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# Characterization of functioning in breast cancer survivors: an interpretive descriptive analysis study based on the International Classification of Functioning, Disability, and Health (ICF) and the Item-Perspective Classification Framework

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## ABSTRACT

**Purpose:** Breast cancer survivors may experience a variety of disabilities that could potentially compromise their independent functioning. This study aimed to examine their perspectives and experts on their functioning and interpret concepts with the International Classification of Functioning, Disability, and Health (ICF) and the Item-Perspective Classification Framework (IPF).

**Methods:** Interpretive descriptive methods were used with in-depth interviewing with 16 breast cancer survivors and 22 experts using a semi-structured interview guide. The interviews were recorded, transcribed, and qualitatively analyzed using thematic analysis. The extracted data were linked to the ICF Core Set for Breast cancer and were interpreted by the IPF.

**Results:** Four main themes emerged to define the functioning of breast cancer survivors: body functioning, physical functioning, social functioning, and mental functioning. Three other factors were also categorized as modifiers of functioning personal, emotional, and environmental. The 592 extracted meaningful concepts were linked to 38 (47%) categories from the ICF: 16 Body Functions, 14 Activities and Participation, and 8 Environmental Factors. The IPF classified all the extracted concepts, and most rational appraisals fell in the biological (B) domain. The concepts that required emotional appraisal were classified in Psychology (P).

**Conclusion:** Psychological and emotional factors were pivotal in defining functioning in patients with BC.

## ARTICLE HISTORY

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## KEYWORDS

Breast cancer survivors;  
ICF; function;  
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Framework; core set

## ► IMPLICATIONS FOR REHABILITATION

- Rehabilitation specialists need to consider a holistic approach to breast cancer survivor care that addresses physical functioning and social, emotional, and environmental factors that may affect their overall well-being.
- The findings suggest that rehabilitation interventions that aim to improve the functioning of breast cancer survivors should target a range of areas, including body functioning, physical functioning, social functioning, and mental functioning.
- It is important for rehabilitation professionals to consider personal, emotional, and environmental factors that influence the functioning of breast cancer survivors when designing interventions.
- Using the ICF Core Set for Breast Cancer and the IPF can help rehabilitation specialists better understand the functioning of breast cancer survivors and develop more effective interventions.

## Introduction

Breast cancer is currently the most widespread cancer among women worldwide, with 2.3 million new cases identified in 2020, accounting for 11.7% of all cancers. It is the fifth leading cause

of cancer mortality worldwide, with 685,000 deaths [1]. The disease's advances in multiple treatment approaches (such as surgery, radiotherapy, chemotherapy, and hormone therapy) have increased the number of breast cancer survivors [2]. After treatment, many survivors will experience a wide range of medical, physical,

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cognitive, and emotional treatment-related symptoms that affect their daily lives [2, 3]. The type and extent of women's problems are significantly different. Fatigue, cognitive problems, pain, lymphedema, fear of disease recurrence, poor body image, premature menopause, mood disorders, and sexual dysfunction have widely caused long-term distress in these patients [4]. Side effects of treatment and inactivity secondary to treatment have impaired women's ability to maintain functioning and participate in meaningful daily activities in self-care, leisure, and social activities, affecting their quality of life and causing long-term disability in these patients [5]. These cases may, in turn, negatively affect the economic situation and disrupt interpersonal relationships [6].

Before, functioning was considered a physical function, such as muscle strength, range of motion (ROM), and cardiopulmonary endurance [7, 8]; however, the International Classification of Functioning, Disability, and Health (ICF) uses this multidimensional or biopsychosocial approach to describe functioning with a broad perspective that includes one's physical condition and aspects of emotional, psychological, and environmental-social conditions [7]. The ICF core sets have been developed for several health conditions, including breast cancer, to facilitate the implementation of the ICF in clinical practice [9]. The core set provides a systematic framework to cover a range of functions and disabilities associated with breast cancer. The core set provides a systematic framework to cover a range of functions and disabilities associated with breast cancer. The core set for breast cancer contains 81 categories in different areas: 26 body functions, 9 body structures, 23 activities and participation, and 23 environmental factors [10]. Previous studies aimed to develop questionnaires that included the items extracted from the core set [11, 12]; however, the content validity of the ICF core set for breast cancer is limited to addressing various cancer-related issues [13].

Findings from validation studies on the ICF core set for breast cancer performed in a limited number of countries, such as Germany, Australia, Ireland, and Korea, have led to adding categories to different parts of this core set [14–17]. The extra extracted codes differ among women with breast cancer in different contexts and environments. For example, in a study by Glaessel et al. some codes were extracted from personal factors, such as lack of knowledge about the disease, pain self-management, and adaptive strategies, which were not considered in the core set of breast cancer [14]. Another study reported extra codes such as changing social attitudes, supportive role of pets, economic policies and systems, placement and employment and categorized them in environmental factors [16].

Therefore, considering the socio-cultural differences in the definition of functioning in patients with breast cancer, we aimed to explore the area of functioning in which the patients would have problems based on the experience of therapists and physicians who treated patients with BC with a quantitative method and link the extracted concepts to the ICF categories.

## Materials and methods

### Study approach/design

*Interpretive description* [18] was used to help us to understand the functions of women with breast cancer. It is an inductive approach that focuses on capturing themes and patterns within subjective perceptions of the patients and generating an interpretive description to help us understand their functioning. In this method, the investigator does not act as an independent observer but co-creates the knowledge using previous theoretical or practical knowledge [19]. This is consistent with the relationship between

the study's clinical researchers and the breast cancer community participant members.

### Sampling, recruitment

We used purposeful sampling for recruiting the patients and snowball sampling for the experts. Our local ethical committee approved the research protocol. Informed consent was obtained from all subjects involved in the study. We did not report personal factors associated with the quotes to keep anonymity.

### Data collection

The interview guide was designed to explore a sequential pathway of topics related to breast cancer patients' functioning and health. We used a semi-structured interview that guided us based on the research question. We included women over 18 years of age, with an initial breast cancer diagnosis, in stages I–III >6 months or <4 years after their initial medical treatment (surgery, radiation therapy, hormone therapy, and chemotherapy). We included patients who could communicate verbally and who consented to express interviews. Hospitalized women with breast cancer were excluded from the study. One experienced occupational therapist conducted the interviews by asking all significant questions and exploring issues that needed clarification or where the participant wished to add additional information based on a semi-structured interview guide. We also interviewed specialists with at least five years of experience treating breast cancer patients. We aimed to know the definition of functioning and the area of functioning in which the patients would have a problem based on the experience of therapists and physicians who treated patients with BC. The participants were interviewed in person or by phone for 45–60 min from November 2020 to April 2021. Most interviews ( $n=35$ ) were conducted remotely due to restrictions from the recent pandemic (COVID-19) (Table 1).

#### Interview guide

##### Sample of questions in the interview guide for patients

The following questions guided the interview (this is a translation from Persian; probes were dependent on responses).

- 1) "Can you tell me how your life has been affected since you experienced the disease and treatment?"
- 2) "What actions can you not do during the day, or what actions make you feel uncomfortable? Alternatively, what actions make you feel most irritated?"
- 3) "What factors can help you cope better with your condition? Or what are the factors that make you perform better? Or what factors are making your functional condition worse?"
- 4) "What factors hold back your progress in doing your actions? Or what factors stop you from doing your actions better?"
- 4) "What factors hold back your progress in doing your actions? Or what factors stop you from doing your actions better?"

### Analysis of data

Data analysis was conducted in three main phases.

#### Phase one: Thematic analysis

The recorded interviews were transcribed and qualitatively analyzed using thematic analysis within an interpretive description approach. Thematic analysis was used to help us identify, categorize, analyze the transcript, and report the themes concerning the study purpose [20]. The analysis was performed based on the proposed six phases of thematic analysis described by Braun and

**Table 1.** Demographic characteristics of patients and experts.

	Patients		Experts		
	Mean (SD)	frequency	Mean (SD)	frequency	
Age	46.38 (9.164)	16	Age	41.14 (6.213)	22
Education	Diplom or High school	10	Oncologist and surgeon		4
	Bachelor or lower	5	Lymph therapist		3
	Higher	1	Physical therapist		3
Job	Employed	2	Occupational therapist		3
	Retired	1	Psychologist		3
	Housewife	13	Nurse		3
Marital status	married	15	Social worker		3
	single	1			
Time passed from surgery	<1 year	7	Year of experience	5 years	10
	1-2 years	7		5-10 year	9
	>2 years	2		Higher than 10 years	3
Involved side	Right	9			
	Left	7			
Type of Surgery	Mastectomy	5			
	Non-mastectomy	11			

**Table 2.** Formulas for ICF linkage coverage.

ICF linkage	Formula
Absolute linkage	Number of items linked to a code (s) appearing in the Core Set/Total numbers of the item in a measure $\times 100\%$
Core set representation	Number of unique ICF codes from the measure that appear in the Core Set/Total number of the codes in coreset $\times 100\%$
Core set unique disability representation	Number of unique ICF codes from the measure that appear in the Core Set/Total number of the disability codes in core set $\times 100\%$

Clarke (familiarizing with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report) [19,21,22].

We did the repeated coding, classifying, and linkages with repeated immersion into the data several times. We also used the field notes on the data collection process and used them for reflection on the themes. Two authors read the transcribed interviews independently and assigned a descriptive phrase or code to the core concepts. After collecting a set of basic codes, they then compared the codes in a joint session until an agreement on them and their meanings. With the identification of new concepts, the codes were expanded or integrated into different conceptual categories, thereby creating the final main themes, subthemes, and initial codes.

### Trustworthiness of findings

We did the concurrent data collection and analysis. We used constant comparative analysis to verify our data. To improve trustworthiness, we asked two authors to do the coding independently and multiple groups of patients and experts to assess questions and feedback before finalizing the paper. Any identified gap/differences were discussed amongst the researchers until consensus was obtained [23].

### Phase two: Linking to ICF

The meaningful concepts (codes) extracted from the interviews were linked to categories of the ICF core set for breast cancer based on the modified ICF linking rules [24]. Different viewpoints and categorizations of responses were considered in the linking process. Two authors implemented the initial link independently, and any disagreements were resolved by discussion and agreement in a joint session. A third reviewer was consulted to

determine the appropriate category for cases with persistent disagreement. The extracted meaningful concepts were linked to the second and third levels of the ICF codes. In the absence of an ICF category covering a specific aspect of a concept, that concept was linked to the "other specified" category; if little information existed for a concept to be assigned to an ICF category, it was linked to the unspecified category. If there were multiple meanings for a meaningful unit, it was linked to more than one ICF category. If a meaningful concept was not covered by the ICF categories but was defined explicitly as personal factors by the ICF, that concept was designated as "pf." Concepts unrelated to the ICF were expressed in two ways. If a concept was not sufficiently defined to decide on its belonging to an ICF category, it was expressed as "nd" (non-definable). If the ICF did not represent a concept, it was labelled "nc" (not covered) (Rule 10) [24].

The ICF linkage was calculated based on the recommendation formula; we calculate absolute linkage to know the percentage of items from a measure that could be linked to ICF codes (Number of items linked to a code (s) appearing in the Core Set/ Total numbers of the item in a measure  $\times 100\%$ ), Core Set Representation ((Number of unique ICF codes from the measure that appear in the Core Set/total number of the codes in coreset)  $\times 100\%$ ), and Core Set Unique Disability Representation ((Number of unique ICF codes from the measure that appear in the Core Set/total number of the disability codes in core set)  $\times 100\%$ ) [25] (Table 2).

### Phase three: Classification using IPF

We linked the contents of psychological functioning, the experience of emotions or the impact of negative thinking, which were important for patients with the Item Perspective Classification (IPF) [23]. The extracted meaningful concepts from the interviews were classified based on the guidelines proposed by Rosa et al.

[23]. In the first step, the context of the meaningful concept was determined, and the type of appraisal presented with the concept (rational or emotional) was identified. Extracted concepts were classified as either "emotional" or "rational" appraisals [26]. "Emotional" appraisals (E) were used when the concept was related to the patient's emotions or feelings at present time. Any inquiries into emotions/feelings that have occurred in the *past* or "*in general*" were classified as rational appraisals (R) since they require retrieval of memories of previous psychological states.

At the second step, we identified the concept domains represented in extracted meaningful concepts. Based on the IPF framework, four concept domains represent all subjective and objective evolutionary levels of reality that are amenable to human perception, namely inorganic (I), for example: "Does your chair have a proper armrest?"; biological (B), for example, "rate the level of your pain?"; social (S), for example, "if the pain affected your social life?" or psychological (P), "do you feel depressed or feel less capable because of your pain?" [27].

In the final step, the relationships between two or more concepts presented within a meaningful concept were identified and described. We used the symbols to classify the nature of relationships, including *interactive* relationships "\*", "no relationship." Vague, unclear concepts were classified as "open-ended" ("X").

## Results

### Themes

The present study aimed to provide a comprehensive overview of the functional problems faced by breast cancer (BC) survivors, as well as to identify the factors that act as facilitators and barriers to their functioning. The data was obtained through interviews with BC survivors and specialists who had experience working with this group of patients. A total of 849 initial codes were extracted, from which 660 (78%) codes were related to functioning in BC survivors.

Nine subthemes were identified that defined the factors contributing to functioning in BC patients. These subthemes included factors related to impairment, physical function, mental function, social life, self-perception, emotional interactions with family and friends, cost of treatment, health system, and personal emotions. The subthemes were further categorized into four main themes, including body functioning (189, 29%), physical functioning (186, 28%), social functioning (108, 16%), and mental functioning (177, 27%).

In addition to the functional codes, we also identified other factors that acted as modifiers affecting the level of function. These modifiers were categorized as personal, emotional, and environmental factors. The findings of this study emphasize the importance of considering the multidimensional aspects of functioning in BC survivors and highlight the need for tailored rehabilitation interventions that target the specific needs of these patients (Table 3).

### Body functioning

The most reported impairments that were problematic for patients in this study were pain, sensation (74 extracted codes which compromised 39% of entire body function and structured codes) and fatigue (57 extracted codes which compromised 30% of entire body function and structured codes). Sixteen patients (P) and 21 experts (E) reported problems with pain, sensation, fatigue, lymph, skin, heart, and respiratory dysfunctions.

"I have pain in my axilla and side of the affected side" (P12: 21 months since surgery), "I have severe pain in the scapula of the affected side" (P16: one year after surgery), ("Pain in the shoulder area, pain in the chest and back, pain in the arm, pain in the lateral part of the trunk and sides, pain in the axilla, neck pain due to the heaviness of the hand edema." (E11: 5 years of experience in surgery)

### Physical functioning

The study identified the most common physical functioning problems reported by patients with disabilities. The most frequently reported issues were related to difficulties in performing self-care, including basic Activities of Daily Living (ADL) such as bathing, dressing, grooming, toileting, eating, and transferring oneself from one place to another, as well as more complex Instrumental Activities of Daily Living (IADL) such as shopping, cooking, managing finances, using transportation, and performing household chores. Seventy-three codes (39% of the body's functional ICF codes) were extracted in this category.

Patients also reported difficulties in sexual (38 extracted codes, 20% of the entire contents of ICF in body functioning), overhead functioning (29 extracted codes, 16% of the entire contents of ICF in body functioning), weightlifting (27 extracted codes, 14.5% of the entire contents of ICF in body functioning), manipulation and pushing (10 extracted codes, 5% of the entire contents of ICF in body functioning), and sleep (9 extracted codes, 5% of the entire contents of ICF in body functioning). These problems were directly related to the patient's impairment level, including pain and sensation, fatigue, and lymph.

Among the categories, problems with self-care, ADL, and IADL were more commonly reported by both groups of participants (16 patients and 16 experts). Household chores such as dusting, cleaning, washing dishes, making the bed, and sweeping received more complaints.

Overall, the study highlights the challenges faced by patients with disabilities in their daily lives, particularly concerning self-care, ADL, and IADL. These findings underscore the importance of addressing these issues in rehabilitation and support services to improve the quality of life for patients with disabilities.

"I cannot clean and dust the house with the injured hand due to heaviness, edema and pressure on the hand" (P14). "By doing repetitive tasks such as sweeping, the hand becomes swollen" (E7: 5 years of experience) and "they are unable to do continuous housework." (E2:10 years of experience)

"I am much slower in housework. I am not as hard as I used to be working and living; I cannot go up the stairs quickly, for example, I cannot do housework in a row; whatever I do, I must sit for a quarter to twenty minutes to find some energy to start the next work again." (P2: under 1 year since surgery)

Ever since I got sick, I have felt sad and sad about the future of my family life as I cannot support them anymore and I cannot do even my self-care; I think I have been depressed" (P13: 2 years since surgery)" I'm sad that I cannot have the previous routine of my life. (P12: 21 months since surgery)

### Social functioning

The study identified a total of 108 extracted codes related to different areas of life experienced by patients with disabilities. Most of the problems in the social functioning category were raised by 15 patients and 20 experts, which accounted for 59 codes (55% of the whole ICF social functioning). The other areas identified were leisure and sport (20 codes, 18.5%), work (18 codes, 17%), religious (10 codes, 9%), and driving (1 code, 1%).

**Table 3.** Frequencies of main themes, and initial codes (core codes) of functioning in patients and experts.

Themes		Meaningful concepts	Frequency Patients	Frequency experts	
Impairment (189) [patient (16), experts (21)]	Pain and sensation (74) [patient (14), experts (18)]	Pain at rest in the upper limb of the affected side	6	16	
		Pain in the upper limb of the affected side during daily activities	11	5	
		Sense of numbness at rest in the upper limb of the affected side	2	4	
		Sense of numbness in the upper limb of the affected side during daily activities	4	1	
		Sense of stretching or prickling in the upper limb of the affected side during daily activities	11	1	
		Sense of heaviness in the upper limb of the affected side during daily activities	1	6	
		Tingling sensation in the upper limb of the affected side	3	3	
		Total	38	36	
		Fatigue (57) [patient (14), experts (17)]	Decreased physical ability and fatigue during daily activities	12	17
			Decreased physical ability and fatigue during work activities	5	8
	Performing repetitive and long-term movement activities with the upper limb of the shoulder and elbow (such as reaching hands behind the neck and the back, closing buttons on the back of the neck, underwear tie)		3	0	
	Performing long-term movements with fingers and wrists (e.g., writing, drawing, using a knife to chop vegetables or making salads, grating, long-time holding of books/cellphones)		7	5	
	Total		27	30	
	Lymph and skin (44) [patient (12), experts (18)]		Skin problems such as skin discoloration, darkening, dryness, thinness, tightness, and changes in nails	8	10
		Swelling in the upper limb and torso of the affected side (edema)	8	18	
		Total	16	28	
	Hearth and respiratory (14) [patient (8), experts (5)]	Respiratory problems such as dyspnea and severe coughs	0	2	
		Heart problems	8	4	
		Total	8	6	
	Physical function (186) [patient (16), experts (22)]	Sexual (38) [patient (7), experts (15)]	Difficulty with weight maintenance (obesity and overweight)	4	3
			Problems with sexual function	3	11
			Problems with menstrual functions	2	9
			Problems with pregnancy function (sterility/infertility)	1	5
			Total	10	28
		Overhead functioning (29) [patient (10), experts (13)]	limited ROM of the shoulder	1	13
			Performing overhead movements, such as raising hands above the shoulder level (picking items from the top floor of refrigerators, kitchen cabinets)	9	6
			Total	10	19
Manipulation and pushing (10) [patient (7), experts (1)]		Pressing tough/hard things with the affected hand such as pushing the door	1	0	
		Screwing lids on stiff bottles	2	0	
	Grasping fine/small objects with hands	1	0		
	Squeezing and pressing clothes, cleaning clothes	5	1		
	Total	9	1		
Weightlifting (27) [patient (14), experts (13)]	Lifting and carrying heavy equipment and loads (e.g., heavy shopping bags, carrying bags on the shoulder, moving heavy pots while sieving rice)	14	13		
	Total	14	13		
Self-care, ADL and IADL (73) [patient (16), experts (16)]	Dressing/undressing clothes	8	7		
	Personal hygiene (e.g., bathing or showering, washing hair, cleaning after defecation, make-up)	8	2		
	Doing household chores (e.g., dusting and cleaning the house, washing dishes, making the bed, sweeping)	15	13		
	Cooking	3	6		
	Caring for others (e.g., hugging babies, caring for children and others)	3	8		
	Total	37	36		
	Sleep (9) [patient (6), experts (3)]	Sleeping on the affected side	6	3	
		Total	6	3	
Mental functioning (10) [patient (2), experts (5)]	Cognition (10)	attention and concentration problems in doing daily activities	1	4	
		Problems with memory and amnesia in doing daily tasks	1	4	
		Total	2	8	

(Continued)

Table 3. Continued.

Themes	Meaningful concepts	Frequency Patients	Frequency experts	
Emotional function (167) [patient (15), experts (21)]	Sense of losing the beauty of appearance such as muddled appearance and unfitting appearance/clothing	3	3	
	One's lifestyle	11	8	
	One's viewpoints and attitudes toward disease and life	2	3	
	Levels of education and literacy	0	6	
	Sense of distress and sadness	11	15	
	Sense of loneliness	2	1	
	Sense of fear and fear of relapse	9	13	
	Concern about the disease impact on personal life	1	11	
	Feeling worried about the future of the disease	3	14	
	Feeling worried about the future	5	4	
	Feel guilty	1	2	
	Sense of burdensomeness and inattention in the family	0	3	
	Lack of motivation and impatience	2	4	
	Sense of hopelessness about the future	2	6	
	Sense of disability and disablement	5	5	
	Sense of failure in performing tasks and duties	1	0	
	Irritability/angriness and losing temper	3	0	
	Non-expression of feelings and emotions/not talking about one's feelings and emotions toward people and daily life events	2	4	
	Mental fatigue	0	2	
	Total	50	87	
Social functioning (108) [patient (15), experts (20)]	Driving (1) [patient (1)]	1	0	
	Social life and interaction/communication (59) [patient (13), experts (19)]	1	5	
	Spousal relationships such as intimate and sexual relationships	5	15	
	Communication with family members such as father, mother, sister, brother, and children	0	6	
	Communication with other people such as friends, relatives, acquaintances, and colleagues	9	10	
	Communication with recovered individuals and peer groups	3	4	
	Going out of the house	0	1	
	Total	18	41	
	Work (18) [patient (5), experts (13)]	Job-related matters	5	13
	Leisure and sport (20) [patient (8), experts (7)]	Light sports activities (such as walking)	2	2
		Heavy sports activities (such as yoga, aerobics, swimming, badminton)	2	3
		Doing finger-related leisure activities (e.g., writing, sewing, knitting, working with cellphones, playing musical instruments)	6	5
	Total	10	10	
	Religious (10) [patient (7), experts (3)]	Patients' religious beliefs	7	3
	Modifiers: Personal factors Factor related to self-perception (37) [patient (4), experts (19)]	Body scheme (17)	1	16
Changes in the appearance of the breast and hand by mastectomy and swelling of the affected side		1	4	
Decreased self-confidence		4	11	
Problems with body image		6	31	
Factor related to Emotional interactions with family and friends (53) [patient (12), experts (18)]	Total	3	4	
	Lack of emotional support from spouse, children, and family members such as father, mother, sister and brother	2	0	
	Emotional support from relatives, acquaintances, friends and colleagues	7	14	
	lack of help, accompaniment and support of spousal, children, and family members in daily activities	4	4	
	Compassionate and sympathetic behaviors of companions	5	10	
	Incorrect judgments of companions about one's disease	21	32	
Total	21	32		
Modifiers: environmental factors Factors related to the cost of treatment (49) [patient (8), experts (18)]	High costs of disease treatment	5	15	
	inaccessibility to medicines from distribution centers such as pharmacies	5	2	
	Non-coverage of treatment costs by health insurance firms	2	11	
	Financial inability to provide assistive devices such as breast prostheses, bandages, and compression sleeves (use of support systems or donors to undertake treatment costs)	2	7	
	Total	14	35	

(Continued)

Table 3. Continued.

Themes	Meaningful concepts	Frequency Patients	Frequency experts
Factor related to health system (50) [patient (9), experts (14)]	Insufficient information about the disease and its treatments from treatment team members	3	10
	Lack of support, understanding, and accompaniment of the patient treatment team	6	7
	Lack of psychological and palliative support to the patient during treatment	2	4
	Lack of support and accompaniment from employers, such as employers' understanding of the patient's disease	1	2
	Inaccessibility to disease-related educational programs and its treatments at hospitals and medical clinics such as group therapy programs, etc.	0	5
	Poor service quality at public hospitals	2	2
	Screening of healthy women by the health system	2	4
Total		16	34

The problems reported by both patients and experts indicated that the level of impairment and physical functions are significant factors contributing to difficulties in these areas. Notably, the most common problem in social functioning was "Spousal relationships such as intimate and sexual relationships."

These findings highlight the various challenges faced by patients with disabilities in different areas of their lives. Therefore, a comprehensive approach to rehabilitation and support services is necessary to address the diverse needs of patients with disabilities.

"Sex with my wife was interrupted because my body's ability and endurance were deficient; then, the menopausal symptoms bothered me a lot; the injections I was taking to disable the ovaries and uterus bothered me a lot." (P2: under one year since surgery). "Decreased sexual intercourse with the spouse and dissatisfaction with sexual activities due to a disorder in the body's appearance and hiding one's appearance from the spouse, discomfort in bed during sexual intercourse due to swelling of the hands and trunk." (E15: 10 years of experience)

### **Mental functioning**

The study identified a total of 10 extracted codes related to mental functions mentioned by two patients and five experts. These codes were related to problems with attention, concentration (5 codes, 50% of the extracted codes), and memory and amnesia (5 codes extracted which accounted for 50% of the entire ICF codes) in daily tasks.

The content of mental functions also revealed that breast cancer survivors experienced various negative emotions such as loneliness, concerns about the disease's impact on personal life, worry about the disease's future, feelings of guilt, hopelessness about the future, among others. The reciprocal relationship between difficulties in performing ADL, IADL, and self-care with emotional problems was also evident. Patients reported negative emotions in response to their level of functioning in self-care, ADL, and IADL. They also expressed that they cannot perform their functional activities due to emotional problems.

### **Modifiers of function**

We also extracted codes that were modifiers of functioning and categorized them into three themes: environmental, personal, and emotional factors.

### **Environmental factors**

**Factors related to the costs of treatment.** The study also investigated environmental factors that may impact breast cancer survivors'

ability to access necessary treatments and support systems. Eight patients and 18 experts reported problems related to the costs of treatment. The extracted codes in this theme included the high cost of treatment (20 codes extracted, which were 41% of the whole ICF environmental factors), lack of insurance coverage for some drugs (13 codes, 26.5%), difficult access to some drugs (7 codes, 14%), and a lack of support systems and charities in the community to pay for assistive devices such as breast prostheses, bandages, and pressure gloves (9 codes, 18%). These findings highlight the financial burden faced by breast cancer survivors and the need for accessible and affordable healthcare options.

**Factors related to health systems.** The study conducted by nine patients and 14 experts revealed 13 extracted codes related to environmental factors classified as factors related to the healthcare system. The most commonly reported problem was the "insufficient information about the disease and its treatments from treatment team members" and the "lack of support, understanding, and accompaniment of the patient treatment team," accounting for 26% of the whole ICF codes for the environmental factors.

Concepts related to health systems in this study by breast cancer survivors and specialists mainly indicated deficiencies in providing psychological and palliative services, educational programs, and screening of healthy women. In many cases, there was also a poor understanding and support of the treatment team in informing patients, which could be an inhibitor in improving the performance of these women.

Women are not trained to examine their breasts; if this is done, it will cause women to come sooner, and their disease condition will not worsen, and they will not have to have their breasts removed completely. (P8: under 1 year since surgery)

### **Personal and emotional factors**

**Factors related to personal emotions.** According to the study, personal and emotional factors were associated with 48 extracted codes, as reported by 15 patients and 21 experts. The two most common issues in this domain were a "sense of distress and sadness," which accounted for 26 codes (54% of the personal and emotional factors codes), and a "sense of fear and fear of relapse," which accounted for 22 codes (46% of the personal and emotional factors codes). Negative emotions experienced by breast cancer survivors included a sense of loneliness, concerns about the disease's impact on their personal life, worries about the future of the disease, feelings of guilt, and hopelessness about the future. The most frequently mentioned negative emotions by patients were a sense of distress and sadness and a sense of fear and fear

of relapse. They reported that these negative emotions affected their ability to perform self-care, activities of daily living (ADL), and instrumental activities of daily living (IADL).

"I am sad that I cannot have the previous routine of my life (P12: 21 months since surgery). Ever since I got sick, I have felt sad and sad about the future of my family life; I think I have been depressed" (P13: 2 years since surgery). (The patient becomes depressed and isolated due to a change in their breast appearance and edema of the hand, they feel uncomfortable with the tightness of the clothes she has already worn with the swelling created in her hand." (E9: 5 years of experience)

"I am always stressed by the negative impact of chemotherapy and cancer" (P12: 21 months since surgery). "I am afraid of disease and death" (P8: under 1 year since surgery) "Patients have stress and anxiety due to not returning to normal life activities (whether housework or work activities) and are also afraid of leaving their spouse and remarking." (E15: 10 years of experience)

**Factor related to self-perception.** Out of all the ICF codes related to personal and emotional factors, 46% of the extracted codes were related to problems in self-perception. Specifically, four patients and 19 experts reported such problems. The most common complaint in this area was related to body scheme, which accounted for 17 codes, which are equivalent to 46% of the total codes for emotional factors in the ICF. These issues included changes in appearance resulting from the removal of all or part of the breast, as well as swelling caused by the removal of lymph nodes, which affected the individual's mental image. The impact of self-perception on communication in social life was also highlighted.

"I was afraid of the bad reaction of my children and my wife to the mutilation and removal of my breast" (P2: under one year since surgery)" Young women felt the loss of physical beauty and acceptance of breast resection." (E16: 8 years of experience)

**Factors related to emotional interactions with family and friends.** Twelve patients and 18 experts reported a total of codes on personal and emotional factors related to problems in emotional interactions with family and friends. These codes accounted for a certain percentage of the overall ICF codes related to personal and emotional factors. The most frequently reported problem in this category was a lack of help, accompaniment, and support from spouses, children, and family members in daily activities, with a total of 21 codes, equivalent to 40% of the codes related to emotional interactions with family and friends. Participants expressed their concerns about emotional interactions, help, and companionship with those who interacted with them in the family and community environment. Some patients reported negative feelings due to incorrect judgments about their capabilities or receiving excessive support or compassion. The most common concept mentioned by patients and specialists in this theme was the need for help, accompaniment, and support from spouses, children, and family members in daily activities, which played a significant role in their emotional interactions with others.

"Sometime after my illness, my wife refused to accompany me, and I even paid for the hospital myself, "everyone around me was kind of tired, or I finally gave up, and after two years, I was left alone. " I need someone to accompany me for chemotherapy. I called my relatives to be by my side, but they refused, so I am alone for about 7 or 8 sessions now." (P2: under 1 year since surgery).

We also extracted some extra 30, 3.5% codes that could not be classified as functioning directly; however, they could be

considered facilitators or barriers to functioning in BC survivors. Most of the extracted codes were related to coping strategies (19, 63% codes), level of literacy and education (6, 20% codes), and personal views and attitudes toward illness and life (5, 17% codes).

For example, some patients stated that their perception of life had changed for the better:

"My outlook on life and the world has changed since I became ill, and I try to enjoy my life more and increase my satisfaction with life and the present" (P7:1 year since surgery), or another patient would say, "After the illness, I try to enjoy more of my free time with my family." (P12: 21 months since surgery)

Experts also indicated that individuals' literacy levels sometimes helped them benefit from educational facilities (brochures or YouTube links). However, interviews revealed that patients with lower literacy levels were better able to cope with their illness. In contrast, patients with higher literacy levels were more stressed. Some patients indicated that they tried to change their lifestyle to cope with the illness. They increased the time in their leisure time and tried to have healthy eating and practice doing their self-care independently.

"I think doing my self-care can help me a lot. Everyone should take care of themselves so that one does not take care of oneself and cannot expect from others. For example, I now regularly take my medicine, regularly check with my doctor, or communicate and reach Completely to the sport that I have at home" (P1: 20 months since surgery) " After the illness, my compatibility has improved to cope with the appearance of my body. I listen to music to increase my peace of mind and reduce my mental distress." (P16: under 1 year since surgery) (Figure 1)

### Linking to ICF

#### Extracted meaningful concepts from the interview with breast cancer survivors

Of the 338 concepts extracted from patient interviews, 146 (43%) concepts were linked with the ICF Body function and structure, 121(36%) to activity and participation, 44(13%) to environmental factors and 11 (3%) to personal factors category.

Patients reported difficulty in different areas of body function such as Chapter B1: mental function (44, 30%), Chapter B7: Neuromusculoskeletal and movement-related functions (25, 17%), Chapter B4: Functions of the cardiovascular, hematological, immunological, and respiratory systems (33, 23%), and Chapter B2: Sensory functions and Pain (23, 16%). The highest frequency of reported functional problems was related to b152 Emotional functions (25, 17%), b2801 Pain in body parts, and b455 Exercise tolerance functions (17, 12%).

Patients reported difficulties in D4: Mobility 37 (30.5%), D5: Self-care (16,13%), D6: Domestic life (21, 17%), D7: Interpersonal interactions and relationships (17, 14%), D8: Major life areas (12, 10%) and D9: Community, social and civic life (18,15%). The majority of the raised problem in the activity and participation area were Doing housework (d640-15,12%) and lifting and carrying objects (d430-14, 11.5%).

Some of the raised difficulty areas from the patient's view could not be linked with any codes and categories of the core set for breast cancer. However, they were linked to eight codes from body function and 14 codes from activity and participation (Table 4).

The other 27 concepts could not be linked to the ICF. The content of the meaningful concepts, which could not be assigned to the most precise ICF categories, were classified into three

concepts based on the updated linking. The concept refers to mental health (nd-mh: Sense of losing the beauty of appearance, Sense of loneliness, feeling guilty, sense of hopelessness about the future, Sense of disability and disablement and Sense of failure in performing tasks and duties) and concepts that cannot be covered by the ICF (nc; non-coverage of treatment costs by health insurance firms), and the concepts referred to personal factors (one's lifestyle) (Table 4).

#### *Extracted meaningful concepts from the interview with specialists*

Of the 511 concepts extracted from specialists' interviews, 246 (48%) concepts were linked with the ICF Body function and structure, 147 (29%) to activity and participation, 71 (14%) to environmental factors and 14 (3%) to personal factors category. Specialists reported difficulty in different areas of body function such as were Chapter B1: mental function (104, 42%), Chapter B7: Neuromusculoskeletal and movement-related functions (26, 10%), Chapter B4: Functions of the cardiovascular, hematological, immunological, and respiratory systems (49, 20%), Chapter B2: Sensory functions and Pain (26, 10%), and Chapter B6: Genitourinary and reproductive functions (25, 10%). The highest frequency of reported functional problems was related to b152 Emotional functions (32, 13%), b160 Thought functions (29, 12%), b1801 Body image (27, 11%), b455 Exercise tolerance functions (25, 10%), and b2801 Pain in body parts 21 (8.5%).

Specialists reported difficulties in D4: Mobility 22 (15%), D5: Self-care (9, 6%), D6: Domestic life (28, 19%), D7: Interpersonal interactions and relationships (35, 24%), D8: Major life areas (35, 24%) and D9: Community, social and civic life (18, 12%). The majority of raised problem in activity and participation area were Economic self-sufficiency (d 870-22, 15%), Intimate relationships (d770-15, 10%), Lifting and carrying objects with (d430-13, 9%), Doing housework (d640-13, 9%) and Remunerative employment (d850-13, 9%).

Some of the raised difficulty areas from the specialists' view could not be linked with any codes and categories of the core set for breast cancer. However, they were linked to nine codes from body function and ten codes from activity and participation (Table 5).

The other 47 concepts could not be linked to the ICF. The content of the meaningful concepts, which could not be assigned to the most precise ICF categories, were classified into three concepts based on the updated linking. The concept refers to mental health (nd-mh: Sense of losing the beauty of appearance, Sense of loneliness, feeling guilty, Sense of burdensomeness and inattention in the family, Sense of hopelessness about the future, Sense of disability and disablement, mental fatigue) and concepts that cannot be covered by the ICF (nc; non-coverage of treatment costs by health insurance firms), and the concepts referred to personal factors (one's lifestyle, levels of education and literacy) (Table 5).

In total, 592 meaningful concepts were linked with at least a comprehensive ICF Core Set category for BC, resulting in an absolute linkage score of 70%. Thirty-eight meaningful concepts were linked with a unique code comprehensive Core Set for BC, resulting in a unique linkage score of 4%. Concepts extracted in this study represented the Core Set for BC with 47% of coverage. The disability representation score for the extracted concepts was 61%.

#### *Classification of the extracted meaningful concepts based on ICF*

Two hundred seventy-one concepts from the interview with patients and 398 concepts extracted from the interview with

specialists required rational appraisal. In contrast, 67 concepts from the interview with patients and 113 meaningful concepts extracted from the interview with the specialist required emotional appraisal.

Out of 271 Concepts from the interview with patients which required rational appraisal, 195 concepts fell within the biological (B) domain, 34 concepts in the social (S) domain, 11 concepts in the psychological (P) domain, 18 concepts in the Inorganic (I) domain and 13 Concepts in open-ended (X) domain. 41 concepts of the biological domain (B) were interactively related to this domain (B\*B), and 19 other concepts of this domain were related to Social (S) domain (B\*S).

Also, out of 67 concepts from interviews with patients which required emotional appraisal, 58 concepts were classified in the domain of Psychology (P) and nine concepts in the domain of Biology (B). 9 concepts of the biological domain (B) were related to concepts of the psychological domain (P)(B\*P), and 16 of the concepts of Psychological (P) were related to concepts of the social domain (S) (B\*S).

Among the 398 meaningful concepts extracted that required rational appraisal from interviews with experts, 255 concepts fell in the biological (B) domain, 71 concepts in the social (S) domain, 14 concepts in the psychological (P) domain, 41 Concepts in Inorganic (I) domain and 17 concepts in open-ended (X) domain. Thirty-eight concepts of the biological domain (B) were interactively related to this domain (B\*B), and 42 other concepts of this domain were related to the social(S) domain (B\*S).

Also, out of 113 concepts from the interview with experts that required emotional appraisal, 105 concepts were classified in the psychological domain (P) and eight in the biological domain (B). Eight concepts of the biological domain (B) were related to the concepts of the psychological domain (P) (B\*P), and 22 of the concepts of Psychological (P) were related to the concepts of the social domain (S) (B\*S).

The domains of concepts and their relationships are presented in Tables 3–5. In the patients' chart, 60% of the extracted concepts were related to the biological (B) domain. Among the concepts appraised in the biological domain, 41% were classified as "No-related," which indicated no relationship between 41% of the biological concepts and other concepts. In contrast, 19% of the concepts appraised in the biological domain provided dynamic/interactive relationships with biological concepts (B\*B) (12%), social concepts (B\*S) (5%), and psychological concepts (2%).

In the experts' chart, 51% of the extracted concepts were appraised to the biological (B) domain. Among the concepts appraised in the biological domain, 34.5% were classified as "No-related," which indicated no relationship between biological concepts and other concepts extracted from medical specialists. In contrast, 16.5% of concepts appraised in the biological domain provided dynamic/interactive relationships with biological concepts (7%), social concepts (8%), and psychological concepts (1.5%).

## **Discussion**

In this study, we aimed to use the ICF core set for breast cancer to identify areas of functioning in breast cancer survivors from the perspectives of both patients and specialists. Our results showed that breast cancer survivors reported impairments in body functions and structures, activity limitations, and participation restrictions that were different from what experts defined as functional problems in this population. Patients reported difficulties in mobility, support, relationship, and mental function, while

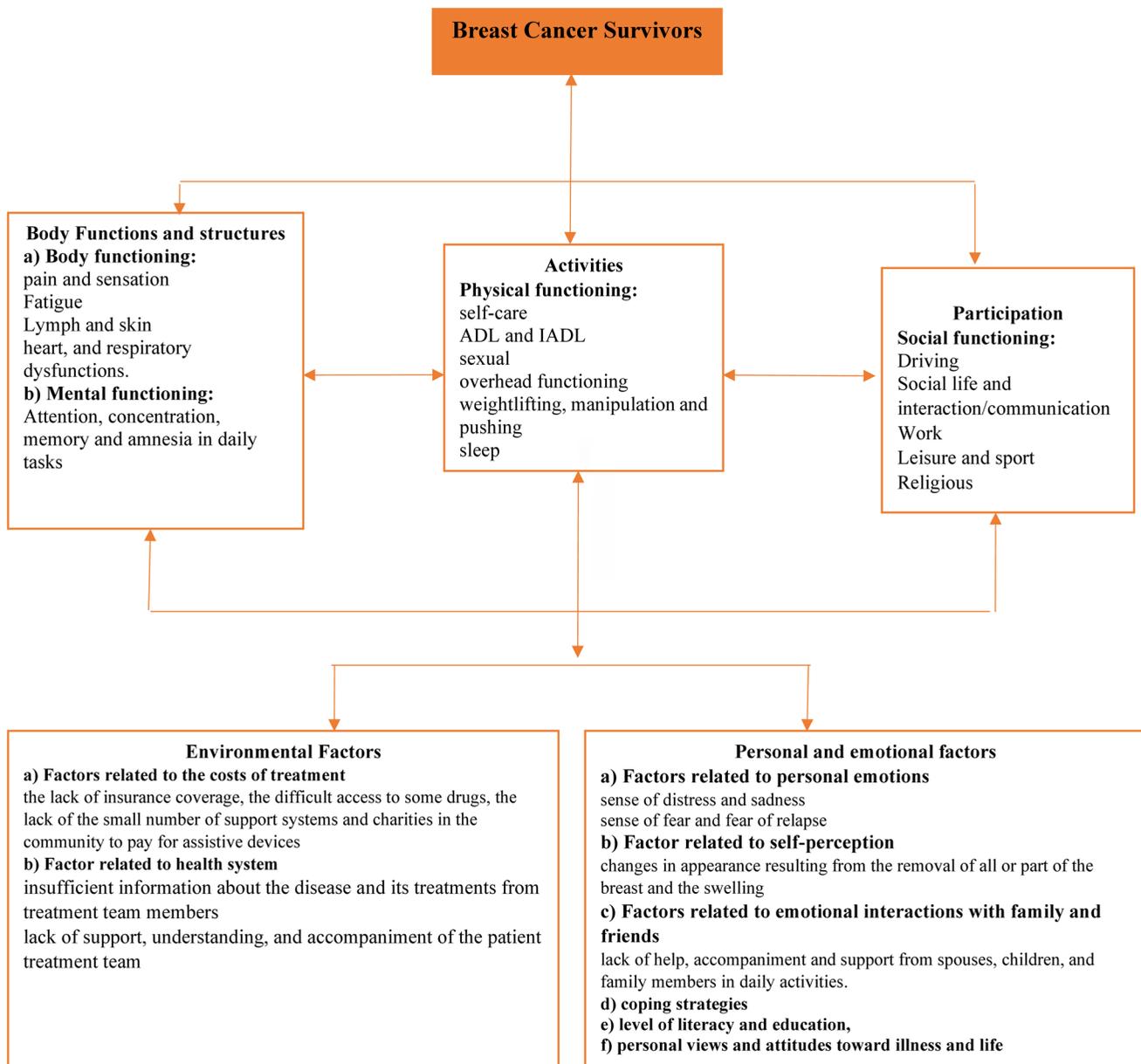


Figure 1. Interactions between the components of ICF.

experts considered emotional problems as the cause of physical function limitations in breast cancer survivors.

BC survivors experience problems and difficulties in response to changes in their body function and structure, affecting their level of function and interaction with society. Most of their problems were related to support, relationship, mental function, and mobility. Patients reported problems in mobility; however, the experts considered emotional problems as a cause for physical function limitations in breast cancer survivors. The results of linking the extracted meaning concepts with IPF [23] showed that patients had problems in the biological (B) domain, which required emotional appraisal and were categorized in the field of Psychology (P). Both groups indicated that problems in support and relationship and attitudes are the most prominent aspect of difficulties in this population.

This study identified problematic body function and structure, which affected the functioning of the patients. The research participants reported problems in different categories in the current version of the comprehensive core set. Besides, similar to previous

studies, additional ICF categories were identified that are not currently included in the Comprehensive Core Set for breast cancer [10]. Previous qualitative studies also reported similar problems extracted from interviews with patients and experts, such as reduced physical ability and fatigue during daily living and working activities [17], skin problems such as skin discoloration, darkening, dryness, thinness, tightness, and changes in nails [16,28], respiratory problems such as dyspnea and severe cough, and heart problems [14,16]. Like previous studies, we also identified cognitive and emotional problems, such as attention and concentration problems, memory problems, and amnesia resulting from chemotherapy and hormonal therapy, affecting the patient's daily activities [14,16,17,29].

Our study identified several issues that were not included in the current ICF core set for breast cancer, such as difficulties with completing long-term movements with fingers and wrists, grasping fine/small objects by hands, maintaining a lying position on the affected side, and numbness. Including patients in the chronic phase may have contributed to these differences, as, they may

**Table 4.** ICF categories and IPC linked to the meaningful concepts were obtained from the interview with breast cancer survivors.

Meaningful concepts	Number of codes	ICF Core Set for breast cancer	General ICF	IPF code
Body functions: 146 [patient (16)]				
B1: Mental functions: 44 [patient (16)]				
Decreased self-confidence :	1	b126 Temperament and personality functions		E_P
Lack of motivation and impatience :	2	b130 energy and drive functions		E_P
Attention and concentration problems in doing daily activities	1		b140 Attention functions	R_B*B
Problems with memory and amnesia in doing daily tasks	1		b144 Memory functions	R_B*B
Sense of distress and sadness:	11	b152 Emotional functions		E_P
Sense of fear and fear of relapse:	9	b152 Emotional functions		E_P
Irritability/angriness and losing temper:	3	b152 Emotional functions		E_P
Non-expression of feelings and emotions/ not talking about one's feelings and emotions toward people and daily life events:	2	b152 Emotional functions		E_P
Concern about the disease impact on personal life	1		b160 Thought functions	E_P
Feeling worried about the future of the disease	3		b160 Thought functions	E_P
Feeling worried about the future	5		b160 Thought functions	E_P
Changes in the appearance of the breast and hand by mastectomy and swelling of the affected side	1	b1801 Body image		R_B
Problems with body image	4	b1801 Body image		R_P
B2: Sensory functions and pain: 23 [patient (14)]				
Sense of numbness at rest in the upper limb of the affected side	2	b265 Touch function		R_B
Sense of numbness in the upper limb of the affected side during daily activities	4	b265 Touch function		R_B*B
Pain at rest in the upper limb of the affected side	6	b2801 Pain in body parts		R_B
Pain in the upper limb of the affected side during daily activities	11	b2801 Pain in body parts		R_B*B
B4: Functions of the cardiovascular, haematological, immunological and respiratory systems: 33 [patient (16)]				
Heart problems	8		b410 Heart functions	R_B
Swelling in the upper limb and torso of the affected side (edema)	8	b4353 Functions of lymphatic vessels		R_B
Decreased physical ability and fatigue during daily activities	12	b455 Exercise tolerance functions	b4552 Fatiguability	R_B*B
Decreased physical ability and fatigue during work activities	5	b455 Exercise tolerance functions	b 4552 Fatiguability	R_B*S
B5: Functions of the digestive, metabolic and endocrine systems: 4 [patient (4)]				
Difficulty with weight maintenance (obesity and overweight)	4	b530 Weight maintenance functions		R_B
B6: Genitourinary and reproductive functions: 6 [patient (6)]				
Problems with sexual function	3	b640 Sexual functions		R_B
Problems with menstrual functions	2	b650 Menstruation functions		R_B
Problems with pregnancy function (sterility/infertility)	1	b660 Procreation functions		R_B
B7: Neuromusculoskeletal and movement-related functions: 25 [patient (12)]				
Limited ROM of the shoulder	1	b710 Mobility of joint functions		R_B
Performing overhead movements, such as raising hands above the shoulder level (picking items from the top floor of refrigerators, kitchen cabinets)	9	b710 Mobility of joint functions		R_B
Performing repetitive and long-term movement activities with the upper limb of the shoulder and elbow (such as reaching hands behind the neck and the back, closing buttons on the back of the neck, underwear tie)	3	b710 Mobility of joint functions		R_B
Sense of heaviness in the upper limb of the affected side during daily activities	1	b780 Sensations related to muscles and movement functions		R_B*B
Sense of stretching or prickling in the upper limb of the affected side during daily activities	11		b7808 Sensations related to muscles and movement functions, other specified	R_B*B

(Continued)

Table 4. Continued.

Meaningful concepts	Number of codes	ICF Core Set for breast cancer	General ICF	IPF code
B8: Functions of the skin and related structures: 11 [patient (9)]				
Skin problems such as skin discoloration, darkening, dryness, thinness, tightness, and changes in nails	8	b810 Protective functions of the skin	b860 Functions of nails, b849 Functions of the skin, other specified and unspecified	R_B
Tingling sensation in the upper limb of the affected side	3	b840 Sensation related to the skin		R_B
Activity and participation: 121 [patient (16)]				
D4: Mobility: 37 [patient (15)]				
Sleeping on the affected side	6		d415 Maintaining a body position	R_B
Lifting and carrying heavy equipment and loads (e.g., heavy shopping bags, carrying bags on the shoulder, moving heavy pots while sieving rice)	14	d430 Lifting and carrying objects		R_B
Performing long-term movements with fingers and wrists (e.g., writing, drawing, using a knife to chopping vegetables or making salads, grating, long-time holding of books/cellphones)	7		d440 Fine hand use	R_B
Grasping fine/small objects with hands	1		d 4402 Manipulating, d4401 Grasping	R_B
Pressing tough/hard things with the affected hand such as pushing the door	1	d445 Hand and arm use	d4451 Pushing	R_B
Screwing lids on stiff bottles	2	d445Hand and arm use	d 4453 Turning or twisting the hands or arms	R_B
Squeezing and pressing clothes, cleaning clothes	5	d445Hand and arm use	d4453 Turning or twisting the hands or arms	R_B
Driving	1		d475 Driving	R_S
D5: Self-care: 16 [patient (10)]				
Personal hygiene (e.g., bathing or showering, washing hair, cleaning after defecation, make-up)	8	d510 Washing oneself, d520 Caring for body parts		R_B
Dressing/undressing clothes	8	d540 Dressing		R_B
D6: Domestic life:21 [patient (15)]				
Cooking	3	d630 Preparing meals		R_B
Doing household chores (e.g., dusting and cleaning the house, washing dishes, making the bed, sweeping)	15	d640 Doing housework		R_B
Caring for others (e.g., hugging babies, caring for children and others)	3	d660 Assisting others		R_S
D7: Interpersonal interactions and relationships: 17 [patient (13)]				
Communication with other people such as friends, relatives, acquaintances, and colleagues	9	d750 Informal social relationships	d740 Formal relationships	R_S
Communication with recovered individuals and peer groups	3		d 7504 Informal relationships with peers	R_S
Spousal relationships such as intimate and sexual relationships	5	d770 Intimate relationships		R_B*S
D8: Major life areas: 12 [patient (7)]				
Job-related matters	5	d 850 Remunerative employment		R_B*S
High costs of disease treatment	5		d 870 Economic self-sufficiency	R_I
Financial inability to provide assistive devices such as breast prostheses, bandages, and compression sleeves (use of support systems or donors to undertake treatment costs)	2		d 870 Economic self-sufficiency	R_I
D9: Community, social and civic life: 18 [patient (10)]				
Participation in gatherings such as attending meetings, religious ceremonies, friendly and formal parties, attending workplace	1		d910 Community life	R_S
Light sports activities (such as walking)	2	d920 Recreation and leisure	d9201 Sports, d450 Walking	R_B*S

(Continued)

Table 4. Continued.

Meaningful concepts	Number of codes	ICF Core Set for breast cancer	General ICF	IPF code
Heavy sports activities (such as yoga, aerobics, swimming, badminton)	2	d920 Recreation and leisure	d9201 Sports	R_B*S
Doing finger-related leisure activities (e.g., writing, sewing, knitting, working with cellphones, playing musical instruments)	6	d920 Recreation and leisure	d440 Fine hand use	R_B
Patients' religious beliefs	7		d 930 Religion and spirituality	R_P
Environmental factors: 44 [patient (13)] E1: Products and technology: 5 [patient (5)]				
Inaccessibility to medicines from distribution centers such as pharmacies	5	e110 Products or substances for personal consumption		R_I
E3: Support and relationships: 24 [patient (12)]				
Lack of emotional support from spouse, children, and family members such as father, mother, sister and brother	3	e 310 Immediate family		E_P*S
Emotional support from relatives, acquaintances, friends and colleagues	2	e325 Acquaintances, peers, colleagues, neighbors, and community members, e320 Friends		E_P*S
Lack of support and accompaniment from employers, such as employers' understanding of the patient's disease	1		e330 People in positions of authority	R_S
Lack of support, understanding, and accompaniment of the patient treatment team	6	e 340 Personal care providers and personal assistants, e 355 Health professionals		R_S
Lack of psychological and palliative support to the patient during treatment	2	e 340 Personal care providers and personal assistants, e 355 Health professionals		E_P*S
Insufficient information about the disease and its treatments from treatment team members:	3	e355 Health professionals		R_S
Lack of help, accompaniment and support of spousal, children, and family members in daily activities	7		e398 Support and relationships, other specified	R_S
E4: Attitudes: 11 [patient (7)]				
Compassionate and sympathetic behaviors of companions	4	e425 Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		E_P*S
Incorrect judgments of companions about one's disease	5	e425 Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		E_P*S
One's viewpoints and attitudes toward disease and life	2		e498 Attitudes, other specified	R_X
E5: Services, systems and policies: 4 [patient (3)]				
Poor service quality at public hospitals	2	e580 Health services, systems, and policies		R_I
Screening of healthy women by the health system	2	e580 Health services, systems, and policies		R_I
Personal factors:11 [patient (11)]				
One's lifestyle Nd-mh: 14 [patient (7)]	11	Pf	pf	R_X
Sense of losing the beauty of appearance such as muddled appearance and unfitting appearance/clothing	3	nd-mh	nd-mh	E_B*P
Sense of loneliness	2	nd-mh	nd-mh	E_P
Feel guilty	1	nd-mh	nd-mh	E_P
Sense of hopelessness about the future	2	nd-mh	nd-mh	E_P
Sense of disability and disablement	5	nd-mh	nd-mh	E_B*P
Sense of failure in performing tasks and duties	1	nd-mh	nd-mh	E_B*P
Nc : 2 [patient (2)]				
Non-coverage of treatment costs by health insurance firms	2	nc	nc	R_I

Table 5. ICF categories and IPC linked to the meaningful concepts were obtained from the interview with medical specialist.

Meaningful concepts	ICF Core Set for breast cancer	General ICF	IPF code
Body functions: 246 [specialists (22)] B1: Mental functions:104 [specialists (22)] Decreased self-confidence	4 b126 Temperament and personality functions		E_P
Lack of motivation and impatience	4 b130 energy and drive functions		E_P
Attention and concentration problems in doing daily activities	4	b140 Attention functions	R_B*B
Problems with memory and amnesia in doing daily tasks	4	b144 Memory functions	R_B*B
Sense of distress and sadness	15 b152 Emotional functions		E_P
Sense of fear and fear of relapse	13 b152 Emotional functions		E_P
Non-expression of feelings and emotions/not talking about one's feelings and emotions toward people and daily life events	4 b152 Emotional functions		E_P
Concern about the disease impact on personal life	11	b160 Thought functions	E_P
Feeling worried about the future of the disease	14	b160 Thought functions	E_P
Feeling worried about the future	4	b160 Thought functions	E_P
Changes in the appearance of the breast and hand by mastectomy and swelling of the affected side	16 b1801 Body image		R_B
Problems with body image	11 b1801 Body image		R_P
B2: Sensory functions and pain: 26 [specialists (18)] Sense of numbness at rest in the upper limb of the affected side	4 b265 Touch function		R_B
Sense of numbness in the upper limb of the affected side during daily activities	1 b265 Touch function		R_B*B
Pain at rest in the upper limb of the affected side	16 b2801 Pain in body parts		R_B
Pain in the upper limb of the affected side during daily activities	5 b2801 Pain in body parts		R_B*B
B4: Functions of the cardiovascular, haematological, immunological and respiratory systems: 49 [specialists (21)] Heart problems	4	b410 Heart functions	R_B
Swelling in the upper limb and torso of the affected side (edema)	18 b4353 Functions of lymphatic vessels		R_B
Respiratory problems such as dyspnea and severe coughs	2	b440 Respiration functions	R_B
Decreased physical ability and fatigue during daily activities	17 b455 Exercise tolerance functions	b4552 Fatiguability	R_B*B
Decreased physical ability and fatigue during work activities	8 b455 Exercise tolerance functions	b 4552 Fatiguability	R_B*S
B5: Functions of the digestive, metabolic and endocrine systems: 3 [specialists (3)] Difficulty with weight maintenance (obesity and overweight)	3 b530 Weight maintenance functions		R_B
B6: Genitourinary and reproductive functions: 25 [specialists (15)] Problems with sexual function	11 b640 Sexual functions		R_B
Problems with menstrual functions	9 b650 Menstruation functions		R_B
Problems with pregnancy function (sterility/infertility)	5 b660 Procreation functions		R_B
B7: Neuromusculoskeletal and movement-related functions: 26 [specialists (13)] Limited ROM of the shoulder	13 b710 Mobility of joint functions		R_B
Performing overhead movements, such as raising hands above the shoulder level (picking items from the top floor of refrigerators, kitchen cabinets)	6 b710 Mobility of joint functions		R_B
Sense of heaviness in the upper limb of the affected side during daily activities	6 b780 Sensations related to muscles and movement functions		R_B*B
Sense of stretching or prickling in the upper limb of the affected side during daily activities	1	b7808 Sensations related to muscles and movement functions, other specified	R_B*B
B8: Functions of the skin and related structures: 13 [specialists (11)] Skin problems such as skin discoloration, darkening, dryness, thinness, tightness, and changes in nails	10 b810 Protective functions of the skin	b860 Functions of nails, b849 Functions of the skin, other specified and unspecified	R_B
Tingling sensation in the upper limb of the affected side	3 b840 Sensation related to the skin		R_B
Activity and participation: 147 [specialists (21)] D4: Mobility: 22 [specialists (15)] Sleeping on the affected side	3	d415 Maintaining a body position	R_B
Lifting and carrying heavy equipment and loads (e.g., heavy shopping bags, carrying bags on the shoulder, moving heavy pots while sieving rice)	13 d430 Lifting and carrying objects		R_B

(Continued)

Table 5. Continued.

Meaningful concepts		ICF Core Set for breast cancer	General ICF	IPF code
Performing long-term movements with fingers and wrists (e.g., writing, drawing, using a knife to chopping vegetables or making salads, grating, long-time holding of books/cellphones)	5		d440 Fine hand use	R_B
Squeezing and pressing clothes, cleaning clothes	1	d445 Hand and arm use	d4453 Turning or twisting the hands or arms	R_B
D5: Self-care: 9 [specialists (7)]				
Personal hygiene (e.g., bathing or showering, washing hair, cleaning after defecation, make-up)	2	d510 Washing oneself, d520 Caring for body parts		R_B
Dressing/undressing clothes	7	d540 Dressing		R_B
D6: Domestic life:28 [specialists (16)]				
Going out of the house	1	d 620 Acquisition of goods and services		R_B*S
Cooking	6	d630 Preparing meals		R_B
Doing household chores (e.g., dusting and cleaning the house, washing dishes, making the bed, sweeping)	13	d640 Doing housework		R_B
Caring for others (e.g., hugging babies, caring for children and others)	8	d660 Assisting others		R_S
D7: Interpersonal interactions and relationships: 35 [specialists (17)]				
Communication with other people such as friends, relatives, acquaintances, and colleagues	10	d750 Informal social relationships	d740 Formal relationships	R_S
Communication with recovered individuals and peer groups	4		d 7504 Informal relationships with peers	R_S
Communication with family members such as father, mother, sister, brother, and children	6	d760 Family relationships		R_S
Spousal relationships such as intimate and sexual relationships	15	d770 Intimate relationships		R_B*S
D8: Major life areas: 35 [specialists (19)]				
Job-related matters	13	d 850 Remunerative employment		R_B*S
High costs of disease treatment	15		d 870 Economic self-sufficiency	R_I
Financial inability to provide assistive devices such as breast prostheses, bandages, and compression sleeves (use of support systems or donors to undertake treatment costs)	7		d 870 Economic self-sufficiency	R_I
D9: Community, social and civic life:18 [specialists (11)]				
Participation in gatherings such as attending meetings, religious ceremonies, friendly and formal parties, attending workplace	5		d910 Community life	R_S
Light sports activities (such as walking)	2	d920 Recreation and leisure	d9201 Sports, d450 Walking	R_B*S
Heavy sports activities (such as yoga, aerobics, swimming, badminton)	3	d920 Recreation and leisure	d9201 Sports	R_B*S
Doing finger-related leisure activities (e.g., writing, sewing, knitting, working with cellphones, playing musical instruments)	5	d920 Recreation and leisure	d440 Fine hand use	R_B
Patients' religious beliefs	3		d 930 Religion and spirituality	R_P
Environmental factors: 71 [specialists (19)]				
E1: Products and technology: 2 [specialists (2)]				
Inaccessibility to medicines from distribution centers such as pharmacies	2	e110 Products or substances for personal consumption		R_I
E3: Support and relationships:41 [specialists (19)]				
Lack of emotional support from spouse, children, and family members such as father, mother, sister and brother	4	e 310 Immediate family		E_P*S
Lack of support and accompaniment from employers, such as employers' understanding of the patient's disease	2		e330 People in positions of authority	R_S
Lack of support, understanding, and accompaniment of the patient treatment team	7	e 340 Personal care providers and personal assistants, e 355 Health professionals		R_S
Lack of psychological and palliative support to the patient during treatment	4	e 340 Personal care providers and personal assistants, e 355 Health professionals		E_P*S
Insufficient information about the disease and its treatments from treatment team members	10	e355 Health professionals		R_S
lack of help, accompaniment and support of spousal, children, and family members in daily activities	14		e398 Support and relationships, other specified	R_S
E4: Attitudes: 17 [specialists (12)]				
Compassionate and sympathetic behaviors of companions	4	e425 Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		E_P*S

(Continued)

Table 5. Continued.

Meaningful concepts		ICF Core Set for breast cancer	General ICF	IPF code
Incorrect judgments of companions about one's disease	10	e425 Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		E_P*S
One's viewpoints and attitudes toward disease and life	3		e498 Attitudes, other specified	R_X
E5: Services, systems and policies:11 [specialists (8)]				
Poor service quality at public hospitals	2	e580 Health services, systems, and policies		R_I
Screening of healthy women by the health system	4	e580 Health services, systems, and policies		R_I
Inaccessibility to disease-related educational programs and its treatments at hospitals and medical clinics such as group therapy programs, etc.	5		e585 Education and training services, systems, and policies	R_S
Personal Factors:14 [specialists (12)]				
One's lifestyle	8	Pf	Pf	R_X
Levels of education and literacy	6	Pf	Pf	R_X
Nd-mh: 22 [specialists (14)]				
Sense of losing the beauty of appearance such as muddled appearance and unfitting appearance/clothing	3	nd-mh	nd-mh	E_B*P
Sense of loneliness	1	nd-mh	nd-mh	E_P
Feel guilty	2	nd-mh	nd-mh	E_P
Sense of burdensomeness and inattention in the family	3	nd-mh	nd-mh	E_P
Sense of hopelessness about the future	6	nd-mh	nd-mh	E_P
Sense of disability and disablement	5	nd-mh	nd-mh	E_B*P
Mental fatigue	2	nd-mh	nd-mh	E_P
Nc : 11 [specialists (11)]				
Non-coverage of treatment costs by health insurance firms	11	Nc	nc	R_I

be experiencing ongoing emotional and psychological difficulties that are not currently captured in the ICF core set for breast cancer. These problems were also identified and reported in previous qualitative studies on patients with BC [14–16]. This difference between extracted concepts and categories of ICF core set for BC can be due to differences in participants in different studies. The ICF core set for BC was generated from interviewing women with BC in their acute phase after surgery; however, this study and some other validation studies of the ICF core set for BC interviewed patients in their chronic phases [10]. In the chronic phase, psychological and emotional problems also affected the level of function; however, they could not be linked with any ICF categories related to mental health and psychological problems.

The results of the current study showed that women with breast cancer experienced difficulties participating in gatherings such as attending meetings, religious ceremonies, friendly and formal parties, the workplace, and communicating with others, which are absent in the ICF core set for breast cancer. Other studies on cancer survivors have shown that this population faces challenges in sexual activity, sleep, leisure participation, exercise, and education which caused changes in their family roles, loss of relationships and the deterioration of their social roles [15,16,30]. In contrast with other studies on BC patients, this study reported problems in their leisure and sport participation, which was not reported in patients in the early stages of the disease [14–16]. Including patients in the late stages of their diseases increases the frequency of difficulties in their participation.

High costs of treatment, financial inability to provide assistive devices such as breast prostheses, bandages, and pressure sleeves, lack of support and accompaniment from employers, such as employers' understanding of the patient's disease, and inaccessibility of disease-related training programs and its treatments at hospitals and treatment clinics such as group therapy programs were reported by experts and patients in this study. Some additional factors in environmental-personal factors categories were

raised, which may act as barriers to functioning or assisting with everyday living. Among these, the codes "e330 People in positions of authority" and "d870 Economic self-sufficiency" were also identified in previous studies that validated the ICF core set for breast cancer [14–16].

In the interviews of most participants in this study, religious beliefs were considered a facilitating and influential factor in improving their disease and performing their functions, which was reported in previous studies [31]. However, in some cases, they stated that cancer development caused the breakup of their beliefs and religious systems. The multitude of emotional concepts in this study suggests that emotional issues play a pivotal role in defining their functioning despite the treatment completion and the disease's stability, even after 2–3 years of initial treatment. Evidence shows that the BC survivors are concerned least with one emotional problem experienced as a fear of relapse, sense of sadness, emotional turmoil, identity problems, anxiety, and depression, which may be experienced years after diagnosis [28]. In addition, treatment or disease progression can cause a range of neuropsychological consequences (e.g., anxiety, depression, sexual dysfunction, and body image disorder) [30,32,33].

Interpretation of the functioning of breast cancer patients differed between patients and experts in this study. While both groups agreed on reporting difficulties related to body function and structure categories, as well as the influence of emotional and psychological factors, a disagreement was found in the ICF activity and participation category. Patients reported challenges with mobility, whereas experts identified problems in patients' interpersonal and social relationships. Additionally, both patients and experts identified support, relationships, and attitudes as influential factors in patient functioning. These findings suggest that a multifaceted approach, which considers the perspectives of both patients and experts, is necessary for understanding and assessing the functioning in breast cancer survivors.

Previous studies defined *functioning* as a problem in body function and structure *via* the lens of experts, physiotherapists, and oncologists [14,17]. However, patients raised difficulties in other areas of function, such as participation, social interaction, and emotional problem. The patient has reported results that provided valuable information about disorders in the mental, energy, sexual, and pain levels [34]. The results reported by experts provided more valuable information about physical disorders (edema). Activity restrictions and participation restrictions can be obtained through self-report or observation reports.

Definition of functioning varies between different specialists and differs from the patients' view and interpretation. Difficulties in "body structures" categories are mainly limited to surgeons, medical oncologists, oncology nurses, and physiotherapists. On the other side, psychologists and social workers mainly raise problems in the "Activities and Participation" and the "environmental factors" sections [35]. In the early phase of the disease, the most important issues for patients are using bandage socks, the shape of movement-related structures and the support and relationships. However, experts consider problems in health services, systems, and policies; besides the immune system function, looking after one's health, products, and technology for personal use in daily life, and dressing affect the function of BC survivors [36,37].

Our study interviewed both physicians and rehabilitation teams to define health and function in BC survivors comprehensively. Involving both health professionals and patients in this study elucidates the definition of health and function in BC survivors from different perspectives.

### **Strengths and limitations**

This study aimed to identify the functional problems of breast cancer survivors using the International Classification of Functioning, Disability, and Health (ICF) framework. A particular emphasis was placed on gathering the perspectives of rehabilitation specialists and patients to gain a more comprehensive view of the patient's functional issues. In this section, we will discuss the strengths and limitations of this study.

One of the major strengths of this study was the involvement of rehabilitation specialists and patients in identifying the functional problems of breast cancer survivors. The study gained a more nuanced understanding of the patient's experiences by including these experts' opinions. Moreover, the use of the ICF classification allowed for a comprehensive and standardized approach to evaluating the functional problems of these patients.

Another strength of this study was its potential to improve the evaluation, prevention, and treatment strategies for breast cancer survivors. By identifying the major functional problems experienced by these patients, healthcare providers can develop targeted interventions to improve their overall quality of life.

Despite these strengths, the study had limitations. One significant limitation was the inability to conduct face-to-face patient interviews due to the Covid-19 pandemic. As a result, the findings may not be generalizable to all breast cancer survivors, particularly those in different countries or cultures. Cultural differences may influence how patients perceive and describe their level of function, and these findings may not be generalizable to other cultural contexts. Further research could be conducted to examine the relationship between cultural factors and the description of function in breast cancer patients across different countries or regions.

Another limitation was the lack of involvement of physician specialists in rehabilitation medicine in the study. Although efforts were made to include these experts, time constraints and other obstacles prevented their participation. As a result, the study may not have fully captured the perspectives of all medical experts with experience treating breast cancer survivors.

In conclusion, this study has provided valuable insights into breast cancer survivors' functional problems, particularly through the ICF classification and perspectives from rehabilitation specialists and patients. While there were some limitations, such as the inability to conduct face-to-face interviews and the lack of participation from physician specialists in rehabilitation medicine, the study's strengths suggest that it can inform future research in this area and guide the development of more effective interventions for breast cancer survivors.

### **Conclusion**

The main functional problems of breast cancer survivors raised by the patients and experts participating in this study were difficulties in body functions. They indicated that the emotional and psychological issues determined the functioning of this group of patients. The patients indicated problems in their mobility, but the specialists reported that the significant issue in the BC survivor's functioning is in their interpersonal and social relationships. Also, in the environmental factors category, both participants mentioned support, relationship and attitudes as the most influential factors in patient functioning. Psychological and emotional factors define functioning in patients with BC. Different issues in the functioning of the BC survivors are not covered by the ICF core set for BC.

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### **Ethics approval**

To begin sampling, the necessary permits and an ethical code (IR.USWR.REC.1398.198) were obtained from the ethics committee at the University of Social Welfare and Rehabilitation Sciences (Tehran) for the necessary coordination.

### **Consent form**

Informed consent was obtained from all individual participants included in the study.

### **Authors' contributions**

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by FJ, MF and SAH. The first draft of the manuscript was written by MF and FJ and all authors commented on previous versions of the manuscript. The methodology was designed and checked by JCM. Data analysis was checked by MHA, MF and JCM and did the final review. All authors read and approved the final manuscript.

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## Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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