J Rehabil Med 2004; Suppl. 44: 121–127

Taylor & Francis
healthsciences

ICF CORE SETS FOR BREAST CANCER

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Objective: **To report on the results of the consensus process to develop the first version of both a Comprehensive ICF Core Set and a Brief ICF Core Set for breast cancer.**

Methods: **A formal decision-making and consensus process integrating evidence gathered from preliminary studies was realized. Preliminary studies included a Delphi exercise, a systematic review, and an empirical data collection. After training in the ICF and based on these preliminary studies, relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.**

Results: **The preliminary studies identified a set of 317 ICF categories at the second, third, and fourth ICF levels with 150 categories on *body functions*, 44 on *body structures*, 77 on *activities and participation*, and 46 on *environmental factors*. Nineteen experts attended the consensus conference on breast cancer (7 physicians with at least a specialization in physical and rehabilitation medicine, 2 with a specialization in internal medicine and one radiologist, 4 physical therapists, 2 occupational therapists, one psychologist, one epidemiologist and one nurse). Altogether 80 categories (73 second-level and 7 third-level categories) were included in the Comprehensive ICF Core Set with 26 categories from the component *body functions*, 9 from *body structures*, 22 from *activities and participation*, and 23 from *environmental factors*. The Brief ICF Core Set included a total of 40 second-level categories with 11 on *body functions*, 5 on *body structures*, 11 on *activities and participation*, and 13 on *environmental factors*.**

Conclusion: **A formal consensus process integrating evidence and expert opinion based on the ICF framework and classification led to the definition of ICF Core Sets for breast cancer. Both the Comprehensive ICF Core Set and the Brief ICF Core Set were selected.**

Key words: breast cancer, function, disability, outcome assessment, quality of life, ICF.

J Rehabil Med 2004; suppl. 44: 121–127

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 ISSN 1650–1977
DOI 10.1080/16501960410016811

INTRODUCTION

Breast cancer (BC) is the leading cause of cancer among women worldwide (1). In 1990, 322,000 women died of BC and the projected mortality from BC in women worldwide in 2010 is 437,000 (2).

Approximately 1 million women are diagnosed with BC each year. However, incidence and mortality rates vary widely in different countries: they are high in most industrialized countries (except Japan), intermediate in Eastern and Southern Europe, and low in Central and tropical South America, Africa and Asia (3). In the USA in 2001, it is estimated that 192,200 women will be diagnosed with invasive BC, 40,600 with *in situ* carcinoma and 40,200 women will die of BC (4).

Of every 1000 women of 50 years of age, 2 will recently have had BC diagnosed and about 15 will have had a diagnosis made before the age of 50, giving a prevalence of BC of nearly 2% (5).

BC is a multifactorial disease. Both endogenous (including genetic) and exogenous factors are involved in breast carcinogenesis and increased risk of BC (6).

With advances in the treatment of women with BC, including the combined use of surgical intervention, radiation therapy and chemotherapy, cancer survival rates are now above 50% (7). Many BC survivors, however, will experience physical and psychological sequelae that affect their everyday lives. Anxiety, depression, less energy or fatigue and difficulty in sleeping are common responses to stressors (8, 9). A significant proportion of women suffer disturbances in body image and self-concept (10, 11). Social isolation and disruptions in family and sexual relationships are related to fears of recurrence and death (8, 12–14). Pain, limited range of motion, and lymphoedema of the affected arm can result from primary surgical treatment (15–17). The incidence of lymphoedema by axillary node dissection alone is reported to be about 10% (18–21) but with a dissection combined with radiation of the axilla the incidence varies up to 60% (21–24). Untreated lymphoedema gradually worsens with time (25). The side-effects of treatment as well as inactivity secondary to treatment, can impair activity and participation, decrease independence and affect quality of life (8, 26).

Physical functioning can be measured by the Karnofsky Performance Status Scale (KPS) (27, 28) and self concept can be evaluated by the Tennessee Self-Concept Scale (TSCS) (29),

and the Brief Symptom Inventory (BSI) (30), while for body image the Tennessee Self-Concept Scale – the Physical Self (TSCS-PS) can be used. Psychosocial adjustment can be assessed by Psychosocial Adjustment to Illness (PAIS) (31, 32), and the quality of life of BC patients can be evaluated by the condition-specific module of the Quality of Life Questionnaire (QLQ-BC) (33).

However, no systematic framework that covers the spectrum of BC-related symptoms and limitations in functioning and health has been established thus far. With the approval of the new International Classification of Functioning, Disability and Health (ICF, formerly ICIDH-2, http://www.who.int/classification/icf) we can now rely on a globally agreed framework and classification to define the typical spectrum of problems in functioning of patients with BC. For practical purposes and in line with the concept of condition-specific health status measures, it would thus seem most helpful to link specific conditions or diseases to salient ICF categories of functioning (34). Such generally-agreed-on lists of ICF categories can serve as Brief ICF Core Set to be rated in all patients included in a clinical study with BC or as Comprehensive ICF Core Set to guide multidisciplinary assessments in patients with BC. The objective of this paper is to report on the results the consensus process integrating evidence from preliminary studies to develop the first version of the ICF Core Sets for BC.

METHODS

The ICF Core Sets development for BC involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies including a Delphi exercise (35), a systematic review (36), and an empirical data collection, using the ICF checklist (37). After training in the ICF and based on these preliminary studies relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.

Nineteen experts from 5 different countries attended the consensus process for BC. The professional background of the experts (7 physicians with at least a specialization in physical and rehabilitation medicine, 2 with a specialization in internal medicine and 1 radiologist, 4 physical therapists, 2 occupational therapists, 1 psychologist, 1 epidemiologist and 1 nurse) covered the wide spectrum of limitations in functioning that occurs in patients with BC. The decision-making process for BC involved 3 working groups with 6–7 experts each. The process was facilitated by the condition co-ordinator for BC (JM) and the 3 working-group leaders (AC, BE, VFM).

The tables on the pre-conference studies (35–37) presented to the participants included 317 ICF categories at the second, third and fourth levels (150 on *body functions*, 44 on *body structures*, 77 on *activities and participation*, and 46 on *environmental factors*).

RESULTS

Tables I–IV show the second- and third-level ICF categories included in the Comprehensive ICF Core Set. Table V shows the second-level ICF categories that were selected for the Brief ICF Core Set, as well as the percentage of experts willing to include the respective category in the Brief ICF Core Set.

The number of second- and third-level categories in the Comprehensive ICF Core Set is 80, with 73 categories on the second level and 7 categories on the third level. The 7 third-level categories are a further specification of 5 categories on the second level. The total number of second-level categories included in the Brief ICF Core Set is 40. No third-level category was selected for the Brief ICF Core Set.

Table I. *International Classification of Functioning, Disability and Health (ICF) – categories of the component body functions included in the Comprehensive ICF Core Set for breast cancer*

ICF code		ICF category title
2nd level	3rd level	
b126		Temperament and personality functions
b130		Energy and drive functions
b134		Sleep functions
b152		Emotional functions
b180		Experience of self and time functions
	b1801	Body image
b265		Touch function
b280		Sensation of pain
	b2801	Pain in body part
b435		Immunological system functions
	b4352	Functions of lymphatic vessels
	b4353	Functions of lymph nodes
b455		Exercise tolerance functions
b530		Weight maintenance functions
b640		Sexual functions
b650		Menstruation functions
b660		Procreation functions
b670		Sensations associated with genital and reproductive functions
b710		Mobility of joint functions
b720		Mobility of bone functions
b730		Muscle power functions
b740		Muscle endurance functions
b780		Sensations related to muscles and movement functions
b810		Protective functions of the skin
b820		Repair functions of the skin
b840		Sensation related to the skin

Comprehensive ICF Core Set

The 80 categories of the Comprehensive ICF Core Set are made up of 26 (33%) categories from the component *body functions*, 9 (11%) from the component *body structures*, 22 (27%) from the component *activities and participation*, and 23 (29%) from the component *environmental factors*.

Table II. *International Classification of Functioning, Disability and Health (ICF) – categories of the component body structures included in the Comprehensive ICF Core Set for breast cancer*

ICF code		ICF category title
2nd level	3rd level	
s420		Structure of immune system
	s4200	Lymphatic vessels
	s4201	Lymphatic nodes
s630		Structure of reproductive system
	s6302	Breast and nipple
s720		Structure of shoulder region
s730		Structure of upper extremity
s760		Structure of trunk
s810		Structure of areas of skin

Table III. *International Classification of Functioning, Disability and Health (ICF) – categories of the component activities and participation included in the Comprehensive ICF Core Set for breast cancer*

ICF code	ICF category title
d177	Making decisions
d230	Carrying out daily routine
d240	Handling stress and other psychological demands
d430	Lifting and carrying objects
d445	Hand and arm use
d510	Washing oneself
d520	Caring for body parts
d540	Dressing
d550	Eating
d560	Drinking
d570	Looking after one's health
d620	Acquisition of goods and services
d630	Preparing meals
d640	Doing housework
d650	Caring for household objects
d660	Assisting others
d720	Complex interpersonal interactions
d750	Informal social relationships
d760	Family relationships
d770	Intimate relationships
d850	Remunerative employment
d920	Recreation and leisure

Add: d530 Toileting.

Table IV. *International Classification of Functioning, Disability and Health (ICF) – categories of the component environmental factors included in the Comprehensive ICF Core Set for breast cancer*

ICF code	ICF category title
e110	Products or substances for personal consumption
e115	Products and technology for personal use in daily living
e165	Assets
e225	Climate
e310	Immediate family
e315	Extended family
e320	Friends
e325	Acquaintances, peers, colleagues, neighbours and community members
e340	Personal care providers and personal assistants
e355	Health professionals
e410	Individual attitudes of immediate family members
e415	Individual attitudes of extended family members
e420	Individual attitudes of friends
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
e440	Individual attitudes of personal care providers and personal assistants
e450	Individual attitudes of health professionals
e465	Social norms, practices and ideologies
e540	Transportation services, systems and policies
e555	Associations and organizational services, systems and policies
e570	Social security services, systems and policies
e575	General social support services, systems and policies
e580	Health services, systems and policies
e590	Labour and employment services, systems and policies

Twenty-two of the 26 categories of the component *body functions* are at the second and 4 at the third level of the classification. The 26 categories at the second level represent 15% of the total number of ICF categories at the second level in this component. Chapter 1 *mental functions* is represented by 5 categories at the second level and by the third-level category b1801 *body image*, which is a specification of the included second-level category b180 *experience of self and time functions*. Chapter 2 *sensory functions and pain* is represented by 2 categories at the second level and by the third-level category b2801 *pain in a body part*, which is a specification of the selected second-level category b280 *sensation of pain*. Chapter 4 *functions of the cardiovascular, haematological, immunological and respiratory systems* is represented by 2 categories at the second level and by 2 categories at the third level of the classification, which are specifications of the included second-level category b435 *immunological system functions*. Chapter 6 *genitourinary and reproductive functions*, chapter 7 *neuromusculoskeletal and movement-related functions* and chapter 8 *functions of the skin and related structures* are represented by 4, 5 and 3 categories at the second level, respectively.

Six of the 9 categories of the component *body structures* are at the second and 3 categories are at the third level of the classification. The 6 categories at the second level represent 11% of the total number of ICF categories at the second level in this component. Chapter 4 *structures of the cardiovascular, immunological and respiratory systems* is represented by 2 third-level categories s4200 *lymphatic vessels* and s4201 *lymphatic nodes* and by its corresponding second-level category s420 *structure of immune system*. Chapter 6 *structures related to the genitourinary and reproductive systems* is represented on the third level by s6302 *breast and nipple* and by its corresponding second-level category s630 *structure of reproductive system* of which it is a member. Chapter 7 *structures related to movement* is represented by 3 categories and chapter 8 *skin and related structures* by 1 category at the second level of the classification.

The 22 categories of the component *activities and participation* are all at the second level of the ICF hierarchy. They represent 19% of the total number of ICF categories at the second level in this component. Most of the activities and participation categories belong to chapter 5 *self care* (6 categories), chapter 6 *domestic life* (5 categories) and chapter 7 *interpersonal interactions and relationships* (4 categories). However, with exception of chapter 3 *communication*, 8 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 2 and chapter 4 are represented by 2 categories, respectively. Chapter 1 *learning and applying knowledge*, chapter 8 *major life areas* and chapter 9 *community, social and civic life* are each represented by 1 category.

The 23 categories of the component *environmental factors* are all at the second level of the ICF hierarchy. They represent 31% of the total number of ICF categories at the second level of this component. Most of the *environmental-factors* categories belong to chapter 4 *attitudes* (7 categories), chapter 3 *support and relationships* (6 categories) and chapter 5 *services, systems*

Table V. *International Classification of Functioning, Disability and Health (ICF) – categories included in the Brief ICF Core Set for breast cancer. The categories per component are listed according to the conceded rank order. 50% represent a preliminary cut-off. >50% is in bold typeface*

ICF component	%	ICF code	ICF category title
Body functions	**100**	**b152**	**Emotional functions**
	100	**b280**	**Sensation of pain**
	100	**b130**	**Energy and drive functions**
	100	**b180**	**Experience of self and time functions**
	95	**b710**	**Mobility of joint functions**
	79	**b640**	**Sexual functions**
	79	**b134**	**Sleep functions**
	74	**b435**	**Immunological system functions**
	42	b730	Muscle power functions
	37	b126	Temperament and personality functions
	37	b455	Exercise tolerance functions
Body structures	**100**	**s630**	**Structure of reproductive system**
	100	**s420**	**Structure of immune system**
	79	**s720**	**Structure of shoulder region**
	47	s810	Structure of areas of skin
	5	s730	Structure of upper extremity
Activities and participation	**100**	**d240**	**Handling stress and other psychological demands**
	100	**d770**	**Intimate relationships**
	100	**d760**	**Family relationships**
	100	**d445**	**Hand and arm use**
	100	**d230**	**Carrying out daily routine**
	95	**d640**	**Doing housework**
	84	**d850**	**Remunerative employment**
	79	**d430**	**Lifting and carrying objects**
	42	d920	Recreation and leisure
	32	d570	Looking after one's health
	16	d510	Washing oneself
Environmental factors	**100**	**e310**	**Immediate family**
	100	**e410**	**Individual attitudes of immediate family members**
	100	**e420**	**Individual attitudes of friends**
	100	**e320**	**Friends**
	100	**e355**	**Health professionals**
	100	**e450**	**Individual attitudes of health professionals**
	95	**e570**	**Social security services, systems and policies**
	79	**e580**	**Health services, systems and policies**
	74	**e115**	**Products and technology for personal use in daily living**
	58	**e590**	**Labour and employment services, systems and policies**
	47	e165	Assets
	37	e315	Extended family
	16	e465	Social norms, practices and ideologies

and policies (6 categories). However, all 5 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 1 *products and technology* is represented by 3 categories and chapter 2 *natural environment and human-made changes to environment* by 1 category.

Brief ICF Core Set

The Brief ICF Core Set includes a total of 40 second-level categories, which represents 11% of all second-level categories that were chosen in the Comprehensive ICF Core Set.

Eleven categories were chosen from the component *body functions* (representing 50% of selected second-level categories in the Comprehensive ICF Core Set), 5 from *body structures* (83%), 11 from *activities and participation* (50%), and 13 from *environmental factors* (57%).

All ICF categories taken into account in the final decision process are presented in Table V. However, a preliminary cut-off was established at 50% to reflect majority opinion.

DISCUSSION

The formal consensus process integrating evidence from preliminary studies and expert knowledge at the third ICF Core Sets conference led to the definition of the Comprehensive ICF Core Set for multidisciplinary assessment and the Brief ICF Core Set for clinical studies.

A major challenge during the development of the ICF Core Sets for BC was comprehensively to cover the wide spectrum of problems in BC and to avoid the inclusion of co-morbidities or a treatment-specific perspective especially concerning systemic medication therapy and related treatment problems or side-

effects, which are drugs and not condition-specific. BC cannot be seen without a treatment effect, as every patient is treated, however systemic therapy can be regarded as a subset in patients with BC smaller than patients with BC getting surgery and radiation. Therefore, it was decided by the group of experts to address BC taking only into account surgery and radiation treatment.

The Comprehensive ICF Core Set for BC is one of the shortest developed for the 12 most burdensome chronic conditions. However, the Brief ICF Core Set for BC is the largest of the ICF Core Sets developed. The fact that 40 categories are still included in the Brief ICF Core Set reflects the important and complex impairments, limitations and restrictions of *body functions, activities and participation* involved, as well as the numerous interactions with *environmental factors*.

As BC is a multifactorial disease, the number of included *body-functions* categories in both ICF Core Sets for BC demonstrate the complex range of impairments which affect patients with BC. Both ICF Core Sets focus on global and specific *mental functions* such as *emotional functions*, *experience of self and time functions* and *energy and drive functions* besides impairments related *to pain or neuromusculoskeletal and movement-related functions*. Furthermore, functions related to specific organs, such as *immunological system functions*, *exercise tolerance functions* and *sexual functions* are included in both ICF Core Sets as well. In addition, the Comprehensive ICF Core Set includes "functions of the skin". All selected *body-functions* categories in the ICF Core Sets are consistent with current knowledge discussed in the literature. There is evidence of the impact of BC on emotional and social well-being, including symptoms of depression, anxiety, sleep disturbances, sexual problems and problems with *body image* (10, 38–41). Body image dissatisfaction is generally accompanied by insecurity and diminished self-confidence (42) wherefore lymphoedema is one of the greatest problems that women express (43). Further problems in BC are loss of shoulder motion, shoulder girdle and arm pain, upper extremity oedema and loss of arm strength after treatment (20, 44–47). Even without clinically manifest lymphoedema, the majority of patients with BC suffer from an impaired function of the lymphatics (48).

The selection of *body structures* includes those structures that are mainly affected by BC. The majority of patients with BC show impairments of the *reproductive system* (s6302 *breast and nipple*), of the immune system (s4200 *lymphatic vessels* and s4201 *lymphatic nodes*), and of *structures related to movement* such as *shoulder region* and *upper extremity* as well as *skin and related structures*. All these *body structures* are also pointed out as relevant body structures in patients with BC by the American College of Radiology, the American College of Surgeons, the College of American Pathologists and the Society of Surgical Oncology (49). Additionally, *structure of trunk* was selected for the Comprehensive ICF Core Set.

The fact that at the body level (*body functions and body structures*) some categories at the third level of the classification, such as b1801 *body image*, b2801 *pain in body part* and s6302 *breast and nipple*, were included, reflects that a deeper and more detailed description is necessary to address the problems in functioning.

Selected ICF categories in *activities and participation* concern general aspects of *carrying out tasks* and *handling psychological demands*, as well as life areas such as *mobility*, *self care*, *domestic life*, *interpersonal interactions and relationships*, *work and employment*, *community, and social and civic life*. The included ICF categories are consistent with the problems, which are the subject of discussion in the majority of psychosocial literature on BC. Changes in body image and self-concept have a profound effect on sexuality and interpersonal relationships. Women with lymphoedema showed statistically significant impairments in the areas of vocational, domestic, social, and sexual relationships and psychological distress on the PAIS (43). The level of independence in executing activities, the importance of positive relations (50, 51), and the amount of social support is assumed to be a major factor in psychosocial adjustment and influences patient health outcomes (52). The category d530 *toileting*, which was not part of the tables on the preliminary studies would have additionally been included by the expert panel. Therefore the inclusion of this category in the Comprehensive ICF Core Set for test studies is suggested.

The number of categories in the *environmental-factors component* displays the extensive involvement of contextual factors for the effective management of patients with BC. Patients regard *support and relationships* and *attitudes of family, friends and health professionals* to be of high importance (51, 53, 54). BC patients' experiences, for example of lymphoedema after mastectomy very much depend on the attitudes from people in their surroundings, as a lymphoedematous arm is a difficult-to-conceal reminder of the cancer itself and the impaired body image (55, 56). Consistent with results from the psychosocial literature on BC there was general agreement by all experts that women with BC experience difficulties in vocational, domestic and social roles and relationships. The selected ICF categories confirm exactly such often expressed needs, as psychological, physical, informational, household, legal, financial, and spiritual needs (57, 58). Conclusions from the research literature demonstrate the benefit from a strong individual and societal network, the need for social and emotional support, and the requirement of professional help in form of counselling and medical treatment (59, 60). Patients are often least satisfied with information about financial issues and availability of help and facilities for use at home and other resources for health and treatment. Therefore, *health, social security, and labour and employment services, systems and policies* are important sources of support for patients with BC (43, 55, 56, 61).

The ICF Core Sets for BC are based on a broad definition of the underlying condition, BC. Validation and test studies will show whether specific subsets of patients, for example breast-conserving treatment vs mastectomy (62), radiation therapy vs no radiation therapy (63), or younger vs older (40, 64), will differ.

Regarding the comprehensiveness of the ICF, it is most inter-

esting to note that the panel of experts did not identify problems of patients not contained in the ICF. This emphasizes the validity of the ICF classification, which was based on an international development process. The breadth of ICF chapters contained in the Comprehensive ICF Core Set reflects the important and complex impairments, limitations and restrictions of patients with BC in the 4 ICF components. The selection of categories for the Brief ICF Core Set does not result in a bandwidth compression, i.e. the Brief ICF Core Set still contains most of the chapters represented in the Comprehensive ICF Core Set. The approach to patients with BC needs besides the predominantly medical one, a perspective that pays attention to aspects of the impairment and limitation of the physiological and psychological function, the deviation or loss of *body structures*, restrictions in *activities and participation*, and *environmental* factors or socio-cultural factors. The ICF Core Sets could foster a more consistent communication and information process among patients, relatives, and healthcare professionals in the understanding and analysis of patient needs and problems and promote the integration of care by representatives of *health, labour and employment services, systems and policies*. In this way the application of the ICF Core Sets could avoid the lack of identification of patient problems.

Nevertheless, it should be borne in mind that the results of any consensus process may differ with different groups of experts. The importance of the extensive validation of this first version of the ICF Core Sets from the perspectives of different professions and in different countries has to be, thus, emphasized. The first version of the ICF Core Sets will also be tested from the patients' points of view and in different clinical settings. The length of the ICF Core Sets may be reduced based on the results of the test and validation studies. Thus, it is important to note that this first version of the ICF Core Sets is only recommended for validation or pilot studies.

ACKNOWLEDGEMENTS

We are grateful for the contributions made by the following experts attending the conference: Thomas Brockow, Margrit Fäßler, Veronika Fialka Moser, Christoph Gutenbrunner, Claudia Hauser, Brigitte Hüllemann, Robert Jakob, Margot Knobel, Monika Lauper, Susanne Schwarzkopf, Thierry Smets, Anna Sonderegger, Tanja Stamm, Sigrid Stegner, Yvonne Wechsler and Genevieve Zurbriggen.

REFERENCES

1. Parkin D, Pisani P, Ferlay J. Estimates of the worldwide incidence of 25 major cancers in 1990. Int J Cancer 1999; 83: 18–29.
2. Murray C, Lopez A, eds. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Geneva: World Health Organization; 1996.
3. Lacey J, Devesa S, Brinton L. Recent trends in breast cancer incidence and mortality. Environ Mol Mutagen 2002; 39: 82–88.
4. Greenlee R, Murray T, Bolden S. Cancer statistics 2000. CA Cancer J Clin 2000; 50: 7–33.
5. McPherson K, Steel C, Dickosn J. ABC of breast diseases. Breast cancer epidemiology, risk factors and genetics. BMJ 2000; 321: 624–628.
6. Kelsey J, Gammon M. The epidemiology of breast cancer. CA Cancer J Clin 1991; 41: 146–165.
7. ACS. Cancer facts and figures. Atlanta, GA: American Cancer Society; 1994.
8. Dow KH, Ferrell BR, Leigh S, Ly J, Gulasekaram P. An evaluation of quality of life among long term survivors of breast cancer. Breast Cancer Res Treat 1996; 39: 261–273.
9. Shimozuma K, Ganz PA, Petersen L, Hirji K. Quality of life in the first year after breast cancer surgery: rehabilitation needs and patterns of recovery. Breast Cancer Res Treat 1999; 56: 45–57.
10. Kemeny M, Wellisch D, Schain W. Psychosocial outcome in a randomized surgical trial for treatment of primary breast cancer. Cancer 1988 15; 62: 1231–1237.
11. Mock V. Body image in women for breast cancer. Nurs Res 1993; 42: 153–157.
12. Northouse LL. Mastectomy patients and the fear of cancer recurrence. Cancer Nurs 1981; 4: 213–220.
13. Stoll B, ed. Coping with cancer stress. Boston: Martinus Nijhoff; 1986.
14. Northouse L. A longitudinal study of the adjustment of patients husbands to breast cancer. Oncol Nurs Forum 1989; 16: 511–516.
15. Tasmuth T, von Smitten K, Kalso E. Pain and other symptoms during the first year after radical and conservative surgery for breast cancer. Br J Cancer 1996; 74: 2024–2031.
16. Knobf MT. Symptoms and rehabilitation needs of patients with early stage breast cancer during primary therapy. Cancer 1990; 15; 66: 1392–1401.
17. Woods M, Tobin M, Mortimer P. The psychosocial morbidity of breast cancer patients with lymphoedema. Cancer Nurs 1995; 18: 467–471.
18. Kissin MW, Querci della Rovere G, Easton D, Westbury G. Risk of lymphedema following the treatment of breast cancer. Br J Surg 1986; 73: 580–584.
19. Borup Christensen S, Lundgren E. Sequelae of axillary dissection vs axillary sampling with or without irradiation for breast cancer. Acta Chir Scand 1989; 155: 515–519.
20. Tengrup I, Tennvall-Nittby L, Christiansson I, Laurin M. Arm morbidity after breast-conserving therapy for breast cancer. Acta Oncol 2000; 39: 393–397.
21. Johansson K, Ingvar C, Albertsson M, Charlotte E. Arm lymphoedema, shoulder mobility and muscle strength after breast cancer treatment. A prospective 2-year study. Adv Physiotherapy 2001; 3: 55–66.
22. Segestrom K, Bjerle P, Graffman S. Factors that influence the incidence of brachial oedema after treatment of breast cancer. Scan J Plast Reconstr Hand Surg 1992; 26: 223–227.
23. Suneson BL, Lindholm C, Hamrin E. Clinical incidence of lymphoedema in breast cancer patients in Jonkoping County, Sweden. Eur J Cancer Care (Engl) 1996; 5: 7–12.
24. Højris I, Andersen J, Overgaard M, Overgaard J. Late treatment-related morbidity in breast cancer patients randomized to post-mastectomy radiotherapy and systemic treatment versus systemic treatment alone. Acta Oncologica 2000; 39: 355–372.
25. Casley-Smith JR. Alterations of untreated lymphedema and it's grades over time. Lymphology 1995; 28: 174–185.
26. Nail L, Jones L. Fatigue as a side effect of cancer treatment: impact on quality of life. Quality of Life 1995; 4: 8–13.
27. Karnofsky D, Burchenal J. The evaluation of chemotherapy agents in cancer. In: MacCleod C, ed. Evaluation of chemotherapeutic agents. New York: Columbia University Press; 1949, p. 199–205.
28. Yates JW, Chalmer B, McKegney FP. Evaluation of patients with advanced cancer using the Karnofsky performance status. Cancer 1980; 45: 2220–2224.
29. Jenkins H. Self concept and mastectomy. JOGN Nursing Journal of Obstetric, Gynecologic and Neonatal Nursing 1980; 9: 38–42.
30. Derogatis LR, Melisaratos N. The Brief Symptom Inventory: an introductory report. Psychol Med 1983; 13: 595–605.
31. Morrow GR, Chiarello RJ, Derogatis LR. A new scale for assessing patients' psychosocial adjustment to medical illness. Psychol Med 1978; 8: 605–610.
32. Derogatis LR. The psychosocial adjustment to illness scale (PAIS). J Psychosom Res 1986; 30: 77–91.
33. Sprangers MA, Groenvold M, Arraras JI, Franklin J, te Velde A,

Muller M, et al. The European Organization for Research and Treatment of Cancer breast cancer-specific quality-of-life questionnaire module: first results from a three-country field study. J Clin Oncol 1996; 14: 2756–2768.
34. Stucki G, Ewert T, Cieza A. Application of the International Classification of Functioning, Disability and Health (ICF) in Clinical Practice. Disabil Rehabil 2002; 20: 932–938.
35. Weigl M, Cieza A, Andersen A, Kollerits B, Amann E, Füssl M, et al. Identification of the most relevant ICF categories in patients with chronic conditions: a Delphi exercise. J Rehabil Med 2004; 36: suppl 44: 12–21.
36. Brockow T, Wohlfahrt K, Hillert A, Geyh S, Weigl M, Franke T, et al. Identifying the concepts contained in outcome measures of clinical breast cancer trials using the International Classification of Functioning, Disability and Health as a reference. J Rehabil Med 2004; 36: suppl 44: 43–48.
37. Ewert T, Fuessl M, Cieza A, Andersen A, Chatterji S, Kostanjsek N, et al. Identification of the most common patient problems in patients with chronic conditions using the ICF Checklist. J Rehabil Med 2004; 36: suppl 44: 22–29.
38. Lasry JC, Margolese RG, Poisson R, Shibata H, Fleischer D, Lafleur D, et al. Depression and body image following mastectomy and lumpectomy. J Chronic Dis 1987; 40: 529–534.
39. Margolis GJ, Goodman RL, Rubin A, Pajac TF. Psychological factors in the choice of treatment for breast cancer. Psychosomatics 1989; 30: 192–197.
40. Vinokur AD, Threatt BA, Vinokur-Kaplan D, Satariano WA. The process of recovery from breast cancer for younger and older patients. Cancer 1990; 65: 1242–1254.
41. Omne-Ponten M, Holmberg L, Burns T, Adami HO, Bergstrom R. Determinants of the psycho-social outcome after operation for breast cancer. Results of a prospective, comparative interview study following mastectomy and breast conservation. Eur J Cancer 1992; 28A: 1062–1067.
42. Fletcher A. Lymphoedema – what can we do to help? In: Oncology nurses seminar. Brisbane; 1987.
43. Carter BJ. Women's experiences of lymphedema. Oncol Nurs Forum 1997; 24: 875–882.
44. Thompson AM, Air M, Jack WJL, Kerr GR, Rodger A, Chetty U. Arm morbidity after breast conservation and axillary therapy. Breast 1995; 4: 273–276.
45. Gerber L, Lampert M, Wood C, Duncan M, D'Angelo T, Schain W, et al. Comparison of pain, motion, and edema after modified radical mastectomy vs. local excision with axillary dissection and radiation. Breast Cancer Res Treat 1992; 21: 139–145.
46. Wallace MS, Wallace AM, Lee J, Dobke MK. Pain after breast surgery: a survey of 282 women. Pain 1996; 66: 195–205.
47. Kwekkeboom KL. Pain management strategies used by patients with breast cancer and gynecologic cancer with postoperative pain. Cancer Nurs 2001; 24: 378–386.
48. Foldi E. Treatment of lymphedema and patient rehabilitation. Anticancer Res 1998; 18: 2211–2212.
49. Winchester DP, Cox JD. Standards for diagnosis and management of invasive breast carcinoma. American College of Surgeons, College of American Pathologists, Society of Surgical Oncology, CA: A Cancer Journal for Clinicians 1998; 48: 83–107.
50. Pistrang N, Barker C. Partners and fellow patients: two sources of emotional support for women with breast cancer. Am J Community Psychol 1998; 26: 439–456.
51. Lampic C, Thurfjell E, Bergh J, Carlsson M, Sjoden PO. Attainment and importance of life values among patients with primary breast cancer. Cancer Nurs 2003; 26: 295–304.
52. Irvine D, Brown B, Crooks D, Roberts J, Browne G. Psychosocial adjustment in women with breast cancer. Cancer 1991; 15 (67): 1097–1117.
53. Bloom J. Social support, accommodation to stress, and adjustment to breast cancer. Soc Sci Med 1982; 16: 1329–1338.
54. Bloom JR, Spiegel D. The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. Soc Sci Med 1984; 19: 831–837.
55. Mirolo BR, Bunce IH, Chapman M, Olsen T, Eliadis P, Hennessy JM, et al. Psychosocial benefits of postmastectomy lymphedema therapy. Cancer Nurs 1995; 18: 197–205.
56. Johansson K, Holmstrom H, Nilsson I, Ingvar C, Albertsson M, Ekdahl C. Breast Cancer patients' experiences of lymphoedema. Scand J Caring Sci 2003; 17: 35–42.
57. Funch DP, Mettlin C. The role of support in relation to recovery from breast surgery. Soc Sci Med 1982; 16: 91–98.
58. Hileman JW, Lackey NR. Self-identified needs of patients with cancer at home and their home caregivers: a descriptive study. Oncol Nurs Forum 1990; 17: 907–913.
59. Ell K. Social networks, social support and coping with serious illness: the family connection. Soc Sci Med 1996; 42: 173–183.
60. Rustoen T, Begnum S. Quality of life in women with breast cancer: a review of the literature and implications for nursing practice. Cancer Nurs 2000; 23: 416–421.
61. Isaksen AS, Thuen F, Hanestad B. Patients with cancer and their close relatives: experiences with treatment, care, and support. Cancer Nurs 2003; 26: 68–74.
62. Kiebert GM, de Haes JC, van de Velde CJ. The impact of breast-conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: a review. J Clin Oncol 1991; 9: 1059–1070.
63. Taylor SE, Lichtman RR, Wood JV, Bluming AZ, Dosik GM, Leibowitz RL. Illness-related and treatment-related factors in psychological adjustment to breast cancer. Cancer 1985; 55: 2506–2513.
64. Sammarco A. perceived social support, uncertainty and quality of life of younger breast cancer survivors. Cancer Nurs 2001; 24: 212–219.