

ORIGINAL REPORT

RELEVANCE AND COMPLETENESS OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF) COMPREHENSIVE BREAST CANCER CORE SET: THE PATIENT PERSPECTIVE IN AN AUSTRALIAN COMMUNITY COHORT

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Objective: To examine the relevance and completeness of the International Classification of Functioning, Disability and Health (ICF) comprehensive core set for breast cancer using patient reported disability in an Australian cohort.

Method: Cross-sectional community survey of 85 women following definitive treatment for primary breast cancer. Everyday living problems reported by participants (using open ended questionnaires) were linked with ICF categories using 'linkage' rules. Participants rated 'Activities and Participation' and 'Environmental factors' components of ICF checklist using World Health Organisation qualifiers (0–4). The impact of breast cancer on health areas corresponding to 90 ICF categories in these two components was assessed; and compared with ICF categories within the comprehensive breast cancer core set.

Results: Participants identified 16 of 22 categories from 'Activities and Participation' and 11 of 23 categories (barriers) from 'Environmental factors' included in the comprehensive Core Set for BC, as relevant ($\geq 10\%$ of the participants). Median number of problems reported was 4 (IQR 1–9) and 1 (IQR 1–4) for 'Activities and Participation' and 'Environmental factors' categories, respectively. Thirteen additional relevant categories relating to mobility, major life areas, community civic life and societal attitudes currently not included in the breast cancer core set, were identified.

Conclusion: The comprehensive breast cancer core set needs to incorporate issues important to survivors with breast cancer in post-acute settings, prior to its validation from a global perspective.

Key words: ICF; disability; breast cancer; outcome assessment.

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INTRODUCTION

Breast cancer (BC) is the most common malignancy in women comprising 16% of all cancers in women (1). Although patient mortality is reduced due to improved education, screening, surgery and drug treatments, these women have ongoing limitations in activity and participation due to many issues. Recovery from BC treatments can be prolonged. Patients discharged to the community continue to improve over many months. In the transition period various adjustment issues may surface, e.g., the patients' perceptions of self-worth and reversed role within the family (2–4). Families may struggle to cope with new demands associated with increased care needs, inability to return to driving and work, financial constraints, marital stress and general restriction in patients' participation (3).

The International Classification of Functioning, Disability and Health (ICF), defines a common language for describing the impact of disease at different levels (5). Within this framework BC related impairments (lymphoedema, pain), can limit 'activity' or function (decreased mobility, inability to self-care) and 'participation' (work, family, social reintegration). For example: lymphoedema (incidence 10–30%) or post mastectomy pain (incidence 4–27%) may lead to difficulty lifting, carrying, reaching due to axillary scarring and oedema, neck shoulder pain, and a reduced quality of life (QoL) (6). These disabilities can have a cumulative effect over time and cause considerable distress to the cancer survivor, their families, and reduce QoL (4). There are significant costs and socioeconomic implications with increased demand for health care, social and vocational services, and caregiver burden.

Significant progress in the clinical use of ICF has occurred. This includes: ICF checklists (7) to identify patient problems in health conditions (8), implementation of ICF Core Set that include categories from multistage consensus process that identify most relevant aspects of functioning in specific conditions to guide multidisciplinary (MD) assessments; and recent

guidelines for validation of ICF Core Set (9). The first version of the comprehensive Core Set for BC (10) included: 26 categories in ‘Body functions’, 9 in ‘Body structures’, 22 in ‘Activities and Participation’, and 23 in ‘Environmental factors’. In the development of this core set (10) an ICF checklist was used for patients with BC in a defined geographical region (German language speaking) (11) comprising a confirmed malignant neoplasm, but no histopathological, or treatment or time since diagnosis/treatment or other prognostic information for the cohort was provided. This checklist was then used to develop consensus for the Core Set for BC. It can be argued that these factors are not usually considered in core set development, however it is important to note that the longer-term (post treatment) issues in survivors with BC may be different to those identified in acute and immediate post-acute settings. The Core Set for BC has not yet been validated, hence it is not certain if the selected domains are sufficiently comprehensive to cover the prototypical spectrum of limitations in functioning and health encountered in a survivors with BC globally. Identification of problems and barriers that impact functioning from the patient’s perspective is vital to guide clinical assessments. Further, the linkage of ICF categories with the experience of the survivors with BC, and feasibility and reliability of the ICF Core Set in an Australian setting provides an additional context.

The objective of this study was to examine the relevance and completeness of the comprehensive Core Set for BC using patient reported disability in an Australian cohort.

METHODS

Participants and setting

This study was part of a prospective rehabilitation research program for survivors with BC at the Royal Melbourne Hospital (RMH), a tertiary referral centre in Victoria, Australia, and approved by its Ethics Committee.

The source of patients with BC was a pool of persons residing in the community, referred to RMH from public and private medical clinics across greater Melbourne in Victoria. Patients with a confirmed diagnosis of BC (ICD Code ‘C50’, incorporating all 9 subcodes that localize breast tumour; C50.1–C50.9) were identified from the RMH Access Database by cross-indexing of diseases from the Patient Information Management using the Patient Administrator System of the Hospital Information Systems (Department of Health, Victoria). Approximately 298 patients discharged from the hospital between 2007–2010, were eligible for the study based on selection criteria: 18–65 years of age residing in the community (area of greater Melbourne < 60 km radius), able to reliably report the main problems of everyday living with BC; primary BC and fulfil criteria for BC staging system as outlined by the American Joint Committee on Cancer (AJCC) (12), and assessed by a surgeon/oncologist at RMH (Fig. 1).

Procedure

All eligible patients were contacted by mail and invited to participate in this project by an independent project officer, 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 was interviewed using a structured format open-ended questionnaire (13) and asked to nominate a list of the problems affecting their everyday life due to BC. There was no prompting or use of BC problem lists. All information provided was noted (by the second research assistant), checked and clarified with the patient medical record, and RMH database. Any discrepancies were resolved with discussion (with participant) and consensus agreement between reviewers. Authors (FK, BA) trained in ICF, used linking rules (14) to match each problem reported by the participant with an appropriate ICF categories (second level). After data extraction, both reviewers compared their results. Similar to previous reports (15) any disagreements concerning selected categories were resolved by a trained third health professional (LN/MD).

In the ICF-based approach, each participant then reviewed an ICF-checklist (7) comprising 90 ICF categories (all levels of classification) for the components ‘Activity and Participation’ and ‘Environmental factors.’ The 53 categories included in the domain ‘Activities and Participation’ included: 7 categories each for learning and applying knowledge, mobility and self-care, interpersonal interaction and re-

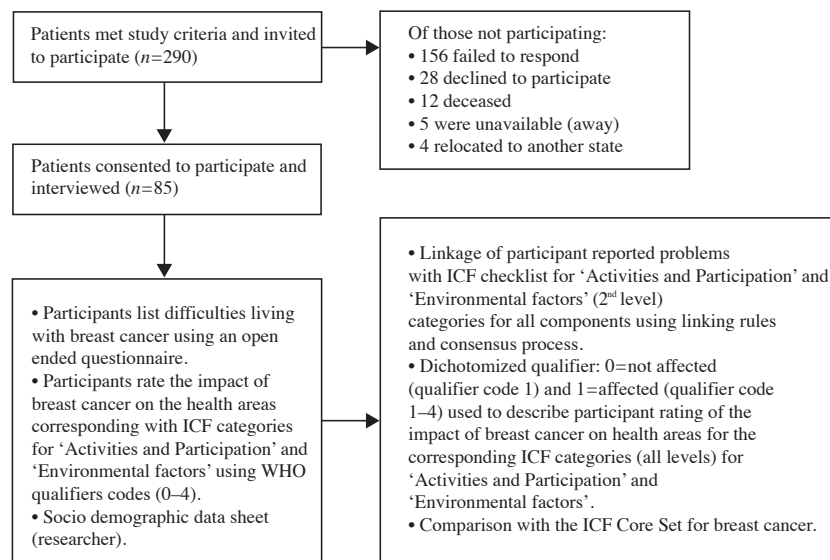


Fig. 1. Recruitment process. ICF: International Classification of Functioning, Disability and Health; WHO: World Health Organization.

relationships, 6 categories for major life areas and 5 categories each for communication, domestic life, community, social and civic life; and 4 categories for general tasks and demands. The 'environment factors' component included 37 categories: 10 for systems and policies, 9 for attitudes, 8 for support and relationships, 7 for products and technology and 3 for natural environment and human made changes. The participants were asked whether BC affected the health areas described in the corresponding ICF categories. They used the World Health Organization (WHO) qualifier scale to rate each category (responses from 0 to 4: 0=not affected 1=mild; 2=moderate; 3=severe, 4=complete) to rate 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 (16). Impact was defined as subjectively perceived costs inherent in under-taking activity, participation and health behaviours (16).

Finally, each of the titles of the ICF chapters from the ICF checklist categories (7) were compared with the categories that were included in the Comprehensive ICF Core Set for BC (10). Each category in the Core Set for BC was assessed for their relevance (i.e., $\geq 10\%$ of the participant response) (17, 18) and compared for correspondence with the ICF checklist reported by the study population. Further, categories reported as relevant by the study population using the ICF checklist were listed for inclusion in the comprehensive Core Set for BC.

Measures

A standard data form collated socio-demographic information and BC disease status. The ICF checklist (7) and comprehensive Core Set for BC (10) assessed 'Activity and Participation' and 'Environmental factors' 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 reveal no additional second level categories (13, 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 and 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 (17, 18). The frequencies of ICF categories reported by the participants were compared with frequency of endorsement of the ICF categories in the Core Set for BC.

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 BC 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 ($n=85$) are shown in Table I. All were women, mean age 55 years and mean time since BC 4.3 years (range 0.6-23.7 years). More than half (54%) had high grade breast tumours (Grade 3) on the Bloom-Richardson-Elston (BRE) system (20, 21). Main residual issues reported were: pain

Table I. Characteristics of participants with breast cancer ($n=85$)

Variables	
Age, years, mean (SD)	55.3 (10.7)
[range]	[32.5-79.5]
Marital status, n (%)	
Married/partner	53 (62.4)
Divorced/separated	18 (21.2)
Single	12 (14.1)
Widowed	2 (2.4)
Education, n (%)	
Primary	2 (2.4)
Secondary	37 (43.5)
Tertiary	43 (50.6)
Other	3 (3.5)
Disease duration, years, mean (SD)	4.3 (4.7)
[range]	[0.6-23.7]
Bloom-Richardson-Elston grading ($n=83$), n (%)	
Grade 1 (low)	10 (12.0)
Grade 2 (intermediate)	28 (33.7)
Grade 3 (high)	45 (54.2)
Estrogen receptor positive ($n=82$), n (%)	70 (85.4)
Lymph node affected, n (%)	56 (65.9)
Surgery, n (%)	85 (100)
≥ 2 surgery episodes	36 (42.4)
Type of surgery, n (%)	
Mastectomy	14 (16.5)
Mastectomy with AC	26 (30.6)
Lumpectomy	12 (14.1)
Lumpectomy with AC	31 (36.5)
Mastectomy/lumpectomy with AC	2 (2.4)
Chemotherapy, n (%)	63 (74.1)
Multiple episode	54 (96.4)
Side effects	60 (70.6)
Radiotherapy, n (%)	63 (74.1)
Multiple episode	48 (76.2)
Side effects	47 (55.3)
Reconstructive surgery or alternatives, n (%)	25 (29.4)
Shoulder limitation in ROM, n (%)	28 (32.9)
Shoulder limitation due to pain, n (%)	26 (30.6)
Lymphoedema, n (%)	25 (29.4)
Pain, n (%)	63 (74.1)
Pain score (0 no pain; 10=extreme pain), mean (SD)	3.8 (2.1)
[range]	[1-8]
Phantom breast pain ($n=77$), n (%)	5 (6.5)
Phantom breast sensation ($n=77$), n (%)	13 (16.9)
Upper limb weakness (MRC motor scale), n (%)	
0 (no contraction)	1 (1.2)
1 (flicker or trace of contraction)	0
2 (active movement, with gravity eliminated)	1 (1.2)
3 (active movement against gravity but no resistance)	5 (5.9)
4 (active movement against gravity and resistance but no full power)	29 (34.1)
5 (normal power)	49 (57.6)
Overall, mean (SD)	4.5 (0.8)

AC: axillary clearance; MRC: Medical Research Council; ROM: range of motion; SD: standard deviation.

(74%), lymphoedema (29%), shoulder limitation in range of motion (33%) and shoulder limitation due to pain (31%). Approximately 96% had some form of upper limb weakness, measured by the Medical Research Council grading for muscle power scale.

Table II. Frequency of participant reported limitations linked with the categories for the International Classification of Functioning, Disability and Health (ICF) components 'Activities and Participation' and 'Environmental factors' (n = 77)

ICF checklist code	ICF category description	Participant-linked responses as affected n (%)
<i>Activities and Participation</i>		
d175	Solving problems	1 (1.3)
d230	Carrying out daily routine	3 (3.9)
d240	Handling stress/other psychological demand	44 (57.1)
d430	Lifting and carrying objects	1 (1.3)
d440	Fine hand use (picking up, grasping)	2 (2.6)
d445	Hand and arm use	6 (7.8)
d465	Moving around and using equipment (wheelchair, skates, etc.)	2 (2.6)
d475	Driving (riding bicycle and motorbike, driving car etc.)	3 (3.9)
d640	Doing housework (cleaning washing, laundry, ironing)	1 (1.3)
d710	Basic interpersonal interaction	2 (2.6)
d750	Informal social relationships	1 (1.3)
d770	Intimate relationships	6 (7.8)
d830	Higher education	1 (1.3)
d850	Remunerative employment	9 (11.7)
d870	Economic self-sufficiency	3 (3.9)
d910	Community life	3 (3.9)
d920	Recreation and leisure	1 (1.3)
<i>Environmental factors</i>		
e310	Immediate family	4 (5.2)
e320	Friends	1 (1.3)
e450	Individual attitudes of health professionals	2 (2.6)
e460	Societal attitudes	1 (1.3)
e575	General social support services, systems and policies	1 (1.3)
e580	Health services, systems and policies	1 (1.3)

Participant reported issues due to breast cancer linked with the ICF categories using linkage rules

Table II lists the patient-reported (n = 77) frequency of limitation in everyday life activity due to BC, using an open ended questionnaire. These were linked with the ICF categories of 'Activities and Participation' and 'Environmental factors' components of the comprehensive ICF checklist (7) using linkage rules (14). A total of 125 relevant concepts corresponding to 23 ICF categories of the ICF checklist were identified: 17 categories in 'Activities and Participation' and 6 in 'Environmental factors' component. The frequent problems reported by the participants with BC linked with 'd240' – handling stress and other psychological demands (57%), and 'd850' – remunerative employment (12%). None of the participants reported additional aspects of health areas that were not covered by the ICF checklist.

Impact of breast cancer 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 with BC for 'Activities and Participation' categories in the ICF checklist ranged from 0 to 42 (median = 4, interquartile range (IQR) = 1–9). All 53 categories of nine chapters of the 'Activities and Participation' component had at least one limitations. Participants identified 28 of the 57 ICF categories of 'Activities and Participation' as relevant (≥10% of participants response). The main problems reported were in chapters: 'd4' – mobility, 'd6' – domestic life, 'd8' – major life areas, 'd9' – community and social activities. The most negative impact reported for corresponding ICF categories included: lifting and carrying objects (57%), handling stress and other physical demands (54%), doing house work (46%),

Table III. Participant linked responses showing frequency and impact for the affected corresponding International Classification of Functioning, Disability and Health (ICF) categories for 'Activities and Participation' (n = 85)

ICF checklist code	ICF category description	Participant-linked responses as affected n (%)	Not affected ^a n (%)	Mild ^b n (%)	Moderate ^c n (%)	Severe ^d n (%)	Complete ^e n (%)
<i>Learning and applying knowledge</i>							
d110	Watching	8 (9.4)	77 (90.6)	3 (3.5)	4 (4.7)	1 (1.2)	0
d115	Listening	2 (2.4)	83 (97.6)	2 (2.4)	0	0	0
d140	Learning to read	4 (4.7)	81 (95.3)	3 (3.5)	0	1 (1.2)	0
d145	Learning to write	4 (4.7)	81 (95.3)	3 (3.5)	0	1 (1.2)	0
d150	Learning to calculate	7 (8.2)	78 (91.8)	5 (5.9)	0	2 (2.4)	0
d175	Solving problems	13 (15.3)	72 (84.7)	10 (11.8)	1 (1.2)	2 (2.4)	0
d177	Making decision	13 (15.3)	72 (84.7)	10 (11.8)	1 (1.2)	2 (2.4)	0
<i>General tasks and demands</i>							
d210	Undertaking a single task	7 (8.2)	78 (91.8)	3 (3.5)	3 (3.5)	1 (1.2)	0
d220	Undertaking multiple tasks	18 (21.2)	67 (78.8)	4 (4.7)	8 (9.4)	5 (5.9)	1 (1.2)
d230	Carrying out daily routine	18 (21.2)	67 (78.8)	4 (4.7)	8 (9.4)	5 (5.9)	1 (1.2)
d240	Handling stress/other psychological demand	46 (54.1)	39 (45.9)	25 (29.4)	13 (15.3)	5 (5.9)	3 (3.6)
<i>Communication</i>							
d310	Communicating with – receiving spoken messages	5 (5.9)	80 (94.1)	4 (4.7)	1 (1.2)	0	0

Table III. Contd.

ICF-checklist code	ICF category description	Participant-linked responses as affected n (%)	Not affected ^a n (%)	Mild ^b n (%)	Moderate ^c n (%)	Severe ^d n (%)	Complete ^e n (%)
d330	Speaking	5 (5.9)	80 (94.1)	4 (4.7)	1 (1.2)	0	0
d335	Producing non-verbal messages	4 (4.7)	81 (95.3)	3 (3.5)	1 (1.2)	0	0
d350	Conversation	5 (5.9)	80 (94.1)	4 (4.7)	1 (1.2)	0	0
Mobility							
d430	Lifting and carrying objects	48 (56.5)	37 (43.5)	20 (23.5)	13 (15.3)	11 (12.9)	4 (4.7)
d445	Hand and arm use	36 (42.4)	49 (57.6)	29 (34.1)	5 (5.9)	1 (1.2)	1 (1.2)
d440	Fine hand use (picking up, grasping)	14 (16.5)	71 (83.5)	8 (8.4)	2 (2.4)	2 (2.4)	2 (2.4)
d450	Walking	18 (21.2)	67 (78.8)	8 (9.4)	3 (3.5)	6 (7.1)	1 (1.2)
d465	Moving around and using equipment (wheelchair, skates, etc)	16 (18.8)	69 (81.2)	6 (7.1)	3 (3.5)	5 (5.9)	2 (2.4)
d470	Using transportation (car, bus, train, plane, etc)	10 (11.8)	75 (88.2)	4 (4.7)	3 (3.5)	1 (1.2)	2 (2.4)
d475	Driving (riding bicycle and motorbike, driving car etc)	12 (14.1)	73 (85.9)	2 (2.4)	3 (3.5)	1 (1.2)	6 (7.1)
Self care							
d510	Washing oneself (bathing, drying, washing hands, etc)	6 (7.1)	79 (92.9)	3 (3.5)	2 (2.4)	1 (1.2)	0
d520	Caring for body parts (brushing teeth, shaving, grooming, etc)	6 (7.1)	79 (92.9)	3 (3.5)	2 (2.4)	1 (1.2)	0
d530	Toileting	3 (3.5)	82 (96.5)	2 (2.4)	1 (1.2)	0	0
d540	Dressing	7 (8.2)	78 (91.8)	3 (3.5)	2 (2.4)	2 (2.4)	0
d550	Eating	3 (3.5)	82 (96.5)	1 (1.2)	0	2 (2.4)	0
d560	Drinking	3 (3.5)	82 (96.5)	1 (1.2)	0	2 (2.4)	0
d570	Looking after one's health	4 (4.7)	81 (95.3)	1 (1.2)	1 (1.2)	2 (2.4)	0
Domestic life							
d620	Acquisition of goods and services (shopping, etc)	20 (23.5)	65 (76.5)	10 (11.8)	3 (3.5)	6 (7.1)	1 (1.2)
d630	Preparation of meals (cooking etc)	19 (22.4)	66 (77.6)	9 (10.6)	7 (8.2)	2 (2.4)	1 (1.2)
d640	Doing housework (cleaning washing, laundry, ironing)	39 (45.9)	46 (54.1)	16 (18.8)	17 (20.0)	5 (5.9)	1 (1.2)
d650	Caring for household objects	20 (23.5)	65 (76.5)	10 (11.8)	3 (3.5)	6 (7.1)	1 (1.2)
d660	Assisting others	20 (23.5)	65 (76.5)	9 (10.6)	3 (3.5)	5 (5.9)	3 (3.5)
Interpersonal interaction and relationship							
d710	Basic interpersonal interaction	9 (10.6)	76 (89.4)	6 (7.1)	2 (2.4)	1 (1.2)	0
d720	Complex interpersonal interaction	10 (11.8)	75 (88.2)	7 (8.2)	1 (1.2)	1 (1.2)	1 (1.2)
d740	Formal relationship	8 (9.4)	77 (90.6)	6 (7.1)	1 (1.2)	1 (1.2)	0
d750	Informal social relationships	14 (16.5)	71 (83.5)	9 (10.6)	2 (2.4)	2 (2.4)	1 (1.2)
d760	Family relationships	12 (14.1)	73 (85.9)	4 (4.7)	3 (3.5)	2 (2.4)	3 (3.5)
d770	Intimate relationships	14 (16.5)	71 (83.5)	4 (4.7)	2 (2.4)	6 (7.1)	2 (2.4)
Major life areas							
d810	Informal education	3 (3.5)	82 (96.5)	2 (2.4)	0	1 (1.2)	0
d820	School education	1 (1.2)	84 (98.8)	0	0	1 (1.2)	0
d830	Higher education	5 (5.9)	80 (94.1)	0	0	1 (1.2)	4 (4.7)
d850	Remunerative employment	26 (30.6)	59 (69.4)	5 (5.9)	7 (8.2)	5 (5.9)	9 (10.6)
d860	Basic economic transactions	13 (15.3)	72 (84.7)	7 (8.2)	3 (3.5)	2 (2.4)	1 (1.2)
d870	Economic self-sufficiency	21 (24.7)	64 (75.3)	7 (8.2)	8 (9.4)	4 (4.7)	2 (2.4)
Community social and civic life							
d910	Community life	18 (21.2)	67 (78.8)	10 (11.8)	3 (3.5)	3 (3.5)	2 (2.4)
d920	Recreation and leisure	32 (37.6)	53 (62.4)	7 (8.2)	14 (16.5)	5 (5.9)	6 (7.1)
d930	Religion and spirituality	10 (11.8)	75 (88.2)	8 (9.4)	1 (1.2)	0	1 (1.2)
d940	Human rights	1 (1.2)	84 (98.8)	0	0	0	1 (1.2)
d950	Political life and citizenship	1 (1.2)	84 (98.8)	0	0	0	1 (1.2)

^a0–4% of the time; ^b5–24% of the time; ^c25–49% of the time; ^d50–95% of the time; ^e>95% of the time.

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

hand and arm use (42%), recreation and leisure (38%), remunerative employment (31%), economic self-sufficiency (25%), acquisition of good and services (shopping) (24%), assisting others (24%), and meal preparation (22%).

Impact of breast cancer 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'

Table IV. Participant linked responses showing frequency and impact for the affected corresponding International Classification of Functioning, Disability and Health (ICF) categories (barriers) for 'Environmental factors' (n = 85)

ICF checklist code	ICF code description	Participant-linked responses as affected n (%)	Not affected ^a n (%)	Mild ^b n (%)	Moderate ^c n (%)	Severe ^d n (%)	Complete ^e n (%)
Products and technology							
e110	For personal consumption (food, medicines)	3 (3.5)	82 (96.5)	0	2 (2.4)	1 (1.2)	0
e115	For personal use in daily livings	1 (1.2)	84 (98.8)	0	1 (1.2)	0	0
e120	For personal indoor and outdoor mobility and transportation	1 (1.2)	84 (98.8)	1 (1.2)	0	0	0
e125	Products for communication	1 (1.2)	84 (98.8)	1 (1.2)	0	0	0
e150	Design, construction and building products and technology of buildings for public use	1 (1.2)	84 (98.8)	0	1 (1.2)	0	0
e155	Design, construction and building products and technology of buildings for private use	1 (1.2)	84 (98.8)	0	1 (1.2)	0	0
e165	Assets	1 (1.2)	84 (98.8)	0	1 (1.2)	0	0
Natural environment and human made changes to environment							
e225	Climate	45 (52.9)	40 (47.1)	19 (22.3)	12 (14.1)	12 (14.1)	2 (2.4)
e240	Light	4 (4.7)	81 (95.3)	3 (3.5)	1 (1.2)	0	0
e250	Sound	5 (5.9)	80 (94.1)	2 (2.4)	3 (3.5)	0	0
Support and relationships							
e310	Immediate family	17 (20.0)	68 (80.0)	6 (7.1)	4 (4.7)	6 (7.1)	1 (1.2)
e315	Extended family	17 (20.0)	68 (80.0)	6 (7.1)	4 (4.7)	6 (7.1)	1 (1.2)
e320	Friends	23 (27.1)	62 (72.9)	13 (15.3)	4 (4.7)	4 (4.7)	2 (2.4)
e325	Acquaintances peers colleagues neighbours and community members	9 (10.6)	76 (89.4)	4 (4.7)	3 (3.5)	1 (1.2)	1 (1.2)
e330	People in position of authority	4 (4.7)	81 (95.3)	1 (1.2)	1 (1.2)	1 (1.2)	1 (1.2)
e340	Personal care providers and personal assistance	3 (3.5)	82 (96.5)	2 (2.4)	0	1 (1.2)	0
e355	Health professionals	16 (18.8)	69 (81.2)	8 (9.4)	5 (5.9)	2 (2.4)	1 (1.2)
e360	Health related professionals	7 (8.2)	78 (91.8)	1 (1.2)	4 (4.7)	1 (1.2)	1 (1.2)
Attitudes							
e410	Individual attitudes of immediate family members	18 (21.2)	67 (78.8)	4 (4.7)	5 (5.9)	8 (9.4)	1 (1.2)
e415	Individual attitudes of extended family members	17 (20.0)	68 (80.0)	6 (7.1)	4 (4.7)	6 (7.1)	1 (1.2)
e420	Individual attitudes of friends	20 (23.5)	65 (76.5)	11 (12.9)	6 (7.1)	1 (1.2)	2 (2.4)
e425	Individual attitudes of acquaintances peers colleagues neighbours and community members	9 (10.6)	76 (89.4)	4 (4.7)	3 (3.5)	1 (1.2)	1 (1.2)
e440	Individual attitudes of personal care providers and personal assistance	3 (3.5)	82 (96.5)	2 (2.4)	0	1 (1.2)	0
e450	Individual attitudes of health professionals	14 (16.5)	71 (83.5)	9 (10.6)	2 (2.4)	2 (2.4)	1 (1.2)
e455	Individual attitudes of health related professionals	6 (7.1)	79 (92.9)	2 (2.4)	2 (2.4)	2 (2.4)	0
e460	Societal attitudes	11 (12.9)	74 (87.1)	4 (4.7)	5 (5.9)	2 (2.4)	0
e465	Social norms, practices and ideologies	2 (2.4)	83 (97.6)	0	0	2 (2.4)	0
Services system and policies							
e525	Housing services, systems and policies	1 (1.2)	84 (98.8)	0	0	0	1 (1.2)
e535	Communication services, systems and policies	0	85 (100)	0	0	0	0
e540	Transportation services, systems and policies	0	85 (100)	0	0	0	0
e550	Legal services, systems and policies	0	85 (100)	0	0	0	0
e555	Associations and organizational services, system and policies	2 (2.4)	83 (97.6)	2 (2.4)	0	0	0
e570	Social security services, system and policies	0	85 (100)	0	0	0	0
e575	General social support services, systems and policies	2 (2.4)	83 (97.6)	2 (2.4)	0	0	0
e580	Health services, systems and policies	6 (7.1)	79 (92.9)	4 (4.7)	2 (2.4)	0	0
e585	Education and training services, systems and policies	0	85 (100)	0	0	0	0
e590	Labour and employment services, systems and policies	4 (4.7)	81 (95.3)	2 (2.4)	1 (1.2)	1 (1.2)	0

^a0–4% of the time; ^b5–24% of the time; ^c25–49% of the time; ^d50–95% of the time; ^e> 95% of the time.

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

component is presented in Table IV. The number of problems reported by participants ranged from 0 to 16 (median = 1, IQR = 1–4). Of the 37 categories of 5 chapters of the ‘Environmental factors’ component, 30 categories had at least one limitations. Twelve of the 37 ICF categories in this component were relevant ($\geq 10\%$ of participant response) and identified as barriers. The most frequent barriers reported for corresponding ICF categories include: ‘e3’ – *support and relationship*: with friends (27%), with immediate family (20%) and with health professional (19%); ‘e4’ – *individual attitudes*: of friends (24%), of immediate family members (21%) and of extended family members (20%); and ‘e2’ – *human made change to natural environment*: climate (53%).

Comparisons with the ICF Core Set for breast cancer

Table V presents the comparison of the ICF categories included in the comprehensive ICF Core Set for BC (10) with the reported frequency of the problem by the study population according to ICF checklist (7). Only two thirds of ICF categories (16 out of 22) from ‘Activities and Participation’ component of the comprehensive Core Set for BC were considered relevant ($\geq 10\%$ of participant response) by study participants. Similarly, less than half of ICF categories (11 out of 23) from ‘Environmental factors’ in the comprehensive core set were identified as being relevant. Participants identified additional relevant ICF categories: 12 from ‘Activities and Participation’ (*mobility, major life areas, community civic life*) and one

Table V. Comparison of the International Classification of Functioning, Disability and Health (ICF) core set for breast cancer and participant linked report for corresponding ICF categories for ‘Activities and Participation’ and ‘Environmental factors’ (n = 85)

ICF Core Set code	ICF checklist code	ICF category description	Participant-linked responses as affected n (%)
<i>Activities and Participation</i>			
<i>Learning and applying knowledge</i>			
	d110	Watching	8 (9.4)
	d115	Listening	2 (2.4)
	d140	Learning to read	4 (4.7)
	d145	Learning to write	4 (4.7)
	d150	Learning to calculate	7 (8.2)
	d175	Solving Problems	13 (15.3)**
d177*	d177	Making decision	13 (15.3)
<i>General tasks and demands</i>			
	d210	Undertaking a single task	7 (8.2)
	d220	Undertaking multiple tasks	18 (21.2)**
d230*	d230	Carrying out daily routine	18 (21.2)
d240*	d240	Handling stress/other psychological demand	46 (54.1)
<i>Communication</i>			
	d310	Communicating with – receiving spoken messages	5 (5.9)
	d315	Communicating with – receiving non-verbal messages	3 (3.5)
	d330	Speaking	5 (5.9)
	d335	Producing non-verbal messages	4 (4.7)
	d350	Conversation	5 (5.9)
<i>Mobility</i>			
d430*	d430	Lifting and carrying objects	48 (56.5)
	d440	Fine hand use (picking up, grasping)	14 (16.5)**
d445*	d445	Hand and arm use	36 (42.4)
	d450	Walking	18 (21.2)**
	d465	Moving around and using equipment (wheelchair, skates, etc)	16 (18.8)**
	d470	Using transportation (car, bus, train, plane, etc)	10 (11.8)**
	d475	Driving (riding bicycle and motorbike, driving car etc)	12 (14.1)**
<i>Self care</i>			
d510	d510	Washing oneself (bathing, drying, washing hands, etc)	6 (7.1)
d520	d520	Caring for body parts (brushing teeth, shaving, grooming, etc)	6 (7.1)
	d530	Toileting	3 (3.5)
d540	d540	Dressing	7 (8.2)
d550	d550	Eating	3 (3.5)
d560	d560	Drinking	3 (3.5)
d570	d570	Looking after one’s health	4 (4.7)
<i>Domestic life</i>			
d620*	d620	Acquisition of goods and services (shopping, etc)	20 (23.5)
d630*	d630	Preparation of meals (cooking etc)	19 (22.4)
d640*	d640	Doing housework (cleaning washing, laundry, ironing)	39 (45.9)
d650*	d650	Caring for household objects	20 (23.5)
d660*	d660	Assisting others	20 (23.5)

Table V. *Contd.*

ICF Core Set code	ICF checklist code	ICF category description	Participant-linked responses as affected n (%)
Interpersonal interaction and relationship			
	d710	Basic interpersonal interaction	9 (10.6)**
d720*	d720	Complex interpersonal interaction	10 (11.8)
	d730	Relating with strangers	8 (9.4)
	d740	Formal relationship	8 (9.4)
d750*	d750	Informal social relationships	14 (16.5)
d760*	d760	Family relationships	12 (14.1)
d770*	d770	Intimate relationships	14 (16.5)
Major life areas			
	d810	Informal education	3 (3.5)
	d820	School education	1 (1.2)
	d830	Higher education	5 (5.9)
d850*	d850	Remunerative employment	26 (30.6)
	d860	Basic economic transactions	13 (15.3)**
	d870	Economic self-sufficiency	21 (24.7)**
Community social and civic life			
	d910	Community life	18 (21.2)**
d920*	d920	Recreation and leisure	32 (37.6)
	d930	Religion and spirituality	10 (11.8)**
	d940	Human rights	1 (1.2)
	d950	Political life and citizenship	1 (1.2)
<i>Environmental factors</i>			
Products and technology			
e110	e110	For personal consumption (food, medicines)	3 (3.5)
e115	e115	For personal use in daily livings	1 (1.2)
	e120	For personal indoor and outdoor mobility and transportation	1 (1.2)
	e125	Products for communication	1 (1.2)
	e150	Design, construction and building products and technology of buildings for public use	1 (1.2)
	e155	Design, construction and building products and technology of buildings for private use	1 (1.2)
e165	e165	Assets	1 (1.2)
Natural environment and human made changes to environment			
e225*	e225	Climate	45 (52.9)
	e240	Light	4 (4.7)
	e250	Sound	5 (5.9)
Support and relationships			
e310*	e310	Immediate family	17 (20.0)
e315*	e315	Extended family	17 (20.0)
e320*	e320	Friends	23 (27.1)
e325*	e325	Acquaintances peers colleagues neighbours and community members	9 (10.6)
	e330	People in position of authority	4 (4.7)
e340	e340	Personal care providers and personal assistance	3 (3.5)
e355*	e355	Health professionals	16 (18.8)
	e360	Health related professionals	7 (8.2)
Attitudes			
e410*	e410	Individual attitudes of immediate family members	18 (21.2)
e415*	e415	Individual attitudes of extended family members	17 (20.0)
e420*	e420	Individual attitudes of friends	20 (23.5)
e425*	e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	9 (10.6)
e440	e440	Individual attitudes of personal care providers and personal assistance	3 (3.5)
e450*	e450	Individual attitudes of health professionals	14 (16.5)
	e455	Individual attitudes of health related professionals	6 (7.1)
	e460	Societal attitudes	11 (12.9)**
e465	e465	Social norms, practices and ideologies	2 (2.4)

Table V. *Contd.*

ICF Core Set code	ICF-checklist code	ICF Category description	Participant-linked responses as affected <i>n</i> (%)
Services system and policies			1 (1.2)
	e525	Housing services, systems and policies	
	e535	Communication services, systems and policies	0
e540	e540	Transportation services, systems and policies	0
	e550	Legal services, systems and policies	0
e555	e555	Associations and organizational services, system and policies	2 (2.4)
e570	e570	Social security services, system and policies	0
e575	e575	General social support services, systems and policies	2 (2.4)
e580	e580	Health services, systems and policies	6 (7.1)
	e585	Education and training services, systems and policies	0
e590	e590	Labour and employment services, systems and policies	4 (4.7)

*Significant corresponding with the ICF Core Set for breast cancer; **significant not corresponding with the ICF Core Set for breast cancer.

(*societal attitudes*) from “Environmental factors” component, these however are not currently included in the comprehensive Core Set for BC.

DISCUSSION

The results of this cross-sectional study, by and large endorse the relevance of the first version of the comprehensive ICF Core Set for BC using patient reported disability in an Australian cohort. Three different approaches in this study provided a comprehensive assessment of the relevance and completeness of the Core Set for BC in a community setting. An open questionnaire approach using ‘linkage rules’ to link problems due to BC reported by the participant; an ICF-based approach where each participant reviewed an ICF-checklist for the components ‘activity and participation’ and ‘Environmental factors’ by using the WHO qualifier scale to rate each category; and a comparative approach of participant report with the ICF Core Set for BC for the domains of ‘activity and participation’ and ‘Environmental factors’. Sixteen of the 22 categories from ‘Activities and Participation’ component and 11 of 23 categories from ‘Environmental factors’ included in the comprehensive Core Set for BC were considered relevant ($\geq 10\%$ of participant response) by the study population. However, 13 additional ICF categories relating to mobility, major life areas, community civic life and societal attitudes identified by survivors with BC are not currently in the Core Set for BC and should be considered for inclusion to incorporate the longer term perspective.

The comprehensive Core Set for BC has not yet been validated. Core set validation approaches include international multicentre studies and consensus from health professionals, but also the validation from perspective of the patient is a key element of this process. The involvement of survivors with BC in the process of development and validation of ICF Core Set is imperative. Participants in this study were community based and a longer time duration since receiving definitive treatment for primary BC. Their perspective provides an additional societal context and adds to the original patient reports ($n = 108$) (11) listing issues following BC, used in the construction of the

first comprehensive Core Set for BC (10). We recommend that additional categories identified by participants in this study be incorporated into the final comprehensive Core Set for BC prior to its validation process worldwide. Additional information from other BC cohorts elsewhere should also be explored. The clinical use of the Core Set for BC will be more successful if it captures issues relevant to a wide spectrum of survivors with BC, especially in the post acute phase and over a longer-term.

Results from this study provide further insight into the course of functioning and health (over a longer time period), related contextual factors and an overall effect of BC on participants’ everyday activities and involvement in life situations. The extended ICF checklist BC incorporates all aspects of life and many categories in ‘Activities and Participation’ were considered relevant by survivors with BC. These include: mobility, domestic life, inter-personal, family and intimate relations, major life areas (economic self-sufficiency, remunerative employment). The main barriers reported for environmental factors included ‘support and relationship’, ‘attitudes’ and ‘climate’ categories. This data are in keeping with the only other published study on ICF linkage in BC (11). Recreation and leisure, and remunerative employment reported by study participants reflect the socio-demographic characteristics, longer duration since treatment and age distribution of participants. The study population included active ‘working age’ persons in the community, educated, mostly living with family, and driving. The categories in ‘Activities and Participation’ such as mobility (especially for longer distances), public transport, interpersonal relationships, home and community activities were relevant and similar to other non-cancer patient populations such as multiple sclerosis and Guillain Barre Syndrome (22, 23).

The BC survivors reported pain (74%), phantom breast sensation (17%) and phantom breast pain (7%), consistent with other reports in the BC population (6). The extent and impact of these however was beyond of scope of this paper. Interestingly, despite a longer time since definitive treatment for BC (mean 4.3 years), study participants reported difficulty with psychological issues such as ‘handling stress and other psychological demand’. These findings are consistent with

the other reports (24, 25) of higher level of emotional distress in women treated for BC than the general population. Approximately, 50% of all BC patients may suffer from emotional distress, this includes a range of symptoms from sadness and worry to disabling depression and anxiety (24, 26). Further, treatment and/or disease progression itself can also cause a range of neuropsychological sequelae (such as anxiety, depression, sexual dysfunction and body dysmorphism, or both) (6, 27, 28). More information on adaptation over time and longer term monitoring for neuropsychological sequelae following BC treatment in this population are needed.

In this study survivors with BC reported more 'environment factors' that impacted on health areas, such as support and relationship, work, attitudes of friends and access to social security and health services, compared with a previous study (11). The understanding of the environmental factors from the participants' with BC perspective can help assess the barriers and facilitators as perceived by the individual. Adaptation and modification of the environment could then eliminate these barriers and improve participation (29).

The measurement of conceptual and methodological issues concerning 'participation' and 'environment factors' in ICF have been described (30). An improved distinction between 'Activities and Participation' and the 'environment' is proposed for future research. The focus needs to be on those aspects of the environment that interact with a person's functional limitations impacting activities and participation for more effective rehabilitation research and intervention. The scope of clinical trials in rehabilitation needs to expand to consider participation as an outcome variable, and the environment as confounder, mediator, intervention or outcome. Improved conceptualization and operationalization of these will lead to more sensitive and valid outcome measures. Social role performance (individual and societal) is a key hallmark of participation and recommended for measurement (30). Further, contextual factors may moderate relationships between activity/activity limitation and participation/participation restriction, depending on their role in the causal chain between former and latter; and have a mediating role (31). Further exploration of the role of environment in affecting 'functioning' of persons following BC is needed.

Our study has some potential limitations. This is a cross sectional survey and does not provide longitudinal information. The sample size is small and consists only of Australian participants. The participants have strict inclusion criteria and are listed on a database of people with BC held at the RMH and who agreed to participate in research projects. 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 'Body functions' of the core set were not included as they comprised most relevant categories for survivors with BC. This study focused on the patient perspective and impact of BC on 'Activities and Participation' and 'Environmental factors'. We were not able to identify and link problems with ICF categories not listed by the participants. The participant report is subject to interviewers' interpretation, however, ICF categories linked were consist-

ent 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.

The ICF framework and categories are comprehensive and incorporate all issues relevant to survivors with BC. The existing ICF comprehensive Core Set for BC is not yet validated. The results of this study provide a 'broader' patient perspective with additional categories in the components 'Activities and Participation' and 'Environmental factors' for possible inclusion in the comprehensive Core Set for BC. Further information from other BC cohorts in different settings regarding relevant health areas for these persons in the community may serve to expand the existing ICF Core Set for BC, prior to its validation globally.

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