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**ORIGINAL REPORT**

# USE OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF) TO DESCRIBE PATIENT-REPORTED DISABILITY IN PRIMARY BRAIN TUMOUR IN AN AUSTRALIAN COMMUNITY COHORT

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***Objective:*** **To describe patient-reported disability in primary brain tumours using the International Classification of Functioning, Disability and Health (ICF); and comparison with categories within the core sets for stroke and traumatic brain injury.**

***Method:*** **A prospective community cross-sectional survey ($n = 106$) following definitive treatment for primary brain tumours. Problems reported by participants were linked with ICF categories using 'linkage' rules. Participants rated 'activities and participation' and 'environmental factor' components of ICF checklist (using qualifiers); and responses compared with categories within core sets for stroke and traumatic brain injury.**

***Results:*** **Participant mean age 51 years, median time since diagnosis 2 years; over a third had high grade tumours. Participants considered 44 categories in 'activities and participation' and 16 categories (barriers) in 'environmental factors' as relevant (≥10% response) using checklist. Reported problems included: *Mobility, Domestic life, General tasks/ demands;* and *Human made changes to environment.* Although the linked categories for brain tumour survivors were similar to those in the core sets for stroke and traumatic brain injury, there was more commonality with the traumatic brain injury core set.**

***Conclusion:*** **The existing comprehensive stroke and traumatic brain injury core sets incorporate issues relevant to brain tumour survivors in post-acute settings. Findings from this report will assist in defining a future core set for brain tumour; the possibility however, of using a single core set relevant to most long-term neurological conditions needs to be explored.**

*Key words:* ICF; disability; brain tumour; outcome assessment; environmental factors.

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## INTRODUCTION

Primary brain tumours are a diverse group of neoplasms with considerable morbidity and mortality, and account for 2% of all cancers (1) affecting approximately 7 per 100,000 population annually worldwide (2). The overall incidence of primary brain tumours is increasing, with the highest increase in patients over 60 years of age (3). In Australia, there are approximately 1,400 new cases and over 1200 deaths from malignant and benign brain tumours annually (4).

Recent advances in the treatment and management of primary brain tumours has resulted in improved survival rates (5). Amongst the treatment modalities, radiation therapy remains the primary treatment; while adjuvant chemotherapy and surgical treatment have recently gained more support as a means of prolonging survival (5, 6). Despite these treatment options, brain tumours remain a significant source of functional and psychosocial impairment, limiting everyday activity and participation in survivors (5, 7). The treatment regimens can cause adverse effects (7); while, the diagnosis itself can have a distressing psychological impact. These result in significant costs and socioeconomic implications, increased demand for health care, social and vocational services, and caregiver burden (7).

Rehabilitation for survivors of primary brain tumour can be challenging as they can present with various combinations of problems, such as physical, cognitive, psychosocial, behavioural and environmental issues (3, 8). Within the framework of the International Classification of Functioning, Disability and Health (ICF), which defines a common language for describing the impact of disease at different levels – brain tumour related impairments (paresis, spasticity, pain, visual deficits, seizures) limit function (mobility, self-care, continence) and participation (driving, work, family, life-situations); and influenced by environmental factors which can act as barriers or facilitators (9). Brain tumour survivors may have ongoing concerns regarding relationships, employment, recurrence etc. (8).

In recent years there has been increased usage of the ICF in clinical settings, including ICF checklists to identify patient reported problems in both acute and chronic conditions.

The development of ICF core sets for common neurological conditions such as stroke (10), traumatic brain injury (TBI) (11, 12), multiple sclerosis (MS) (13) contain categories for the most relevant aspects of functioning in these patients to guide multidisciplinary assessments and treatment. Categories included in these core sets show considerable overlap and commonality, which is not surprising given involvement of the central nervous system (CNS). At present there is no core set for primary brain tumours. The main objective of this study is to describe patient-reported disability using ICF in primary brain tumour survivors in an Australian cohort. Secondly, to compare the ICF categories identified with existing categories in the comprehensive core sets for stroke and TBI. This will provide information, to assist in the development of the core set for brain tumours in future and/or the development of a single core set with categories relevant and applicable to most long-term neurological conditions with prototypical domains.

## METHODS

### *Participants and setting*

This study was part of a prospective rehabilitation research programme for primary brain tumour survivors at the Royal Melbourne Hospital (RMH), a tertiary referral centre in Victoria, Australia. The RMH programme provides acute surgical/oncological and rehabilitative care for these patients in both inpatient and ambulatory settings.

Participants in this study were recruited from the 862 consecutive patients admitted to RMH for acute care between 2007–2011; with the ICD Code (C71) for primary brain cancer (main diagnosis) incorporating all 10 sub-codes that localize the brain tumour (C71.0–71.9) (first admission only; and excludes cranial nerves). These include same and multiday patients and those with recurrent admissions (details available from authors). The RMH Access Database was used for cross-indexing of diseases from the Patient Administrator System (HOMER) of Hospital Information Systems, Department of Health Victoria, Australia. The source of these patients was a pool of persons residing in the community, referred to the RMH from public and private medical clinics across greater Melbourne in Victoria. All participants were aged > 18 years and fulfilled standard diagnostic criteria for brain tumour (benign and malignant tumours) grading system as outlined by the World Health Organization (WHO) for CNS tumours (14); and assessed by a surgeon/oncologist at the RMH. These participants resided in the community (area of greater Melbourne < 60 km radius), and were able to communicate in English. Those who had metastatic brain tumours, significant comorbidities or medically unstable, or psychiatric disorders limiting participation in rehabilitation, those bed-bound and/or institutionalized in nursing homes were excluded (Fig. 1).

The study was approved by the Royal Melbourne Hospital Ethical Committee (HREC no. 2010.216) and informed consent was obtained from all the subjects.

### *Procedure*

All eligible patients were contacted by mail and invited to participate in this project by an independent project officer, and those who returned signed consent forms were recruited for the study. All interviews were conducted by a trained research assistant and a physician who participated in 3 half day structured ICF workshops at RMH and were familiar with ICF checklists, linkage rules and core set principles.

First, each participant (alone or with a carer) was interviewed using a structured format open-ended questionnaire and asked to nominate a list of problems affecting their everyday life due to brain tumour. There was no prompting or use of problem lists. Authors (FK, BA) trained in ICF, used linking rules (15) to match each problem reported by the participant with an appropriate ICF categories (second level) for the components 'activity and participation' and 'environmental factors.' After data extraction, both reviewers compared their results. Similar to previous reports (16) any disagreements concerning selected categories were resolved by a trained third health professional.

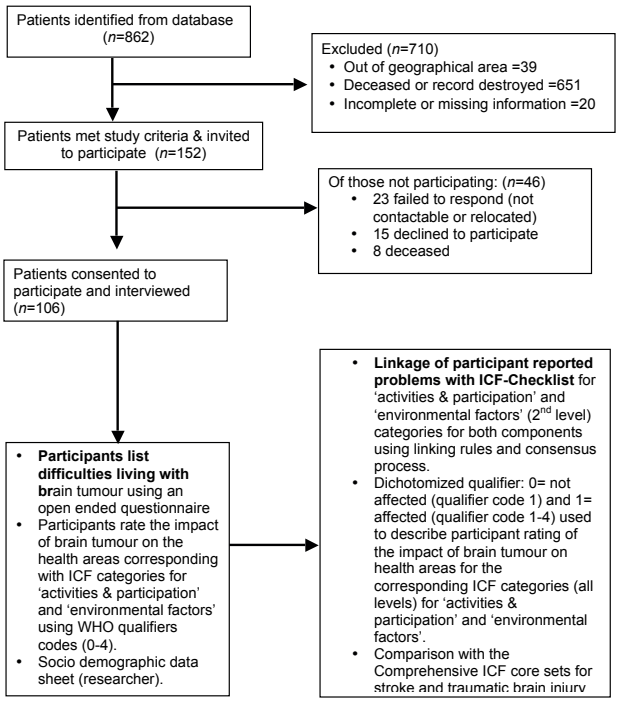


*Fig. 1.* Participant recruitment flow chart.

In the ICF-based approach, each participant then reviewed an ICF-checklist (17) comprising 82 ICF categories (all levels of classification) for the components 'activity and participation' and 'environmental factors.' The 50 categories included in the domain 'activities and participation' included: 7 categories each for learning and applying knowledge, self-care, interpersonal interaction and relationships chapters; 6 each for mobility and major life areas; 5 each for communication, community, social and civic life; and 4 each for domestic life and general tasks and demands chapters. The 'environment factors' component included 32 categories: 9 for systems and policies; 7 each for attitudes, and support and relationships; 6 for products and technology; and 3 for natural environment and human made changes chapters. The participants were asked whether brain tumour affected the health areas described in the corresponding ICF categories. They used the WHO qualifier scale to rate each category (responses from 0 to 4: 0 = not affected 1 = mild; 2 = moderate; 3 = severe, 4 = complete) to the extent of their problem in 'activities and participation' component and barriers for the categories in 'environmental factors'. Barriers (hindrances) were identified as a major influence on a persons' ability to engage in activity, participation and good health practices (18). Impact was defined as subjectively perceived costs inherent in under-taking activity, participation and health behaviours (18). Each category was assessed for their relevance (i.e., ≥ 10% of the participant response) corresponding with the ICF checklist reported by the study population.

Finally, each of the titles of the ICF chapters from the ICF checklist categories for components 'activity and participation' and 'environmental factors' (9) were compared with the categories that were included in the existing comprehensive ICF core sets for stroke (10) and TBI (11, 12). The comprehensive core set for stroke (10) consists of 130 categories (including 51 for 'activity and participation' and 33 for 'environmental factors'); whereas TBI core set (11, 12) consists139 categories (including 61 in 'activities and participation', and 39 in

'environmental factors'). Categories reported as relevant by the study population using the ICF checklist were listed for inclusion in the development of the future comprehensive core set for brain tumour.

*Measures*

A standard data form collated socio-demographic information and brain tumour disease status. The ICF checklist (9) and comprehensive core sets for stroke and TBI assessed 'activity and participation' and 'environmental factor' components (see 'procedure' above).

*Sample size*

The sample size was determined by saturation, defined as the point during data collection and analysis at which an investigator has obtained sufficient information from the field and reveals no additional second level categories (19).

*Statistical methods*

The frequency of participant reported problems was linked with the ICF categories (second level). Descriptive statistics examined the frequencies of limitations in the categories for the component 'Activities & Participation'. For environmental factors, the frequencies of persons reporting a specific category as a barrier are reported. The degree of the qualifiers scale were dichotomized to 0 as 'no problem' (by maintaining response option '0') and 1 as 'problem' (by collapsing the response options 1–4). The ICF categories 'mildly impaired' or represented as a 'barrier' (qualified as 1–4) in at least 10% of the patients was considered relevant (20). The frequencies of ICF categories reported by the participants were compared with frequency of endorsement of the ICF categories in the core sets for stroke and TBI.

If the patient repeatedly assigned one ICF category, it was counted only once to avoid bias. Consensus opinion was used if there was a discrepancy in the brain tumour related problem listed by the participant. All data was entered twice to avoid errors on data entry. SPSS 17.0 for Windows was used for analysis.

## RESULTS

The socio-demographic and disease characteristics of study participants ($n = 106$) are shown in Table I. The mean age of the participants was 51 years (range 21–77 years), majority were female (56%) and married (76%). Median time since brain tumour diagnosis was 2.1 years (interquartile range (IQR) 0.9 to 4.0 years) and more than one third (39%) had high grade brain tumours (grade IV) on the WHO tumour grading system. More than half of participants reported pain (56%), of which 42% reported headache. The participants were satisfied with their current quality of life.

*Participant reported issues due to brain tumour linked with the ICF categories using linkage rules*

Tables II lists the patient reported issue in everyday life activity due to brain tumour, using an open-ended questionnaire. There was 100% agreement between reviewers for linkage of participant-reported problems with the ICF categories. No problems were identified by participants that could not be linked to the standardised ICF checklist. Seventy-five participants (71%) reported at least one issue which was linked with the categories of 'activities and participation' and 'environmental factors' components of the comprehensive ICF-checklist. A total of 121 relevant concepts corresponding to 32 ICF

Table I. *Characteristics of brain tumour participants (*n = *106)*

| Demographic factors | |
|---|---|
| Age, years, mean (SD) [range] | 51.3 (13.6) [20.8–77.28] |
| Sex, female, *n* (%) | 61 (57.5) |
| Marital status, *n* (%) | |
| Married/Partner | 81 (76.4) |
| Single/Divorced/Separated/Widow | 25 (23.5) |
| Living conditions, *n* (%) | |
| Alone | 18 (17.0) |
| Partner/Family | 88 (83.0) |
| Education, *n* (%) | |
| Primary | 4 (3.8) |
| Secondary | 55 (51.9) |
| Tertiary | 47 (44.3) |
| Smokers, *n* (%) | 17 (16.0) |
| Consumes alcohol, *n* (%) | 45 (42.5) |
| Clinical characterisitics | |
| Disease duration, years, median (IQR) | 2.1 (0.8,4.0) |
| WHO tumour grade[a] (*n* = 96), *n* (%) | |
| Grade I | 14 (14.6) |
| Grade II | 30 (31.3) |
| Grade III | 15 (15.6) |
| Grade IV | 37 (38.5) |
| Steriods received during treatment, *n* (%) | 72 (67.9) |
| Surgery, ≥2 surgery episodes, *n* (%) | 105 (99.1), 33 (31.4) |
| Type of surgery(*n* = 91), *n* (%) | |
| Debulk | 74 (70.5) |
| Complete excision | 25 (23.8) |
| Chemotherapy, multiple episode, *n* (%) | 45 (42.5), 19 (42.2) |
| Side effects, severe side effects | 31 (68.9), 1 (2.2) |
| Radiotherapy, multiple episode, *n* (%) | 68 (64.2), 44 (64.7) |
| Side effects, severe side effects | 45 (66.2), 5 (7.4) |
| Co-morbidities, *n* (%) | 65 (61.3) |
| Hypertension | 30 (28.3) |
| Diabetes | 5 (4.7) |
| Depression | 12 (11.3) |
| Pain, mean (SD) [range] | 59 (55.7) |
| Pain score (0 = no pain; 10 = extreme pain) | 3.8 (2.5) [0–10] |
| Pain score > 5 | 16 (27.1) |
| Headaches | 25 (42.4) |
| Limb weakness (MRC motor scale) (0 = no contraction; 5 = normal power), mean (SD) | |
| Left upper limb/Right upper limb | 4.2 (1.0)/4.3 (0.8) |
| Left lower limb/Right lower limb | 4.2 (0.7)/4.4 (0.7) |
| Symptoms, *n* (%) | |
| Ataxia/incoordination | 47 (44.3) |
| Seizures | 45 (42.5) |
| Paresis | 39 (36.8) |
| Cognitive impairment | 38 (35.8) |
| Visual impairment | 37 (34.9) |
| Aphasia | 31 (29.2) |
| Dysarthria | 27 (25.5) |
| Sensory-perceptual deficit | 25 (23.6) |
| Bowel/bladder dysfunction | 21 (19.8) |
| Dysphagia | 11 (10.4) |
| QoL[b], mean (SD) [range] | 3.0 (1.1) [1–5] |
| QoL score > 3 | 13 (12.1) |

[a]Grade I: slow growing, discrete, often surgical cure eg. Astrocytic tumours, meningiomas; Grade II: slow growing but ability to invade adjacent normal tissue and higher grade of malignancy eg. Oligodendrogliomas; Grade III: tumours actively reproducing abnormal cells that can infiltrate adjacent cells eg. anaplastic oligodendroglioma; Grade IV: highly malignant and infiltrating into adjacent tissue eg. glioblastoma. [b]QoL: quality of life (0 = delighted; 6 = terrible). IQR: interquartile range; MRC: Medical Research Council; ROM: Range of Motion; SD: standard deviation; WHO: World Health Organization.

Table II. *Participant reported limitations and the frequency of limitation in the linked categories for the components 'Activities and Participation' and 'Environmental factors'* (n = *106)*

| ICF checklist code | ICF category description | Total number of participants linked responses as affected. *n* (%) |
|---|---|---|
| *Activities and Participation* | | |
| Learning and applying knowledge | | |
| d110 | Watching | 7 (6.6) |
| d175 | Solving problems | 1 (0.9) |
| General tasks and demands | | |
| d220 | Undertaking multiple tasks | 1 (0.9) |
| d230 | Carrying out daily routine | **21 (19.8)** |
| d240 | Handling stress/other psychological demand | **63 (59.4)** |
| Communication | | |
| d310 | Communicating with – receiving – spoken messages | 8 (7.5) |
| d330 | Speaking | 6 (5.7) |
| Mobility | | |
| d430 | Lifting and carrying objects | 3 (2.8) |
| d440 | Fine hand use (picking up, grasping) | 6 (5.7) |
| d450 | Walking | **12 (11.3)** |
| d470 | Using transportation (car, bus, train, plane, etc) | 1 (0.9) |
| d475 | Driving (riding bicycle and motorbike, driving car, etc) | **25 (23.6)** |
| Self care | | |
| d510 | Washing oneself (bathing, drying, washing hands, etc) | 1 (0.9) |
| d550 | Eating | 3 (2.8) |
| d570 | Looking after one's health | 4 (3.8) |
| Domestic life | | |
| d620 | Acquisition of goods and services (shopping, etc) | 1 (0.9) |
| d640 | Doing housework | **24 (22.6)** |
| Interpersonal interaction and relationship | | |
| d710 | Basic interpersonal interaction | 1 (0.9) |
| d760 | Family relationships | 4 (3.8) |
| d770 | Intimate relationships | 2 (1.9) |
| Major life areas | | |
| d830 | Higher education | 1 (0.9) |
| d850 | Remunerative employment | **19 (17.9)** |
| d870 | Economic self-sufficiency | 3 (2.8) |
| Community social and civic life | | |
| d910 | Community life | 3 (2.8) |
| d920 | Recreation and leisure | 2 (1.9) |
| *Environmental factors* | | |
| Support and relationships | | |
| e310 | Immediate family | 2 (1.9) |
| e320 | Friends | 1 (0.9) |
| e355 | Health professionals | 7 (6.6) |
| Attitudes | | |
| e410 | Individual attitudes of immediate family members | 1 (0.9) |
| Services system and policies | | |
| e540 | Transportation services, systems and policies | 1 (0.9) |
| e575 | General social support services, systems and policies | 1 (0.9) |
| e580 | Health services, systems and policies | 2 (1.9) |

All positive responses values over 10% frequencies are bolded.
ICF: International Classification of Functioning, Disability and Health.

categories of the ICF-checklist were identified: 25 categories in 'activities and participation' and 7 in 'environmental factors' components. The most frequent problems reported were linked with 'd240'– *Handling stress and psychological demands* (60%), 'd240' *driving* (24%) and 'd640' *doing housework* (23%). Few participants reported concepts related to 'environmental factors' component and none reported additional aspects of health areas not covered by the ICF checklist.

*Impact of brain tumour on the health areas corresponding with ICF categories for 'activities and participation'*

Table III presents the participants' report of impact (using qualifiers 0–4) and frequency for each ICF category for 'activities and participation'. The number of problems reported by the participants for 'activities and participation' categories in the ICF-checklist ranged from 0 to 4 (median = 16.5, IQR = 7–25). All 50 categories of 9 chapters of 'activities and participation' had at least one limitation, of these all except 6 categories were identified as relevant (≥ 10% of participant's response). The 5 most negative impact reported for corresponding ICF categories of 'activities and participation' included: 'd475'– *driving* (76%); 'd910'– *recreation and leisure* (65%), 'd220' – *undertaking multiple tasks* (59%); 'd240' – *handling stress and other physical demands* (59%), and 'd430' – *lifting and carrying objects* (57%). Thirteen (26%) ICF categories of the checklist were reported by 50% or more of the participants. Category 'd475'– *driving* was highly impaired in 50% of the participants, followed by 'd920' – *remunerative employment* (26.4%).

*Impact of brain tumour on the health areas corresponding with ICF categories for 'environmental factors'*

The frequency and participant response grading for barriers (qualifier 0–4) for each category for 'environmental factors' component is presented in Table IV. The number of problems reported by participants ranged from 0 to 32 (median = 2, IQR = 0–5). All 32 categories of 5 chapters in this component had at least one limitation and 16 categories were identified as relevant barriers (≥ 10% of participant response). The 5 most frequent barriers reported for corresponding ICF categories include: 'e250' – *human made change to natural environment: sound* (28%); 'e320' – *support and relationship: with friends* (27%), 'e420' – *individual attitudes: of friends* (26%), 'e225' – *human made change to natural environment: climate* (23%); and 'e410' – *individual attitudes of immediate family* (20%).

*Impact of brain tumour on the health areas corresponding with ICF chapters (1st level classification)*

Fig. 2 shows the total number of participants indicating 'activity and participation' restriction, as well as barriers in 'environmental factors, corresponding with ICF chapters (1st level classification). The most common chapters, in which participants reported problems (sum of qualifiers 1–4) in both domains were: 'd4' – *mobility* (53.8%); 'd6' – *domestic life* (53.3%); 'd2' – *general tasks and demands* (50.9%); and 'e2' – *natural environment and human made changes to environment* (21.7%).

Table III. *Participant rating of impact of primary brain tumour on health areas and frequency of limitation for corresponding ICF categories for 'Activities and Participation'* (n = *106)*

| ICF checklist code | ICF category description | Total number of participants linked responses as affected *n* (%) | Not affected 0 *n* (%) | Mild 1 *n* (%) | Moderate 2 *n* (%) | Severe 3 *n* (%) | Complete 4 *n* (%) |
|---|---|---|---|---|---|---|---|
| Learning and applying knowledge | | | | | | | |
| d110 | Watching | **44 (41.5)** | 62 (58.5) | 28 (26.4) | 8 (7.5) | 7 (6.6) | 1 (0.9) |
| d115 | Listening | **44 (41.5)** | 62 (58.5) | 33 (31.1) | 9 (8.5) | 2 (1.9) | 0 (0) |
| d140 | Learning to read | **17 (16.0)** | 89 (84.0) | 9 (8.5) | 4 (3.8) | 2 (1.9) | 2 (1.9) |
| d145 | Learning to write | **19 (187.9)** | 87 (82.1) | 10 (9.4) | 4 (3.8) | 1 (0.9) | 4 (3.8) |
| d150 | Learning to calculate | **21 (19.8)** | 85 (80.2) | 17 (16.0) | 2 (1.9) | 1 (0.9) | 1 (0.9) |
| d175 | Solving problems | **43 (40.6)** | 63 (59.4) | 28 (26.4) | 10 (9.4) | 5 (4.7) | 0 (0) |
| General tasks and demands | | | | | | | |
| d210 | Undertaking a single task | **36 (34.0)** | 70 (66.0) | 26 (24.5) | 8 (7.5) | 2 (1.9) | 0 (0) |
| d220 | Undertaking multiple tasks | ***63 (59.4)*** | 43 (40.6) | 17 (16.0) | 16 (15.1) | 21 (19.8) | 9 (8.5) |
| d230 | Carrying out daily routine | **55 (51.9)** | 51 (48.1) | 1 7 (16.0) | 16 (15.1) | 21 (19.8) | 9 (8.5) |
| d240 | Handling stress/other psychological demand | ***62 (58.5)*** | 44 (41.5) | 28 (26.4) | 24 (22.6) | 4 (3.8) | 6 (5.7) |
| Communication | | | | | | | |
| d310 | Communicating with – receiving spoken messages | **21 (19.8)** | 85 (80.2) | 13 (12.3) | 5 (4.7) | 3 (2.8) | 0 (0) |
| d315 | Communicating with – receiving non-verbal messages | **20 (18.9)** | 86 (81.1) | 12 (11.3) | 5 (4.7) | 3 (2.8) | 0 (0) |
| d330 | Speaking | **34 (32.1)** | 72 (67.9) | 23 (21.7) | 7 (6.6) | 3 (2.8) | 1 (0.9) |
| d335 | Producing non-verbal messages | **24 (22.6)** | 82 (77.4) | 13 (12.3) | 5 (4.7) | 4 (3.8) | 2 (1.9) |
| d350 | Conversation | **32 (30.2)** | 74 (69.8) | 20 (18.9) | 7 (6.6) | 4 (3.8) | 1 (0.9) |
| Mobility | | | | | | | |
| d430 | Lifting and carrying objects | ***61 (57.5)*** | 45 (42.5) | 27 (25.5) | 17 (16.0) | 11 (10.4) | 6 (5.7) |
| d440 | Fine hand use (picking up, grasping) | **48 (45.3)** | 58 (54.73) | 20 (18.9) | 12 (11.3) | 12 (11.3) | 4 (3.8) |
| d450 | Walking | **56 (52.8)** | 50 (47.2) | 24 (22.6) | 15 (14.2) | 13 (12.3) | 4 (3.8) |
| d465 | Moving around and using equipment (wheelchair, skates, etc) | **44 (41.5)** | 62 (58.5) | 19 (17.9) | 11 (10.4) | 8 (7.5) | 6 (5.7) |
| d470 | Using transportation (car, bus, train, plane, etc) | **53 (50.0)** | 53 (50.0) | 16 (15.1) | 10 (9.4) | 11 (10.4) | 16 (15.1) |
| d475 | Driving (riding bicycle and motorbike, driving car, etc) | ***80 (75.5)*** | 26 (24.5) | 14 (13.2) | 10 (9.4) | 3 (2.8) | 53 (50.0) |
| Self care | | | | | | | |
| d510 | Washing oneself (bathing, drying, washing hands, etc) | **43 (40.6)** | 63 (59.4) | 20 (18.9) | 9 (8.5) | 10 (9.4) | 4 (3.8) |
| d520 | Caring for body parts (brushing teeth, shaving, grooming, etc) | **38 (35.8)** | 68 (64.2) | 18 (17.0) | 8 (7.5) | 7 (6.6) | 5 (4.7) |
| d530 | Toileting | **37 (34.9)** | 69 (65.1) | 19 (7.9) | 7 (6.6) | 6 (5.7) | 5 (4.7) |
| d540 | Dressing | **41 (38.70)** | 65 (61.3) | 20 (18.9) | 7 (6.6) | 9 (8.5) | 5 (4.7) |
| d550 | Eating | **34 (32.1)** | 72 (67.9) | 21 (19.8) | 8 (7.5) | 3 (2.8) | 2 (1.9) |
| d560 | Drinking | **31 (29.2)** | 75 (70.8) | 21 (19.8) | 5 (4.7) | 3 (2.8) | 2 (1.9) |
| d570 | Looking after one's health | **40 (37.7)** | 66 (62.3) | 22 (20.8) | 8 (7.5) | 5 (4.7) | 5 (4.7) |
| Domestic life | | | | | | | |
| d620 | Acquisition of goods and services (shopping, etc) | **56 (52.8)** | 50 (47.2) | 14 (13.2) | 15 (14.2) | 13 (12.3) | 14 (13.2) |
| d630 | Preparation of meals (cooking, etc) | **54 (50.9)** | 52 (49.1) | 12 (11.3) | 14 (13.2) | 16 (15.1) | 12 (11.3) |
| d640 | Doing housework (cleaning washing, laundry, ironing) | ***59 (55.7)*** | 47 (44.3) | 12 (11.3) | 14 (13.2) | 20 (18.9) | 13 (12.3) |
| d660 | Assisting others | **57 (53.8)** | 49 (46.2) | 19 (17.9) | 2 (1.9) | 16 (15.1) | 20 (18.9) |
| Interpersonal interaction and relationship | | | | | | | |
| d710 | Basic interpersonal interaction | **15 (14.2)** | 91 (85.8) | 10 (9.4) | 1 (0.9) | 3 (2.8) | 1 (0.9) |
| d720 | Complex interpersonal interaction | **30 (28.3)** | 76 (71.7) | 20 (18.9) | 6 (5.7) | 2 (1.9) | 2 (1.9) |
| d730 | Relating with strangers | **19 (17.9)** | 87 (82.1) | 11 (10.4) | 5 (4.7) | 3 (2.8) | 0 (0) |
| d740 | Formal relationship | **15 (14.2)** | 91 (85.8) | 9 (8.5) | 3 (2.8) | 3 (2.8) | 0 (0) |
| d750 | Informal social relationships | **29 (27.4)** | 77 (72.6) | 20 (18.9) | 5 (4.7) | 3 (2.8) | 1 (0.9) |
| d760 | Family relationships | **27 (25.5)** | 79 (745.5) | 17 (16.0) | 8 (7.5) | 0 (0) | 2 (1.9) |
| d770 | Intimate relationships | **34 (32.1)** | 72 (67.9) | 20 (18.9) | 7 (6.6) | 1 (0.9) | 6 (5.7) |
| Major life areas | | | | | | | |
| d810 | Informal education | 7 (6.6) | 99 (93.4) | 5 (4.7) | 1 (0.9) | 0 (0) | 1 (0.9) |

Table III. *Contd.*

| ICF checklist code | ICF category description | Total number of participants linked responses as affected *n* (%) | Not affected 0 *n* (%) | Mild 1 *n* (%) | Moderate 2 *n* (%) | Severe 3 *n* (%) | Complete 4 *n* (%) |
|---|---|---|---|---|---|---|---|
| d820 | School education | 1 (0.9) | 105 (99.1) | 1 (0.9) | 0 (0) | 0 (0) | 0 (0) |
| d830 | Higher education | 10 (9.5) | 96 (90.4) | 2 (1.9) | 3 (2.8) | 0 (0) | 5 (4.7) |
| d850 | Remunerative employment | **55 (51.9)** | 51 (48.1) | 12 (11.3) | 8 (7.5) | 7 (6.6) | 28 (26.4) |
| d860 | Basic economic transactions | **33 (31.1)** | 73 (68.9) | 14 (13.2) | 12 (11.3) | 1 (0.9) | 6 (5.7) |
| d870 | Economic self-sufficiency | **45 (42.5)** | 61 (57.5) | 17 (16.0) | 14 (13.2) | 7 (6.6) | 7 (6.6) |
| Community social and civic life | | | | | | | |
| d910 | Community life | **47 (44.3)** | 59 (55.7) | 16 (15.1) | 11 (10.4) | 14 (13.2) | 6 (5.7) |
| d920 | Recreation and leisure | ***69 (65.1)*** | 37 (34.9) | 20 (19.8) | 19 (17.9) | 20 (18.9) | 9 (8.5) |
| d930 | Religion and spirituality | 5 (4.7) | 101 (95.3) | 4 (3.8) | 1 (0.9) | 0 (0) | 0 (0) |
| d940 | Human rights | 3 (2.8) | 103 (97.2) | 2 (1.9) | 1 (0.9) | 0 (0) | 0 (0) |
| d950 | Political life and citizenship | 2 (1.9) | 104 (98.1) | 2 (1.9) | 0 (0) | 0 (0) | 0 (0) |

0 = no problem (0–4% of the time); 1 = mild (5–24% of the time); 2 = moderate (25–49% of the time); 3 = severe (50–95% of the time); 4 = complete (> 95% of the time).
All positive responses values over 10% frequencies are bolded. The 5 categories with highest positive response frequency are printed bold and italicized.
ICF: International Classification of Functioning, Disability and Health.

*Comparisons with the categories of the existing ICF core sets for stroke and TBI*

Table V presents the comparison of the ICF categories included in the comprehensive ICF core sets for stroke and TBI with the reported frequency of the problem by the study population according to ICF checklist. Total number of relevant ICF categories in 'activities and participation' component identified in brain tumour survivors (44 categories) was less than those in existing ICF core sets for stroke (51 categories) and TBI (61 categories). The categories identified in 'environmental factors" as relevant by the brain tumour survivors (16 categories) was less than half compared to existing categories in stroke (33 categories) and TBI (39 categories) core sets. There was more commonality between categories identified in brain tumour survivors as relevant (≥ 10% of participant response) with TBI core set than with stroke. In total 56 categories were common between brain tumour and TBI core set, compared to 51 categories between brain tumour and stroke core set. Five additional categories (3 in 'activity and participation'; 'd140' – *learning to read*, 'd145' – *learning to write*, 'd150' – *learning to calculate* and 2 in 'environmental factors': 'e225' – *climate*, 'e240' – *light*) were identified by brain tumour survivors that were not included in either of the TBI or stroke core sets.

## DISCUSSION

To our knowledge, this is the first study to link problems reported by brain tumour survivors with ICF categories in the components of 'activities and participation' and 'environmental factors' in an Australian cohort. Three different approaches in this study provide a comprehensive assessment of the ICF checklist for brain tumour survivors in a community setting. An open questionnaire approach used 'linkage rules' to link problems due to brain cancer reported by the participant; an ICF-based approach where each participant rated an ICF-checklist for categories of the components 'activity and participation' and 'environmental factors' using the WHO qualifier scale; and a comparative approach of participant report with the existing ICF core sets for stroke and TBI.

The participant report of a large number of categories of the ICF checklist reflects the clinical complexity of brain tumours, consistent with other studies (3, 21–23). The demographic and clinical characteristics of the study participants are similar to other reports (21–24). The findings from this study suggest that existing ICF checklists and the comprehensive stroke (10) and TBI (11, 12) ICF core sets incorporate most issues important to primary brain tumour survivors in post-acute settings. This comparison of relevant categories highlights a similar prob-

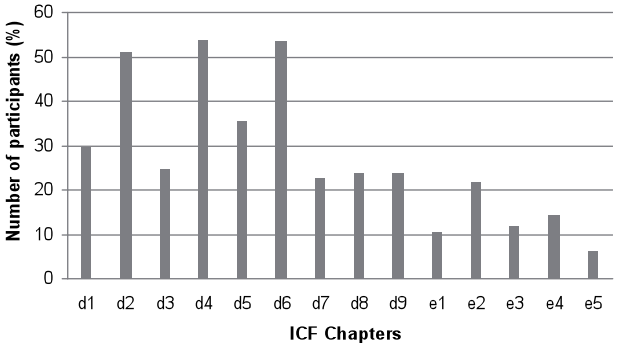


*Fig. 2.* Number of patient (%) in the ICF chapters (1st level classification) (*n* = 106) for the components 'Activity and Participation' (d) and 'Environmental factors' (e). Note: Qualifiers are dichotomized to 0 = response 0; and 1 = response 1–4. ICF chapters: 'Activities and Participation': d1 = learning and applying knowledge; d2 = general tasks and demands; d3 = communication; d4 = mobility; d5 = self care; d6 = domestic life; d7 = interpersonal interaction and relationship; d8 = major life areas; d9 = community social and civic life. "Environmental factors': e1 = products and technology; e2 = natural environment and human made changes to environment; e3 = support and relationships; e4 = attitudes; e5 = services system and policies.

Table IV. *Participant rating of impact of brain tumour on health areas and frequency of limitation for corresponding ICF categories (barriers) for 'Environmental factors' (*n = *106)*

| ICF checklist code | ICF code description | Total participants linked responses as affected *n* (%) | Not affected 0 | Mild 1 | Moderate 2 | Severe 3 | Complete 4 |
|---|---|---|---|---|---|---|---|
| Products and technology | | | | | | | |
| e110 | For personal consumption (food, medicines) | **13 (12.3)** | 93 (87.7) | 5 (4.7) | 7 (6.6) | 0 (0) | 1 (0.9) |
| e115 | For personal use in daily livings | **15 (14.2)** | 91 (85.8) | 6 (5.7) | 8 (7.5) | 0 (0) | 1 (0.9) |
| e120 | For personal indoor and outdoor mobility and transportation | **14 (13.2)** | 92 (86.8) | 5 (4.7) | 5 (4.7) | 3 (2.8) | 1 (0.9) |
| e125 | Products for communication | **11 (10.4)** | 95 (89.6) | 5 (4.7) | 6 (5.7) | 0 (0) | 0 (0) |
| e150 | Design, construction and building products and technology of buildings for public use | 5 (4.7) | 101 (95.3) | 1 (0.9) | 3 (2.8) | 1 (0.9) | 0 (0) |
| e155 | Design, construction and building products and technology of buildings for private use | 8 (7.5) | 98 (92.5) | 3 (2.8) | 3 (2.8) | 1 (0.9) | 1 (0.9) |
| Natural environment and human made changes to environment | | | | | | | |
| e225 | Climate | ***24 (22.6)*** | 82 (77.4) | 15 (14.2) | 8 (7.5) | 1 (0.9) | 0 (0) |
| e240 | Light | **16 (15.1)** | 90 (84.9) | 10 (9.4) | 4 (3.8) | 1 (0.9) | 1 (0.9) |
| e250 | Sound | ***29 (27.4)*** | 77 (72.6) | 13 (12.3) | 11 (10.4) | 4 (3.8) | 1 (0.9) |
| Support and relationships | | | | | | | |
| e310 | Immediate family | **13 (12.3)** | 93 (87.7) | 7 (6.6) | 4 (3.8) | 1 (0.9) | 1 (0.9) |
| e320 | Friends | ***25 (23.6)*** | 81 (76.4) | 17 (16.0) | 5 (4.7) | 2 (1.9) | 1 (0.9) |
| e325 | Acquaintances peers colleagues neighbours and community members | **20 (18.9)** | 86 (81.1) | 14 (13.2) | 5 (4.7) | 1 (0.9) | 0 (0) |
| e330 | People in position of authority | 7 (6.6) | 99 (93.4) | 4 (3.8) | 1 (0.9) | 1 (0.9) | 1 (0.9) |
| e340 | Personal care providers and personal assistance | 3 (2.8) | 103 (97.2) | 2 (1.9) | 1 (0.9) | 0 (0) | 0 (0) |
| e355 | Health professionals | **13 (12.3)** | 93 (87.7) | 8 (7.5) | 4 (3.8) | 1 (0.9) | 0 (0) |
| e360 | Health related professionals | 8 (7.5) | 98 (92.5) | 7 (6.6) | 1 (0.9) | 0 (0) | 0 (0) |
| Attitudes | | | | | | | |
| e410 | Individual attitudes of immediate family members | ***21 (19.8)*** | 85 (80.2) | 15 (14.2) | 5 (4.7) | 0 (0) | 1 (0.9) |
| e420 | Individual attitudes of friends | ***27 (25.5)*** | 79 (74.5) | 21 (19.8) | 5 (4.7) | 0 (0) | 1 (0.9) |
| e440 | Individual attitudes of personal care providers and personal assistance | 5 (4.7) | 101 (95.3) | 3 (2.8) | 2 (1.9) | 0 (0) | 0 (0) |
| e450 | Individual attitudes of health professionals | **18 (17.0)** | 88 (83.0) | 13 (12.3) | 4 (3.8) | 1 (0.9) | 0 (0) |
| e455 | Individual attitudes of health related professionals | 7 (6.6) | 99 (93.4) | 5 (4.7) | 2 (1.9) | 0 (0) | 0 (0) |
| e460 | Societal attitudes | **20 (18.9)** | 86 (81.1) | 15 (14.2) | 4 (3.8) | 1 (0.9) | 0 (0) |
| e465 | Social norms, practices and ideologies | 8 (7.5) | 98 (92.5) | 5 (4.7) | 3 (2.8) | 0 (0) | 0 (0) |
| Services system and policies | | | | | | | |
| e525 | Housing services, systems and policies | 5 (4.7) | 101 (95.3) | 4 (3.8) | 1 (0.9) | 0 (0) | 0 (0) |
| e535 | Communication services, systems and policies | 3 (2.8) | 103 (97.2) | 2 (1.9) | 1 (0.9) | 0 (0) | 0 (0) |
| e540 | Transportation services, systems and policies | 7 (6.6) | 99 (93.4) | 3 (2.8) | 4 (3.8) | 0 (0) | 0 (0) |
| e550 | Legal services, systems and policies | 5 (4.7) | 101 (95.3) | 4 (3.8) | 1 (0.9) | 0 (0) | 0 (0) |
| e570 | Social security services, system and policies | 9 (8.5) | 97 (91.5) | 6 (5.7) | 3 (2.8) | 0 (0) | 0 (0) |
| e575 | General social support services, systems and policies | 4 (3.8) | 102 (96.2) | 3 (2.8) | 1 (0.9) | 0 (0) | 0 (0) |
| e580 | Health services, systems and policies | **12 (11.3)** | 94 (88.7) | 10 (9.4) | 2 (1.9) | 0 (0) | 0 (0) |
| e585 | Education and training services, systems and policies | 5 (4.7) | 101 (95.3) | 3 (2.8) | 2 (1.9) | 0 (0) | 0 (00 |
| e590 | Labour and employment services, systems and policies | 9 (8.5) | 97 (91.5) | 4 (3.8) | 3 (2.80 | 1 (0.9) | 1 (0.9) |

0 = no problem (0–4% of the time); 1 = mild (5–24% of the time); 2 = moderate (25–49% of the time); 3 = severe (50–95% of the time); 4 = complete (> 95% of the time).

All positive responses values over 10% frequencies are highlighted (bold). The 5 categories with highest positive response frequency are printed bold and italicized.

ICF: International Classification of Functioning, Disability and Health.

lem profile in brain tumours survivors compared with other neurological conditions affecting the CNS.

The extended ICF checklist incorporates most aspects of life in 'activities and participation' domain. Within the checklist majority of categories (88%) were relevant to brain tumour survivors, indicating the range of potential problems in: mobility, domestic life, inter-personal, family and intimate relations, and major life areas (economic self-sufficiency, remunerative employment). The issues identified (driving, recreation, and remunerative employment), reflect socio-demographic characteristics and age distribution of participants (working age, educated, living with family). The relevant categories for

Table V. *Comparison of ICF core sets for stroke and TBI, and participant report of the impact of brain tumour on health areas for corresponding ICF categories for 'Activities and Participation' and 'Environmental factors'*

| ICF TBI core set code | ICF stroke core set code | ICF checklist code | ICF category description | Total number of participants linked responses as affected *n* (%) |
|---|---|---|---|---|
| *Activities and Participation* | | | | |
| Learning and applying knowledge | | | | |
| d110 | | d110 | Watching[d] | **44 (41.5)** |
| d115 | d115 | d115 | Listening[a] | **44 (41.5)** |
| | | d140 | Learning to read[c] | **17 (16.0)** |
| | | d145 | Learning to write[c] | **19 (187.9)** |
| | | d150 | Learning to calculate[c] | **21 (19.8)** |
| | d155 | | Acquiring skills | |
| d160 | d160 | | Focusing attention | |
| d163 | | | Thinking | |
| d166 | d166 | | Reading | |
| d170 | d170 | | Writing | |
| | d172 | | Calculating | |
| d175 | d175 | d175 | Solving Problems[a] | **43 (40.6)** |
| d177 | | | Making decision | |
| General tasks and demands | | | | |
| d210 | d210 | d210 | Undertaking a single task[a] | **36 (34.0)** |
| d220 | d220 | d220 | Undertaking multiple tasks[a] | **63 (59.4)** |
| d230 | d230 | d230 | Carrying out daily routine[a] | **55 (51.9)** |
| d240 | d240 | d240 | Handling stress/other psychological demand[a] | **62 (58.5)** |
| Communication | | | | |
| d310 | d310 | d310 | Communicating with – receiving spoken messages[a] | **21 (19.8)** |
| d315 | d315 | d315 | Communicating with – receiving non-verbal messages[a] | **20 (18.9)** |
| | d325 | | Communicating with – receiving non-written messages | |
| d330 | d330 | d330 | Speaking[a] | **34 (32.1)** |
| d335 | d335 | d335 | Producing non-verbal messages[a] | **24 (22.6)** |
| d345 | d345 | | Writing messages | |
| d350 | d350 | d350 | Conversation[a] | **32 (30.2)** |
| d360 | d360 | | Using communication devices and techniques | |
| Mobility | | | | |
| d410 | d410 | | Changing and maintaining body position | |
| d415 | d415 | | Maintain body position | |
| d420 | d420 | | Transferring oneself | |
| d430 | d430 | d430 | Lifting and carrying objects[a] | **61 (57.5)** |
| d440 | d440 | d440 | Fine hand use[a] | **48 (45.3)** |
| d445 | d445 | d445 | Hand and arm use[a] | **48 (45.3)** |
| d450 | d450 | d450 | Walking[a] | **56 (52.8)** |
| d455 | d455 | | Moving around | |
| | d460 | | Moving around in different location | |
| d465 | d465 | d465 | Moving around and using equipment[a] | **44 (41.5)** |
| d470 | d470 | d470 | Using transportation[a] | **53 (50.0)** |
| d475 | d475 | d475 | Driving[a] | **80 (75.5)** |
| Self care | | | | |
| d510 | d510 | d510 | Washing oneself[a] | **43 (40.6)** |
| d520 | d520 | d520 | Caring for body parts[a] | **38 (35.8)** |
| d530 | d530 | d530 | Toileting[a] | **37 (34.9)** |
| d540 | d540 | d540 | Dressing[a] | **41 (38.70)** |
| d550 | d550 | d550 | Eating[a] | **34 (32.1)** |
| d560 | | d560 | Drinking[d] | **31 (29.2)** |
| d570 | d570 | d570 | Looking after one's health[a] | **40 (37.7)** |
| Domestic life | | | | |
| d620 | d620 | d620 | Acquisition of goods and services[a] | **56 (52.8)** |
| d630 | d630 | d630 | Preparation of meals[a] | **54 (50.9)** |
| d640 | d640 | d640 | Doing housework[a] | **59 (55.7)** |
| d660 | | d660 | Assisting others[d] | **57 (53.8)** |
| Interpersonal interaction and relationship | | | | |
| d710 | d710 | d710 | Basic interpersonal interaction[a] | **15 (14.2)** |
| d720 | | d720 | Complex interpersonal interaction[d] | **30 (28.3)** |
| d730 | | d730 | Relating with strangers[d] | **19 (17.9)** |
| d740 | | d740 | Formal relationship[d] | **15 (14.2)** |

Table V. *Contd.*

| ICF TBI core set code | ICF stroke core set code | ICF checklist code | ICF category description | Total number of participants linked responses as affected *n* (%) |
|---|---|---|---|---|
| d750 | d750 | d750 | Informal social relationships[a] | **29 (27.4)** |
| d760 | d760 | d760 | Family relationships[a] | **27 (25.5)** |
| d770 | d770 | d770 | Intimate relationships[a] | **34 (32.1)** |
| Major life areas | | | | |
| | | d810 | Informal education | 7 (6.6) |
| | | d820 | School education | 1 (0.9) |
| d825 | | | Vocational training | |
| d830 | | d830 | Higher education | 10 (9.5) |
| d840 | | | Apprenticeship | |
| d845 | d845 | | Acquiring, keeping and terminating a job | |
| d850 | d850 | d850 | Remunerative employment[a] | **55 (51.9)** |
| d855 | d855 | | Non-remunerative employment | |
| d860 | d860 | d860 | Basic economic transactions[a] | **33 (31.1)** |
| d865 | | | Complex economic transactions | |
| d870 | d870 | d870 | Economic self-sufficiency[a] | **45 (42.5)** |
| Community social and civic life | | | | |
| d910 | d910 | d910 | Community life[a] | **47 (44.3)** |
| d920 | d920 | d920 | Recreation and leisure[a] | **69 (65.1)** |
| d930 | | d930 | Religion and spirituality | 5 (4.7) |
| | | d940 | Human rights | 3 (2.8) |
| | | d950 | Political life and citizenship | 2 (1.9) |
| *Environmental factors* | | | | |
| Products and technology | | | | |
| | e110 | e110 | For personal consumption (food, medicines)[b] | **13 (12.3)** |
| e1100 | | | Food | |
| e1101 | | | Drugs | |
| e1108 | | | Non-medical drugs and alcohol | |
| e115 | e115 | e115 | For personal use in daily livings[a] | **15 (14.2)** |
| e120 | e120 | e120 | For personal indoor and outdoor mobility and transportation[a] | **14 (13.2)** |
| e125 | e125 | e125 | Products for communication[a] | **11 (10.4)** |
| e135 | e135 | | For employment | |
| e150 | e150 | e150 | Design, construction and building products and technology of buildings for public use | 5 (4.7) |
| e155 | e155 | e155 | Design, construction and building products and technology of buildings for private use | 8 (7.5) |
| e160 | | | Products and technology of land development | |
| e165 | e165 | | Assets | |
| Natural environment and human made changes to environment | | | | |
| e210 | e210 | | Physical geography | |
| | | e225 | Climate[c] | **24 (22.6)** |
| | | e240 | Light[c] | **16 (15.1)** |
| e250 | | e250 | Sound[d] | **29 (27.4)** |
| Support and relationships | | | | |
| e310 | e310 | e310 | Immediate family[a] | **13 (12.3)** |
| e315 | e315 | | Extended family | |
| e320 | e320 | e320 | Friends[a] | **25 (23.6)** |
| e325 | e325 | e325 | Acquaintances peers colleagues neighbours and community members[a] | **20 (18.9)** |
| e330 | | e330 | People in position of authority | 7 (6.6) |
| e340 | e340 | e340 | Personal care providers and personal assistance | 3 (2.8) |
| e355 | e355 | e355 | Health professionals[a] | **13 (12.3)** |
| e360 | e360 | e360 | Health related professionals | 8 (7.5) |
| Attitudes | | | | |
| e410 | e410 | e410 | Individual attitudes of immediate family members[a] | **21 (19.8)** |
| e415 | | | Individual attitudes of extended family members | |
| e420 | e420 | e420 | Individual attitudes of friends[a] | **27 (25.5)** |
| e425 | e425 | | Individual attitudes of acquaintances, peers, colleagues, neighbours and community members | |
| e440 | e440 | e440 | Individual attitudes of personal care providers and personal assistance | 5 (4.7) |

Table V. *Contd.*

| ICF TBI core set code | ICF stroke core set code | ICF checklist code | ICF category description | Total number of participants linked responses as affected *n* (%) |
|---|---|---|---|---|
| e450 | e450 | e450 | Individual attitudes of health professionals[a] | **18 (17.0)** |
| e455 | e455 | e455 | Individual attitudes of health related professionals | 7 (6.6) |
| e460 | e460 | e460 | Societal attitudes[a] | **20 (18.9)** |
| | | e465 | Social norms, practices and ideologies | 8 (7.5) |
| Services system and policies | | | | |
| e515 | e515 | | Architecture and construction services, system and policies | |
| e525 | e525 | e525 | Housing services, systems and policies | 5 (4.7) |
| e535 | e535 | e535 | Communication services, systems and policies | 3 (2.8) |
| e540 | e540 | e540 | Transportation services, systems and policies | 7 (6.6) |
| e550 | e550 | e550 | Legal services, systems and policies | 5 (4.7) |
| | e555 | | Associations and organizational services, systems and policies | |
| e570 | e570 | e570 | Social security services, system and policies | 9 (8.5) |
| e575 | e575 | e575 | General social support services, systems and policies | 4 (3.8) |
| e580 | e580 | e580 | Health services, systems and policies[a] | **12 (11.3)** |
| e585 | | e585 | Education and training services, systems and policies | 5 (4.7) |
| e590 | e590 | e590 | Labour and employment services, systems and policies | 9 (8.5) |

[a]Corresponding with ICF core set for both stroke and TBI.
[b]Corresponding with ICF core set for stroke.
[c]Not corresponding with ICF core set for both stroke and TBI.
[d]Corresponding with ICF core set for TBI.
All positive responses values (reported by study participants) over 10% frequencies are bolded.

mobility (especially for longer distances), public transport, interpersonal relationships, home and community activities are similar to reports in other cancer populations (25, 26). The barriers for 'environmental factors' include categories for: support, relationship and attitudes, similar to reports in other neurological populations (27–29). In addition, brain tumour survivors reported sensitivity to light and sound (climate), similar to those with TBI, migraine, myasthenia gravis and Parkinson's disease (27, 28). The results from this study provide insight into the functioning and health (over a longer-time period), and related contextual factors in this population.

As anticipated, study participants reported difficulty with psychological issues such as *'handling stress and other psychological demand'*, consistent with other studies reporting higher levels of emotional distress, cognitive impairment and alteration in functional status compared with the general population (1, 30, 31). Approximately, 50–80% of patients may show some form of cognitive dysfunction at the time of diagnosis (31), which result in short-term memory loss, reduced concentration, personality changes and mood alteration (32). Further, treatment and/or disease progression itself can also cause a range of neuropsychological sequelae (such as anxiety, depression, stress) (33). More information on adaptation over time and longer term monitoring for neuropsychological sequelae in this population are needed.

Various studies have compared patient reported issues between different neurological conditions using ICF framework (such as Guillain-Barre Syndrome (GBS) and MS (34); Motor Neuron Disease (MND), GBS and MS (35); migraine, myasthenia gravis and Parkinson's disease (28); "post-acute neurological conditions" (29). However, a recent report compared findings from focus groups of mild TBI with the existing Core Sets for TBI, and found that some frequent patient reported problems were not included within the Brief TBI Core Set (36). These reports suggest commonality and relevance of many ICF categories in the domains 'activity and participation' and 'environmental factors' for a number of longer-term neurological conditions; and provide information on domains which need to be explored further (e.g. mobility in migraine, genitourinary or sexuality issues in GBS and psychological issues in MND) (29, 34, 35). These findings potentially facilitate further development of a 'general' core set for a number of longer-term neurological conditions affecting the CNS, which may allow clinicians to provide targeted intervention and facilitate communication, assessment and management.

Currently commonly used outcome measures in cancer rehabilitation (including brain tumour) do not capture the all relevant complex clinical constructs (37). Generic measures in rehabilitation for brain tumour (and other cancer) populations (e.g. the Functional Independence Measure or Barthel Index) have ceiling effects and do not show change following intervention (37, 38). Similarly, quality of life measures (e.g. Cancer Rehabilitation Evaluation System, Short Form 36), are difficult to measure as many factors impact quality of life; and restriction in activities alone explains only a minor part in the variance (39). A core set for primary brain tumours will guide treating multidisciplinary teams and facilitate clinical care and agreement, and in the future develop an outcome measure through ICF item banking and scale development techniques (40).

This study has some potential limitations. This is a cross sectional survey and does not provide longitudinal information. The sample size is a selective cohort from one tertiary institution of Australian participants. The participants have strict inclusion criteria and are listed on a database held at the RMH and who agreed to participate in research projects. However, the cohort covers a wide geographical population in Victoria, and is representative of the wider sample of brain tumour survivors living in the community. In an attempt to reduce recall bias, all questions were limited in the main to the current situation. Medical records were used only to confirm participant report and no additional information was obtained. The ICF components 'body structures and functions' of the core set were not included as they comprised most relevant categories for brain tumour survivors. This study focused on the patient perspective and impact of brain tumour on 'activities and participation' and 'environmental factors'. Interviews were challenging given the fragile emotional and physical status of most participants. Only patient-reported problems were linked to the ICF categories, which is subject to interviewers' interpretation, however ICF categories linked were consistent with medical information available for participants. This consistency can therefore be interpreted as cross validation of the results. The generalizability and validity of these findings will need to be established in future studies. Participants rated categories contained in the ICF checklist and not those contained within the core sets for stroke and TBI.

Brain tumour rehabilitation is challenging due to high mortality rates, complex physical, psychological and cognitive disabilities and participatory limitations that require an integrated interdisciplinary approach (4). These preliminary findings are a first step towards developing an ICF core set for brain tumours from an Australian perspective, which in the future may assist in facilitating clinical care and agreement, and in development of outcome measurement through ICF item banking and scale development techniques (40). Further, the possibility of a single core set comprising categories relevant to most patients with longer-term neurological conditions that affect the CNS should be explored.

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