

Research Article

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Clinical Application and Feasibility of Using ICF Cancer Survivor Core Set of Breast Cancer to the Health Condition of a Post-Menopausal Breast Cancer Survivor.

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ABSTRACT

Background: The case report is of 52-year-old female complaining of fatigue, depression post modified radical mastectomy. She was under four weeks of exercise program. The purpose of this study was to consider the clinical application of ICF Cancer survivor Core set to describe the health condition of the patient by mapping the components of assessment tools used in this study.

Method: The outcome measures -Revised piper fatigue scale, Beck's depression Inventory, FACT B questionnaire was mapped to ICF categories of body function using linking rules.

Results and Discussion: Most of the body function described for outcome measures of depression, fatigue, quality of life like feeling sad, irritation, lack of energy, was third level category except for weight loss which was second level.

Conclusion: The mapping of the above outcome measures in ICF framework should be considered for future studies on large number of patients.

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Introduction

Breast cancer is the most common malignancy in women comprising 16 % of all cancers in women. With the advances in the treatment of breast cancer, including combined use of surgical intervention, radiation therapy and chemotherapy survival rates have increased. However, many breast cancer survivors continue to experience physical and psychological health issues that affect their quality of life, long after the surgical and medical treatment have been completed. Most breast cancer survivors suffer from anxiety, depression, fatigue, sleep problems and body image disturbances. These women may struggle to cope with new demands associated with their inability to return to work and general restriction in participation in activities of life. Since quality of life questionnaires and ICF represents two different perspective regarding functionality and health, they are expected to be used simultaneously in clinical practice..Tools to support clinical use of ICF have been developed, including ICF checklist to identify patient's problem in health functioning . The ICF core sets include categories identified using multistage consensus process to identify

most relevant aspects of functioning associated with a specific condition to guide multidisciplinary assessment..According to Cieza and Stucki ,to assess health status ,items from different instruments can be linked to corresponding ICF categories [1-3].

Studies done by Brach et al have described the use of Comprehensive ICF Core set of breast cancer to describe the categories of Body structure, Body function ,Activities and Participation .The Comprehensive ICF core set of breast cancer is made up of 26 categories from body function, 9 from component of body structure ,22 from activities and participation and 23 from environmental factors.4But the core set for breast cancer has not been yet validated ,hence it is not certain if selected domains are sufficiently comprehensive to cover spectrum of limitations in functioning and health encountered in survivors with breast cancer globally. Also, the long term, post treatment issues, in cancer survivors with breast cancer may be different to those identified in acute and immediate post-acute settings. Thus, the need to use Cancer Survivor Core set which represents most relevant health related problems in adult cancer survivor instead of or as well as the Comprehensive ICF Core set of breast cancer. The Cancer survivor core set consists of 19 ICF categories -5 for

body structure and body function, 8 for Activities and participation and 6 for environmental factors. Hence this study was done to consider the practical application and feasibility of using ICF Cancer Survivor Core Set to describe the health of a breast cancer survivor post radical mastectomy by mapping the components of assessment tools [4,5].

Aim: Clinical Application and feasibility of using ICF Cancer Survivor Core set to monitor the health condition of a post-menopausal breast Cancer Survivor.

Objective: The coverage of the core set was assessed by mapping the items from the range of assessment tools used in the clinical situation against the ICF using linking rules published in 20.

To identify the categories that are important for people who are recovering from breast cancer, those that are missing, overlap or are inconsistent with the ICF and those that cannot be documented using the ICF.

Case Study

The example case is paper documents the situation of a breast cancer survivor in the ICF framework to this case report which is already published in International Journal of YOGA. The subject is a 52-year-old, postmenopausal female, working as an attendant in college. She was diagnosed with duct carcinoma of the left breast. The patient underwent modified radical mastectomy and completed six cycles of chemotherapy post-surgery. She complained of extreme fatigue and depression which made it difficult for her to do her daily household activities and she was unable to go back to her job for one year which created a huge financial drain for her. She is a widow and she stayed with her son and her daughter in law, who took care of her. She has felt lonelier since her husband's death and has lost her energy and drive after her illness. After taking written informed consent, the patient's pre intervention scores for the outcome measures were taken. The revised Piper Fatigue scale as used to evaluate her fatigue level. The score was 4.1 indicating moderate fatigue. The patient had a total score of 22 on Beck's Depression Inventory. She then undertook a six-minute walk test. This is a sub maximal exercise test that entails measurement of the distance walked over a span of six minutes. She covered a distance of 390 meters, which was reduced as compared to her predicted walking distance. Her quality of life was evaluated using Functional Assessment of Cancer Therapy questionnaire for breast cancer. The patient's score in all four domains was 77 out of 164. Score of 164 corresponds to major well-being of the patient. means [6].

The patient was given a structured program of modified version of Hath yoga, for four weeks. The program included fifteen minutes of pranayama, followed by a series of nine modified Yog asanas for 30 minutes. This comprised of gentle stretching and strengthening exercises specifically targeting the upper body. After four weeks of intervention, there was reduction of her fatigue levels from 4.1 to 2.6, depression scores from 22 to 15 and her walking distance increased from 390 to 450 meters. Her quality of life also improved in all four domains with total score of 64.

Materials

1) ICF Cancer Survivor Core Set – The Cancer Survivor Core set represents most relevant health related issues for adult cancer survivors. The Cancer Survivor Core set consists of 19 ICF categories. There are 5 categories from the Body structure and function components, 8 categories from Activities and Participation component and 6 for Environmental factors. The core set was developed by using Delphi method. Patient's perspective was prioritised and content validity was confirmed by using validated Cancer survivorship questionnaire.

Methodology

This study was undertaken as a part of an education programme on the WHO ICF. The mapping of the outcome measures was done on a case study 5 with an attempt to know whether it is feasible to document the health condition of the patient in ICF framework.

After getting approval for the project, the case documentation, that is health condition of the patient was described in the framework of ICF by using Cancer Survivor Core Set. The categories related to health condition of the patient, that is, Body structure, Body function, Activity and Participation and contextual factors, which were self-reported or patient perceived health problems, both physiological and psychological, along with patient's self-reported contextual factors were mapped according to ICF cancer survivor core set and the components that were missing or not described in core set was noted.

The questions of the outcome measures for self-reported fatigue, depression, quality of life and exercise tolerance test of the patient were mapped for the categories of Body function and Activity and participation by using ICF manual and practical guide. For each item we identified primary ICF codes which corresponds to the conceptual definition of corresponding item/question of the outcome measure. Secondary ICF codes were identified for other meaningful concepts included in the item stem. In accordance to mapping method described by Cieza et al and recommended ICF practises, items with meaningful concepts that do not have sufficient information, to select ICF category were labelled not definable (nd). If meaningful concept of item were not in ICF category but were defined as personal factor by ICF, it was labelled as pf (personal factor). If, however meaningful concepts contained in the items were not contained in ICF and was not a personal factor, it was considered to be not covered by ICF (nc). This mapping of all items was then independently reviewed by the subject expert, who was an additional investigator in agreement with mapping. For each outcome measure, we identified different ICF codes for Activities and Participation and Body functions as both primary and secondary concept. The mapping exercise of the components of outcome measure to ICF helped us to know whether it would be possible to link all the questions of the outcome measures to ICF framework and whether self-reported history of patient for those components were sufficient. The data collected from patient was mapped using ICF checklist and results were documented.

Results

Table 1: Description of functioning of the patient in ICF format by using ICF Cancer Survivor Coreset

ICF Component	Assessment concept	Map to ICF category	Note
Body Functions	Body fatigue		not covered in Cancer survivor Core set
	Exercise tolerance/ aerobic capacity		Not covered in Cancer survivor set
	Quality of life		Not covered in Cancer Survivor set/can be described by WHOQOL
	Depression –Emotional function	b 130	Second level category
Body Structure	Structure of breast/nipple removed		Not covered in Cancer Survivor set
Activities and Participation	To be able to carry daily activities		Not covered in Cancer Survivor set
	Assessment of work capacity to join to work again		
Participation	Exercise (YOGA) intervention, looking after one’s health	d 570	Second level
	Absenteeism at work –remunerative employment	d 870	Second level
Environmental factors	Supporting son and daughter in law	e 310 Immediate family	Second level
	Yoga	e 580	e 580 Second level
Personal factors	Female, postmenopausal		
	Widow		
	Lives with son and daughter in law		
	Lower middle socioeconomic class		

Table 2: Mapping Questions of Becks Depression Inventory for Categories of Body Functions and Activities and Participation in ICF framework.

Becks Depression Inventory	Body Functions	Domains/Chapters	Categories	Codes	Qualifier
Questions	Feel sad	Emotional function –Range of emotion	Third level	b 1522	Yes 0 to 3
	Anxiety about future	Same as above	Same as above	Same as above	
	Satisfaction with everything I do	Regulation of emotion	Third	b 1521	
	Feeling of guilt	Range of emotions	Third level	b 1522	
	Feeling of being punished	Range of emotions	Third level	b 1522	
	Hate myself	Range of emotions	Third level	b 1522	
	Blame myself	Range of emotion	Third level	b 1522	
	Anger /Kill myself	Range of emotion	Third level	b 1522	
	Able to cry	Regulation of emotion	Third level	b 1521	Yes 0 to 3
	Get irritated	Regulation of emotion	Third level	b 1521	
	Lose interest in others	Regulation of emotion	Third level	b 1521	
	Feel I look worse	Body Image	Third level	b 1801	
	Ability to work like before	Experience of self	Third level	b 1800	
	Amount of sleep	Sleep function	Third level	b 1340	
	Getting tired	Fatigability	Third level	b 4552	
	Appetite	Sensation associated with digestive system unspecified	Third level	b 1302	
	Lost weight	Weight maintenance function	Second level	b 530	
	Worry about health	Emotional function, other specified	Third level	b 1528	
	Interest in sex	Function of sexual interest	Third level	b 6400	

Table 3: Mapping of Question of FACT – B Questionnaire in the Categories of Body functions and Activities and Participation using ICF framework

FACT B (VERSION 4)	Body functions	Domains	Category	Code	Qualifier
Physical Wellbeing questions	Lack of energy	Energy levels	Third level	b 1300	Yes 0 to 4
	Have nausea	Sensation of nausea	Third level	b 5350	
	Have pain	Pain in body part, unspecified	Fourth level	b 28019	
	Bothered by side effects of medicines	Range of emotions	Third level	b 1522	
	Feel ill	Range of emotions	Third level	b 1522	
	Forced to spend time in bed	Sleep function, unspecified	Third level	b 1349	
	Activities and Participation-				
	Have trouble meeting needs of family	Assisting others	Second level	d 660	Yes 0 to 4
	Activities and Participation				
	Feel close to my friends	Informal relationship with my friends	Third level	d 7500	Yes 0 to 4
	Emotional support from family	Australian qualifier, satisfaction with level of acceptance			
	Get support from my friends	Support and relationships with friends	Third level	d 7100 check once	
	Satisfied with family's concern about my illness	Australian qualifier - satisfaction with level of acceptance		s	
	Feel close to partner	Intimate relationship, unspecified	Third level	d 7709	
	Body function – Satisfied with sex life	Sexual function, unspecified	Third level	b 6409	Yves 0 to 4
Emotional wellbeing	Feel Sad	Range of emotion	Third level	b 1522	Yes 0 to 4
	Feel nervous	Range of emotion	Third level	b 1522	
	Satisfied with how i am coping with my illness	Emotional function, unspecified	Third level	b 1529	
	Losing hope in fighting against my illness	Emotional function, unspecified	Third level	b 1529	
	Worry about dying	Emotional function, unspecified	Third level	b 1529	
	Worry that condition might get worse	Emotional function, unspecified	Third level	b 1529	
Functional well being	Body function Am sleeping well now	Quality of sleep	Third level	b 1343	
	Activities and Participation				
	Am able to work (including work at home)	General task, demand unspecified	Second level	d 299	Yes 0 to 4
	My work is fulfilling	-Australian qualifier	-	-	
	Am able to enjoy life	Australian qualifier			
	Enjoying things I usually do	Australian qualifier			
	Am content with quality of life now	Australian qualifier			
Additional concerns	Body function				

	Shortness of breath	Sensation associated with cardiovascular and respiratory functions	Second level	b 460	Yes 0 to 4
	Self-conscious about way I dress	Body Image	Third level	b 1801	
	I feel both my arms are swollen/tender				
	I feel sexually attractive	Body image	Third level	b 1801	
	Bothered by hair loss	Body image	Third level	b 1801	
	Worry that members of my family might get illness	Emotional function unspecified	Third level	b 1529	
	Worry about effect of stress on my illness	Emotional function unspecified	Third level	b 1529	
	Bothered about change in weight	Body image	Third level	b 1801	
	Able to feel like a woman	Body image	Third level	b 1801	
	Have certain parts of body where I have pain	Pain in body part, unspecified	Fourth level	b 28019	

Table 4: Mapping the questions of Revised Piper Fatigue Scale in the categories of Body functions and Activities using ICF frame work

Revised Piper Fatigue Scale	Activities and Participation	Domain	Category	Code	Qualifier
Behavioural –degree of fatigue	Interfering with ability to socialise	Participation in Community life	Second level	d 910	
	Interfering with work /school				Yes 0 to 10 0 – mild, 10 –severe
	Interfering with sexual activity	Participation in intimate relationships		d 770	
	Interfere with activities you are doing				
Affective					
Describe the fatigue you are experiencing now	Activities and Participation				
	Pleasant /unpleasant	Australian qualifiers			0-pleasant 10 – unpleasant
	Agreeable /disagreeable				0-agreeable 10 – disagreeable
	Protective/destructive				0-protective 10-destructive
	Positive/Negative				0-positive 10-negative
	0-positive 10-negative				0-normal 10-abnormal
Sensory					Yes 0-10
Feeling of fatigue now					
	Strong/weak	Australian qualifier			0-strong 10-weak
	Awake/sleepy				0-awake 10-sleepy

	Lively/listless				0-lively 10-listless
	Refreshed/Tired				0-refreshed 10-tired
	Energetic/unenergetic				0-energetic 10-unenergetic
Cognitive					
	Relaxed/Tensed	Australian qualifiers			0-relaxed 10-tensed
	Exhilarated/Depressed				0-exhilarated 10-depressed
	Body functions	Domain	Category	Code	Qualifiers
	concentration	Sensory attention	Third level	b 1400	0-able to concentrate 10-unable to concentrate
	To remember	Memory function, unspecified	Third level	b 1449	0-able to remember 10-unable to remember
	Think clearly	Thought function, unspecified	Third level	b 1609	0-able to think 10-unable to think clearly

Table 5: Description of Body function of six-minute walk test in ICF frame work

Six Minute Walk Test	Body Function	Domain	Category	Code	Qualifier
	Exercise tolerance function	Aerobic capacity	Third	b 4551	No

Discussion

This study provides valuable information about how the questions /item level content of the outcome measures could relate to ICF. The outcome measure items were mapped for only Body functions and Activities and Participation. The reason for highlighting only these components of body function and activities and participation was to do the study with the aim of knowing the effect of structured YOGA programme on functional outcomes of the patient like fatigue , depression , quality of life and exercise tolerance on a breast cancer survivor .It has been observed in clinical practice that these functional components are generally affected post radiation and surgery and have huge impact on patient s participation in their domestic and social life.

The first objective of the study was to do describe the health condition in ICF framework and do the mapping of patient’s body structure, body function, activity and participation and contextual factors by using Cancer Survivor Core set. It was seen that body functions like fatigue and exercise tolerance were not covered in ICF Cancer survivor core set. Though quality of life is not described or included in ICF, it is mentioned to be complementary. Thus, the use of WHO –QOL tool or a shorter tool like EQ5D could be considered relevant. Though depression is coded as b130 under emotional function, it is separately coded in ICD and emotional function is one facet of depression .The problem for mapping YOGA intervention was to include under Activities and Participation as looking after oneself as in the given case or to consider it as environmental facilitator, e 580 because YOGA intervention had proved effective in improving her physical problems like fatigue and aerobic capacity, quality of life and reducing depression level . The body structure components and activities and participation components like removal of breast tissue, able to carry daily activities are described in ICF Breast cancer core set but not in Cancer survivor core set. But the

reason for choosing ICF Cancer survivor core set over Core set for breast cancer was the disabilities and health issues experienced by a cancer survivor vary over period of time and patient may still have side effects of radiation and psychological problems like anxiety related to resuming to their normal life and fear of cancer recurrence. Thus, future studies are recommended to have ICF Cancer survivor core set for breast cancer including fatigue, exercise tolerance and quality of life which are commonly experienced by such patients.

Certain issues were faced while mapping process related to outcome measures. There were some questions in the outcome measures where more than one meaningful concept was included. For instance, in the component of functional well-being of FACT B questionnaire – am able to work (including work at home). There seems to be two codes implicated in this question –remunerative employment and domestic life. In considering domestic life, one needs to think about how to aggregate the codes that are relevant to women into one score or collect all relevant codes.

For certain questions related to emotional well-being, like satisfied with how I am coping with my illness and body function like feeling sad, feeling nervous were considered as emotional function unspecified but coping styles are considered personal factors. Satisfaction is a quality-of-life component which can be described in the form of Australian qualifiers. Australian Qualifiers denote the rating of person s degree of satisfaction with participation in domain of life in relation to current life goals. Satisfaction with participation correspond s to person s own perspective in participation in various life areas. It is essentially a summary measure in which are embedded concepts of choice, opportunity and importance. However emotional well-being items listed are usual responses to illness, bereavement so emotional function is normal in this context. Also, ICF does not classify varied emotions

separately, there are no distinct categories for each of emotional concept. The fourth level of ICF categories for emotion function has sub categories of appropriateness of emotion, regulation of emotion and range of emotion. Hence most of the components like anxiety, anger, irritated were mapped to the same ICF code [7].

For most of the questions related to affective and sensory components of Revised piper fatigue scale, use of Australian qualifiers was implemented. Australian qualifiers are used to rate person s degree of satisfaction, with participation in different domains of life .7 For questions like to what degree of fatigue you are feeling now - pleasant or unpleasant, positive or negative, normal or abnormal, Australian qualifier was used to describe subjective experience of the objective component of fatigue in ICF framework.

Appendix

Table 6: Summaries The Mapping Results of All the Outcome Measures Used in the Study for the Self -Reported Health Condition of the Patient

ICF Components and Categories	Cancer Survivor Core set	Beck Depression Inventory	FACT–B Questionnaire	Revised Piper Fatigue Scale	Six Minute Walk Test	Note
Body functions						
b28019 Pain in body part, unspecified			Have pain Have certain parts of body where i have pain			
b1300 Energy level	Body fatigue		Lack of energy			
b1302 Appetite		Appetite				
b1340 Amount of sleep		Amount of sleep	Forced to spend time in bed			
b1343 Quality of sleep			Am sleeping well now			
b1400 Sustaining attention				Concentration		0–able to concentrate 10-unable to concentrate
b1449 Memory functions, unspecified				To remember		0–able to remember 10-unable to remember
b4551 Exercise tolerance	Not covered in Cancer survivor Core set				Distance walked in six minutes. Not validated to ICF qualifier	
b150 Emotional functions	Depression					Second level category
b152 Emotional functions		Worry about health				
b1521 Regulation of emotion		Satisfaction with everything I do Able to cry Get irritated Lose interest in others				

Limitation of the study

It is single case study; use of mapping was done for only patient reported health functions outcome measures.

Clinical Implication

The mapping process implemented in these outcome measures can be used for large number of patients /breast cancer survivors’ assessment and treatment protocol.

Conclusion:

Cancer survivor core set for Breast cancer can be considered as feasible tool in documenting health condition of a breast cancer survivor. However, impairments related to body function like fatigue, depression and quality of life needs to be considered or included as they are commonly reported chronic health issues in these patients.

b1522 Range of emotion		Feeling sad Anxiety about future Feeling of guilt Feeling of being punished Hate myself Blame myself Anger/ kill myself	Bothered by side effects of medicines Feel ill Feel Sad Fell nervous Satisfaction with how I am coping with may illness Losing hope in fighting against my illness Worry about dying Worry that condition might get worse			
b1609 Thought functions, unspecified				Think clearly		0-able to think 10-unable to think
b1801 Body image		Feel I look worse				
b4552 Fatiguability		Getting tired				
b530 Weight maintenance functions		Lost weight				
b5350 Sensation of nausea			Have nausea			
b6400 Functions of sexual arousal phase		Interest in sex				
Body structure						
s6302 Breast and nipple. 1st qualifier for extent, 2nd for nature of the change, partial or total absence and 3rd qualifier for laterality (L) or (R)	Structure of breast/nipple removed.					Not covered in Cancer Survivor set
Activities and participation						
p570 Looking after one's health	Yoga					Second level
p660 Assisting others			Have trouble meeting needs of family			
p7500 Informal relationships with friends			Feel close to my friends			
d760 Family relationships			Satisfied with family's concern about my illness			Satisfaction with participation in support and relationships
p7701 Spousal relationships			Feel close to partner			
p770 Intimate relationships			Degree of fatigue Interfering with sexual activity			

p839 Education, unspecified				Degree of fatigue Interfering with work/school. Measure 10 point scale mild/severe		
p859 Work and employment, other	Capacity to join in work again. Absenteeism at work.	Ability to work like before	Am able to work (including work at home) My work is fulfilling	Degree of fatigue Interfering with work/school. Measure 10 point scale mild/severe		Satisfaction with participation
p870 Economic self-sufficiency	Economic situation					Second level
p910 Community life				Degree of fatigue Interfering with ability to socialise		
p? Depends on the activities the person is doing	To be able to carry out daily activities			Degree of fatigue Interfering with activities you are doing		
p920 Recreation and leisure (includes taking part in programmes of physical fitness)	Yoga					
Environmental factors						
e 310 Immediate family	Supporting son and daughter in law			Emotional support from family		Second level
e320 Friends				Get support from my friends		
e580 Health services, systems and policies	Yoga					Second level
Personal factors						
Personal factors are recognised, but not classified in the ICF.	Female					
	Post menopausal					
	Widow					
	Lives with son & daughter-in-law					
	Lower middle socioeconomic class					
Quality of life and wellbeing						
NOT an ICF concept	Quality of life		Am able to enjoy life Enjoying things i usually do Am content with quality of life now			Not covered in Cancer Survivor set/can be described by WHOQOL

				Describe the fatigue you are experiencing now. Measure 10 point scales Pleasant/unpleasant Agreeable/disagreeable Protective/destructive Positive/negative		
				Feeling of fatigue now Measure 10 point scales Strong/weak Awake/sleepy Lively/listless Refreshed/tired Energetic/unenergetic		

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