ICF category according to the linking rules using all levels of ICF classifications (18, 19). ICF designations for personal factors (“pf”); not definable concepts (“nd”); and not covered concepts (“nc”) were not used in the linking, for practicability.

**Confirmation of the ICF Core Sets for traumatic brain injury**

From the ICF linking process, all ICF categories were simplified to the respective 2-level ICF classification for comparison with the ICF Core Sets for TBI, which use 2-level ICF classification (except for 1 item in the Brief ICF Core Set for TBI). Also, ICF categories within d5 “self-care” were converted to a 1-level ICF classification for matching with the Brief ICF Core Set for TBI, which uses d5 “self-care” to represent all self-care related concepts. An ICF category was confirmed as relevant if it was identified in 1 or more focus groups. Given the broad spectrum of problems in TBI, it was hypothesized that 70% or more (i.e. 98 or more of the 139 categories) of the Comprehensive ICF Core Set for TBI and 100% (23 of the 23 categories) of the Brief ICF Core Set for TBI would be confirmed by the focus groups.

**Saturation of data**

Saturation of data was defined as the point at which the number of new categories identified by an additional focus group was less than 5% of the cumulative number of ICF categories identified from the Comprehensive ICF Core Set for TBI.

**Additional ICF categories**

New ICF categories at 2-level classification were presented as additional categories if these were identified in 2 or more groups and were not included in the Comprehensive ICF Core Set for TBI.

**Peer-review of ICF linking**

Peer-review involved reviewing the text analysis and independent ICF linking of a sample of transcribed data. From the full transcription, 15% of meaning units were randomly selected by their unique identification number using the Microsoft Excel 2010’s random number generator. The meaning units were linked to a 2-level classification in the ICF through the independent peer-review process by FK or BA for agreement with the ICF linking by PC. Kappa statistic for agreement was calculated using IBM SPSS v23 (IBM SPSS Statistics, Armonk, NY).

**RESULTS**

**Participants**

A total of 21 patients were included for participation. Potential participants who responded after the study reached saturation were excluded from the study. The study was conducted in 3 focus groups (n = 14) and 2 pooled-analyses of interviews (n = 7) to maximize variation within the groups (Table I). The focus group discussions lasted 69–83 min (mean 76 min), and individual interviews lasted 18–47 min (mean 33 min).

**Data collection**

The median age of participants was 59 years at injury (interquartile range (IQR) 47–66 years) and 76% of participants were male (n = 16) (Table I). All categories of rurality, education levels and pre-injury health status were represented by the participants. The majority of injuries were sustained in transport accidents (n = 11) and fall from heights (n = 8), with 38% of the injuries being compensable. All categories of TBI severities using GCS were represented in the study, including 29% with severe TBI, 24% with moderate TBI and 67% with a mild TBI. Participants had an acute hospital length of stay of 14 days (median, IQR 9–18 days) before being discharged to another health facility (n = 13) or home (n = 8). At the time of the study, participants were 2.6 years from injury (median IQR 1.9–4.0 years). All participants were living in the community in private residences, including 4 participants who lived alone. Eighteen participants were working at the time of the injury. Over half of the participants reported a change in occupational status due to the injury. Participants worked reduced hours (n = 3) or did not return to work (n = 9). A diagnosis of depression or anxiety was reported by 10 (48%) of the study participants, including 6 participants who were diagnosed with depression or anxiety following the TBI.
Qualitative analysis and linking to ICF

The qualitative analysis found 1,142 meaning units. From these, 810 meaningful concepts were linked to ICF categories, with 92–236 ICF categories identified per group. After accounting for repeated ICF categories, the study identified a total of 217 unique ICF categories (Table II). These were in Body Functions (n = 88); Body Structures (n = 5); Activities and Participation (n = 70); and Environmental Factors (n = 54). Most frequently linked categories were: b144 “memory functions” (n = 33); b126

Table II. Identified International Classification of Functioning, Disability and Health (ICF) categories by ICF components

| Characteristics | Body functions | Body structures | Activities and participation | Environmental factors | Total |
|-----------------|----------------|----------------|-------------------------------|-----------------------|-------|
| Number of ICF categories in the Comprehensive ICF Core Sets for TBI, n (by ICF category) | 37 (26.6) | 2 (1.4) | 61 (43.9) | 39 (28.1) | 139 (100) |
| ICF Categories from the Comprehensive ICF Core Set for TBI identified in the study, n (of all identified categories) | 33 (30.6) | 2 (1.9) | 43 (39.8) | 30 (27.8) | 108 (100) |
| Coverage of Comprehensive ICF Core Set for TBI from the study, % | 89.2 | 100 | 70.5 | 76.9 | 77.7 |
| Coverage of issues experienced by the participants using the Comprehensive ICF Core Set for TBI, % | 37.5 | 40 | 61.4 | 55.6 | 49.8 |

TBI: traumatic brain injury.
Validation of ICF Core Sets for TBI from Australian community patient perspectives

The saturation of data was reached at 5 groups (Fig. 1), with the fifth group contributing an additional 4 (3.8%) ICF categories from the Comprehensive ICF Core Set for TBI.

**Confirmation of the ICF Core Sets for traumatic brain injury**

A total of 108 of the 139 (77.7%) ICF categories of the Comprehensive ICF Core Set for TBI and all 23 categories (100%) of the Brief ICF Core Set for TBI were identified in the study (Table II). The coverage of the Comprehensive ICF Core Set for TBI in the study were 70.5% for Activities and Participation; 76.9% for Environmental Factors; 89.2% for Body Functions; and 100% in Body Structures. The full lists of items covered are presented according to the ICF components in Tables III–V. Eleven ICF categories were identified as relevant in all 5 groups in the study. Eight of these,

| ICF category | Coverage of the Comprehensive ICF Core Sets for TBI (% of groups) | Coverage of the Brief ICF Core Sets for TBI (% of groups) |
|--------------|---------------------------------------------------------------|----------------------------------------------------------|
| b110         | CONSCIOUSNESS FUNCTIONS                                       | 40                                                       |
| b114         | Orientation functions                                         | 20                                                       |
| b126         | Temperament and personality functions                        | 100                                                      |
| b130         | ENERGY AND DRIVE FUNCTIONS                                   | 80                                                       |
| b134         | Sleep functions                                               | 100                                                      |
| b140         | ATTENTION FUNCTIONS                                           | 80                                                       |
| b144         | MEMORY FUNCTIONS                                              | 80                                                       |
| b147         | Psychomotor functions                                         | 0                                                        |
| b152         | EMOTIONAL FUNCTIONS                                           | 100                                                      |
| b156         | Perceptual functions                                          | 20                                                       |
| b160         | Thought functions                                             | 60                                                       |
| b164         | HIGHER-LEVEL COGNITIVE FUNCTIONS                              | 80                                                       |
| b167         | Mental functions of language                                  | 60                                                       |
| b210         | Seeing functions                                              | 80                                                       |
| b215         | Functions of structures adjoining the eye                     | 20                                                       |
| b235         | Vestibular functions                                          | 60                                                       |
| b240         | Sensations associated with hearing and vestibular function    | 60                                                       |
| b255         | Smell function                                                | 60                                                       |
| b260         | Proprioceptive function                                       | 20                                                       |
| b280         | SENSATION OF PAIN                                             | 100                                                      |
| b310         | Voice functions                                               | 20                                                       |
| b320         | Articulation functions                                        | 40                                                       |
| b330         | Fluency and rhythm of speech functions                        | 20                                                       |
| b420         | Blood pressure functions                                      | 0                                                        |
| b455         | Exercise tolerance functions                                  | 80                                                       |
| b510         | Ingestion functions                                           | 20                                                       |
| b525         | Defecation functions                                          | 40                                                       |
| b555         | Endocrine gland functions                                     | 0                                                        |
| b620         | Urination functions                                           | 40                                                       |
| b640         | Sexual functions                                              | 60                                                       |
| b710         | Mobility of joint functions                                   | 0                                                        |
| b730         | Muscle power functions                                        | 20                                                       |
| b735         | Muscle tone functions                                         | 20                                                       |
| b755         | Involuntary movement reaction functions                       | 80                                                       |
| b760         | CONTROL OF VOLUNTARY MOVEMENT FUNCTIONS                      | 60                                                       |
| b765         | Involuntary movement functions                                | 80                                                       |
| b770         | Gait pattern functions                                        | 60                                                       |
| s110         | STRUCTURE OF BRAIN                                            | 60                                                       |
| s710         | Structure of head and neck region                             | 20                                                       |

Categories of Body Functions & Structures covered, %, n of total:

| Category                          | Coverage | n of total |
|-----------------------------------|----------|------------|
| s110 STRUCTURE OF BRAIN           | 60       | 9 of 9     |
| Categories of Body Functions & Structures covered, %, n of total | 89.7 (35 of 39) | 100 (9 of 9) |

ICF categories in the Brief ICF Core Sets for TBI are shown in all capital letters.
which were included in the Brief ICF Core Set for TBI, were: b152 “emotional functions”; b280 “sensation of pain”; d350 “conversation”; d450 “walking”; d845 “acquiring, keeping and terminating a job”; d920 “recreation and leisure”; e115 “products and technology for personal use in daily living”; and e120 “products and technology for personal use in daily living”.

Table IV. Coverage of the International Classification of Functioning, Disability and Health (ICF) Core Sets for traumatic brain injury (TBI) for Activities and Participation

| ICF category | Coverage of the Comprehensive ICF Core Sets for TBI (% of groups) | Coverage of the Brief ICF Core Sets for TBI (% of groups) |
|--------------|-------------------------------------------------------------------|----------------------------------------------------------|
| d110 Watching | 0                                                                 | 0                                                       |
| d115 Listening | 0                                             | 0                                                       |
| d155 Acquiring skills | 40                                             | 40                                                       |
| d160 Focusing attention | 20                                              | 20                                                       |
| d163 Thinking | 20                                               | 20                                                       |
| d166 Reading | 0                                               | 0                                                       |
| d170 Writing | 20                                               | 20                                                       |
| d175 Solving problems | 20                                              | 20                                                       |
| d177 Making decisions | 60                                              | 60                                                       |
| d210 Undertaking a single task | 60                                             | 60                                                       |
| d220 Undertaking multiple tasks | 80                                              | 80                                                       |
| d230 CARRYING OUT DAILY ROUTINE | 80                                              | 80                                                       |
| d240 Handling stress and other psychological demands | 100                                             | 100                                                      |
| d310 Communicating with - receiving - spoken messages | 0                                              | 0                                                       |
| d315 Communicating with - receiving - nonverbal messages | 40                                             | 40                                                       |
| d330 Speaking | 60                                               | 60                                                       |
| d335 Producing nonverbal messages | 0                                              | 0                                                       |
| d345 Writing messages | 0                                              | 0                                                       |
| d350 CONVERSATION | 100                                             | 100                                                      |
| d360 Using communication devices and techniques | 0                                              | 0                                                       |
| d410 Changing basic body position | 20                                             | 20                                                       |
| d415 Maintaining a body position | 0                                              | 0                                                       |
| d420 Transferring oneself | 20                                             | 20                                                       |
| d430 Lifting and carrying objects | 0                                              | 0                                                       |
| d440 Fine hand use | 40                                              | 40                                                       |
| d445 Hand and arm use | 0                                              | 0                                                       |
| d450 WALKING | 100                                              | 100                                                      |
| d455 Moving around | 60                                              | 60                                                       |
| d465 Moving around using equipment | 0                                              | 0                                                       |
| d470 Using transportation | 20                                             | 20                                                       |
| d475 Driving | 80                                               | 80                                                       |
| d5 SELF-CARE | 40                                               | 40                                                       |
| d510 Washing oneself | 0                                              | 0                                                       |
| d520 Caring for body parts | 0                                              | 0                                                       |
| d530 Toileting | 0                                               | 0                                                       |
| d540 Dressing | 0                                               | 0                                                       |
| d550 Eating | 20                                               | 20                                                       |
| d560 Drinking | 0                                               | 0                                                       |
| d570 Looking after one’s health | 40                                             | 40                                                       |
| d620 Acquisition of goods and services | 20                                             | 20                                                       |
| d630 Preparing meals | 40                                              | 40                                                       |
| d640 Doing housework | 20                                             | 20                                                       |
| d660 Assisting others | 0                                              | 0                                                       |
| d710 Basic interpersonal interactions | 60                                             | 60                                                       |
| d720 COMPLEX INTERPERSONAL INTERACTIONS | 80                                             | 80                                                       |
| d730 Relating with strangers | 20                                             | 20                                                       |
| d740 Formal relationships | 0                                              | 0                                                       |
| d750 Informal social relationships | 40                                             | 40                                                       |
| d760 FAMILY RELATIONSHIPS | 20                                             | 20                                                       |
| d770 Intimate relationships | 80                                             | 80                                                       |
| d825 Vocational training | 20                                             | 20                                                       |
| d830 Higher education | 40                                             | 40                                                       |
| d840 Apprenticeship (work preparation) | 20                                             | 20                                                       |
| d845 ACQUIRING, KEEPING AND TERMINATING A JOB | 100                                             | 100                                                      |
| d850 Remunerative employment | 80                                             | 80                                                       |
| d855 Non-remunerative employment | 40                                             | 40                                                       |
| d860 Basic economic transactions | 20                                             | 20                                                       |
| d865 Complex economic transactions | 40                                             | 40                                                       |
| d870 Economic self-sufficiency | 20                                             | 20                                                       |
| d890 Community life | 20                                             | 20                                                       |
| d920 RECREATION AND LEISURE | 100                                             | 100                                                      |
| d930 Religion and spirituality | 20                                             | 20                                                       |

Categories of Activities and Participation covered, %, n of total

|                | Coverage of the Comprehensive ICF Core Sets for TBI (% of groups) | Coverage of the Brief ICF Core Sets for TBI (% of groups) |
|----------------|-------------------------------------------------------------------|----------------------------------------------------------|
|                | 70.5 (43 of 61)                                                    | 100 (8 of 8)                                              |

ICF categories in the Brief ICF Core Sets for TBI are shown in all-capital letters.
technology for personal indoor and outdoor mobility and transportation”. Three ICF categories identified by all focus groups, but not included in the Brief ICF Core Set for TBI, were: b126 “temperament and personality functions”; b134 “sleep functions”; and d240 “handling stress and other psychological demands”.

**Additional ICF categories**

The overall coverage of issues experienced by the focus groups using the Comprehensive ICF Core Set for TBI was 49.8%, with 37.5% in Body Functions; 40% in Body Structures; 61.4% in Activities and Participation; and 55.6% in Environmental Factors (Table II). From the concepts not covered in the Comprehensive ICF Core Set for TBI, 6 2-level ICF categories were identified by 2 or more groups, but were missing in the Comprehensive ICF Core Set for TBI. These were: b180 “experience of self and time functions”; b250 “taste function”; b265 “touch function”; b530 “weight maintenance function”; b780 “sensation related to muscles and movement”; and d650 “caring for household objects” (Table VI). In ICF, b780 “sensation related to muscles and movement” refers to muscle

**Table V.** Coverage of the International Classification of Functioning, Disability and Health (ICF) Core Sets for TBI (TBI) for Environmental Factors

| ICF category | Coverage of the Comprehensive ICF Core Sets for TBI (% of groups) | Coverage of the Brief ICF Core Sets for TBI (% of groups) |
|--------------|---------------------------------------------------------------|----------------------------------------------------------|
| e1100 Food   | 20 0                                                          | 20 0                                                     |
| e1101 Drugs  | 0 60                                                         | 0 60                                                     |
| e1108 Non-medical drugs and alcohol | 20 20 | 20 20 |
| e115 PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING | 100 60 | 100 60 |
| e120 PRODUCTS AND TECHNOLOGY FOR PERSONAL INDOOR AND OUTDOOR MOBILITY AND TRANSPORTATION | 100 0 | 100 0 |
| e125 Products and technology for communication | 0 20 | 0 20 |
| e135 Products and technology for employment | 0 0 | 0 0 |
| e150 Design, construction and building products and technology of buildings for public use | 20 0 | 20 0 |
| e155 Design, construction and building products and technology of buildings for private use | 0 20 | 0 20 |
| e160 Products and technology of land development | 0 40 | 0 40 |
| e165 Assets | 0 40                                                         | 0 40                                                     |
| e210 Physical geography | 20 0 | 20 0 |
| e250 Sound | 0 40                                                         | 0 40                                                     |
| e310 IMMEDIATE FAMILY | 80 20 | 80 20 |
| e315 Extended family | 0 0 | 0 0 |
| e320 FRIENDS | 40 0 | 40 0 |
| e325 Acquaintances, peers, colleagues, neighbours and community members | 60 0 | 60 0 |
| e330 People in positions of authority | 0 20 | 0 20 |
| e340 Personal care providers and personal assistants | 0 0 | 0 0 |
| e355 Health professionals | 60 60 | 60 60 |
| e360 Other professionals | 20 40 | 20 40 |
| e410 Individual attitudes of immediate family members | 0 60 | 0 60 |
| e415 Individual attitudes of extended family members | 0 20 | 0 20 |
| e420 Individual attitudes of friends | 0 0 | 0 0 |
| e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members | 40 20 | 40 20 |
| e440 Individual attitudes of personal care providers and personal assistants | 0 0 | 0 0 |
| e450 Individual attitudes of health professionals | 20 80 | 20 80 |
| e455 Individual attitudes of other professionals | 0 20 | 0 20 |
| e460 Societal attitudes | 20 40 | 20 40 |
| e515 Architecture and construction services, systems and policies | 0 0 | 0 0 |
| e525 Housing services, systems and policies | 0 0 | 0 0 |
| e535 Communication services, systems and policies | 0 0 | 0 0 |
| e540 Transportation services, systems and policies | 0 20 | 0 20 |
| e550 Legal services, systems and policies | 0 0 | 0 0 |
| e570 SOCIAL SECURITY SERVICES, SYSTEMS AND POLICIES | 20 60 | 20 60 |
| e575 General social support services, systems and policies | 0 20 | 0 20 |
| e580 HEALTH SERVICES, SYSTEMS AND POLICIES | 60 60 | 60 60 |
| e585 Education and training services, systems and policies | 20 0 | 20 0 |
| e590 Labour and employment services, systems and policies | 60 40 | 60 40 |

Categories of Environmental Factors covered, %, n of total: 76.9 (30 of 39), 100 (6 of 6)

*ICF categories in the Brief ICF Core Sets for TBI are shown in all capital letters.

**Table VI.** Additional International Classification of Functioning, Disability and Health (ICF) categories identified in 2 or more groups

| ICF category | (% of groups) |
|--------------|---------------|
| b180 Experience of self and time functions | 40 |
| b250 Taste function | 40 |
| b265 Touch function | 40 |
| b530 Weight maintenance function | 80 |
| b780 Sensation related to muscles and movement | 40 |
| d650 Caring for household objects | 60 |

TBI: traumatic brain injury.
stiffness, spasms and involuntary contractions, which is separate from b260 “‘proprioceptive’ function”.

Peer review of ICF linking

A total of 173 meaning units underwent peer-review (15.1%). ICF linking at 2-level classification resulted in a Cohen’s kappa statistic of 0.602 for agreement and a chance agreement of 0.00276, which suggests moderate inter-rater agreement (20).

DISCUSSION

This is the first study in the validation of the ICF Core Sets for TBI in Australia. The study found that Australian community-dwelling persons with TBI identified 77.7% and 100% of the categories of the Comprehensive and Brief ICF Core Sets for TBI, respectively, as relevant to their experience.

The study participants discussed a broad range of issues affecting their lives following TBI, with 810 meaningful concepts linked to 217 unique ICF categories. The breadth of the concepts identified in this study exceeded previous studies, which identified 108 ICF categories in patients with mild TBI (n = 17) (14); 144 ICF categories in patients with all TBI severities (n = 41) (15); and 129 ICF categories in caregivers of patients with all TBI severities (n = 41) (15).

The study identified additional concepts of potential relevance to TBI survivors not included in the ICF Core Sets for TBI. Some of the missed concepts in the Comprehensive ICF Core Set for TBI were subjective problems or experiences. Missed concepts included sensory functions of taste, touch and muscle stiffness or spasms. Altered or distorted taste functions usually accompany impaired smell functions (b255 “smell function” in the Comprehensive ICF Core Set for TBI), but gustatory disorder following TBI is often a separate phenomenon in patients (21). From the patient’s perspective, the distorted taste is a different challenge to anosmia. It can exacerbate problems with cooking and appetite and result in unintentional weight gain or excessive consumption of alcohol or salt. Altered touch sensation and muscle stiffness are known issues in TBI, but it is difficult to assess, quantify and treat the patients’ subjective symptoms. These symptoms probably differ from pain or spasms with spasticity and dystonia. There may be additional subjective and quality of life benefits in ensuring that clinicians acknowledge and optimize the care of sensory problems following TBI. Participants also described their experience of adjusting to living through a period of amnesia, where there were gaps in memories lasting for weeks to months at times. The concept of b180 “experience of self and time functions” is expected to affect all persons emerging from PTA. There may be a role for dedicated psychological interventions to help patients adjust to this experience. There were 3 ICF categories that were not included in the Brief ICF Core Set for TBI, but were identified as relevant in all 5 groups. These were b126 “temperament and personality functions”; b134 “sleep functions”; and d240 “handling stress and other psychological demands”. These are, again, subjective issues with unclear aetiology and treatment options from the clinicians’ perspectives.

Some categories within the Comprehensive ICF Core Sets for TBI were not identified as relevant in this study. Some issues may not be reported in persons with mild to moderate injuries. For example, d166 “reading” and d310 “communicating with – receiving – spoken messages” could be difficult following mild TBI with post-concussive symptoms, but d110 “watching” and d115 “listening” may not be reported as a problem. Other problems are time-limited issues in TBI recovery and resolve with time, except in catastrophic injuries or injuries with focal ischaemia or haemorrhage, including d445 “hand and arm use”, d510 “washing oneself” and d560 “drinking”. Finally, patients may not be aware of specific problems in their experience due to decreased awareness; for example, with b555 “endocrine functions” or d335 “producing nonverbal messages”, respectively.

Most categories in the Environmental Factors of the Comprehensive ICF Core Set for TBI were identified as relevant (76.9%). Participants in the study experienced significant changes to their physical, social and attitudinal environment, especially with occupational and social roles. However, many of the changes were not described as a facilitator of, or a barrier to, functioning from the patient’s perspective, but merely as a change. The reason for this is not clear, but it is possible that participants’ perceptions changed or adapted with time as a part of an acceptance process. The study also provided insight into the complex nature of family interactions, as participants recognized the importance of the immediate family for decreasing disability (e310 “immediate family” – facilitator in 80%, barrier in 20%), but the attitudes of the immediate family were often perceived to be a barrier to functioning (e410 “individual attitudes of immediate family members” – barrier in 60%). This highlights the importance of addressing the physical and attitudinal environment of a TBI survivor as separate issues. Multidisciplinary rehabilitation in persons with TBI often requires a family member’s involvement as a caregiver for safety and social functioning (22). Additional care and support are encouraged for TBI survivors’ family members, recognizing that adjustment can be challenging for the patient and families, with altered relationships and social roles due to supervision needs, emotional difficulties, and work capacity loss.
Study limitations

The study was limited in the range of complexities and adverse outcomes of TBI because participants responding to the invitation lived in the community, had access to the same residential address, were able to consent, and communicated verbally. The data collection may have been affected by some participants not having access to the visual presentation and being interviewed individually. Participants of this study were selected from Victoria, with limited generalizability to other states and territories of Australia. Using PTA as selection criteria likely resulted in excluding persons with extremely severe injuries (where PTA testing may not have commenced during the acute trauma admission). Major trauma definition may have excluded persons with isolated mild TBIs.

Conclusion

This study provided patient perspectives for the validation of the ICF Core Sets for TBI in the Australian community-dwelling persons with TBI with a period of PTA, and included all severities of TBI. This study supports the use of the ICF Core Sets for TBI in comparable populations. Additional ICF categories were identified as relevant and could be included in research in comparable populations.

ACKNOWLEDGEMENTS

This paper was submitted by Dr Pearl Chung for completion of a PhD (Section III, Chapter 10) (23) and presented as a poster at the International Brain Injury Association Eleventh World Congress on Brain Injury (24). The authors thank the study participants; the Royal Melbourne Hospital Trauma Registry; Dr Bhasker Amatya for assistance with the data analysis; and Associate Professors Ian Baguley, Associate Professor Louisa Ng and Dr Clayton King for feedback.

The authors have no conflicts of interest to declare.

REFERENCES

1. Dewan MC, Rattani A, Gupta S, Baticulon RE, Hung Y-C, Punchak M, et al. Estimating the global incidence of traumatic brain injury. J Neurosurg 2019; 130: 1080.
2. AIHW A. Australia’s Health 2008. Canberra: Australian Institute of Health and Welfare Cat No AUS 99; 2008.
3. Pozzato I, Tate RL, Rosenkootter U, Cameron ID. Epidemiology of hospitalised traumatic brain injury in the state of New South Wales, Australia: a population-based study. Aust N Z J Public Health 2019; 43: 382–388.
4. Cotrell V, Schulz R. The perspective of the patient with Alzheimer’s disease: a neglected dimension of dementia research. The Gerontologist 1993; 33: 205–211.
5. World Health Organization (WHO). ICF: International Classification of Functioning, Disability and Health. Geneva: World Health Organization; 2001.
6. Bickenbach J, Cieza A, Rauch A, Stucki G. ICF core sets: manual for clinical practice for the ICF research branch, in cooperation with the WHO collaborating centre for the family of international classifications in Germany (DIMDI). Cambridge; Hogrefe Publishing; 2012.
7. Laxe S, Zaslzer N, Selb M, Tate R, Tormos JM, Bernabeu M. Development of the International Classification of Functioning, Disability and Health core sets for traumatic brain injury: an international consensus process. Brain Inj 2013; 27: 379–387.
8. Bernabeu M, Laxe S, Lopez R, Stucki G, Ward A, Barnes M, et al. Developing core sets for persons with traumatic brain injury based on the international classification of functioning, disability, and health. Neurorehabil Neural Repair 2009; 23: 464–467.
9. Chung P, Yun SJ, Khan F. A comparison of participation outcome measures and the International Classification of Functioning, Disability and Health Core Sets for traumatic brain injury. J Rehabil Med 2014; 46: 108–116.
10. Stier-Jarmer M, Grill E, Muller M, Strobl R, Quittan M, Stucki G. Validation of the comprehensive ICF Core Set for persons in geriatric post-acute rehabilitation facilities. J Rehabil Med 2011; 43: 102–112.
11. Coenen M, Cieza A, Stamm TA, Amann E, Kollerits B, Stucki G. Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for rheumatoid arthritis from the patient perspective using focus groups. Arthritis Res Ther 2006; 8: R84.
12. Hieblinger R, Coenen M, Stucki G, Winkelmann A, Cieza A. Validation of the International Classification of Functioning, Disability and Health Core Set for chronic widespread pain from the perspective of fibromyalgia patients. Arthritis Res Ther 2009; 11: R67.
13. Glassel A, Coenen M, Kollerits B, Cieza A. Validation of the extended ICF core set for stroke from the patient perspective using focus groups. Disabil Rehabil 2012; 34: 157–166.
14. Sveen U, Ostenso S, Laxe S, Soberg HL. Problems in functioning after a mild traumatic brain injury within the ICF framework: the patient perspective using focus groups. Disabil Rehabil 2012; 35: 749–757.
15. Pistorini C, Aiachini B, Coenen M, Pisoni C. Functioning and disability in traumatic brain injury: the Italian patient perspective in developing ICF Core Sets. Disabil Rehabil 2011; 33: 2333–2345.
16. Patton M. Qualitative evaluation and research methods. Newbury Park, CA: Sage; 1990.
17. Guest G, Bunce A, Johnson L. How many interviews are enough?: an experiment with data saturation and variability. Field Methods 2006; 18: 59–82.
18. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G. ICF linking rules: an update based on lessons learned. J Rehabil Med 2005; 37: 212–218.
19. Cieza A, Brockow T, Evert T, Amman E, Kollerits B, Chat­terji S, et al. Linking health-status measurements to the International Classification of Functioning, Disability and Health. J Rehabil Med 2002; 34: 205–210.
20. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med (Zagreb) 2012; 22: 276–282.
21. Schoefield PW, Doty RL. Chapter 23 – the influence of head injury on olfactory and gustatory function. In: Doty RL, editor. Handbook of clinical neurology 164. The Nether­lands; Elsevier: 2019. p. 409–429.
22. Hanks RA, Rapport LJ, Vangel S. Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. Neurorehabilitation 2007; 22: 43–52.
23. Chung P. Rehabilitation in traumatic brain injury [disserta­tion]. Melbourne: The University of Melbourne; 2016.
24. Chung P, Khan F, Judson R, Baguley IJ, Ng L. Validation of the International Classification of Functioning, Disability and Health (ICF) Core Sets for Traumatic Brain Injury from Australian community patient perspective. In: Accepted Abstracts from the International Brain Injury Association’s Eleventh World Congress on Brain Injury. Brain Inj 2016; 30: 481–817.