

Who provides support and how?

Breast cancer patients and nurses evaluate patient support

Tarja Suominen, R.N., Ph.D., Helena Leino-Kilpi, R.N., Ph.D.,
and Pekka Laippala, Ph.D.

Breast cancer patients' opinions of the support they receive have been studied from the viewpoint of both patients and nurses. However, few studies have compared the opinions of both patients and nurses. A project was designed to investigate the support provided for breast cancer patients in Finland and the evaluation of this support by patients and nurses. Two questionnaires were developed, and 109 patients and 125 nurses responded. Both patients and nurses reported that patient support was insufficient before and after hospitalization. Patients primarily expected informative support, whereas nurses underlined the role of psychological support. Furthermore, during hospitalization patients felt that they did not receive the support that they needed, whereas nurses felt that they provided a great deal of support. The theoretical assumption was that patients find it important that the health-care staff have a pleasant and friendly attitude toward their patients. This topic was one of

the variables measured. The current study confirmed previous research that patients consider the attitude of the health-care staff important for their recovery. It was found in the statistical analysis that both groups of subjects usually stressed the importance of the same support-related issues. However, as patients and nurses seem to disagree on the most important forms of support, further studies are needed to explore the underscoring factors.

Key Words: Breast cancer—Support—Nurses' and patients' perceptions—Finland.

Cancer produces high levels of stress not only in the patients themselves but also in their partners and their families (1–6). Psychological, social, and material factors all affect health after stressful experiences (7–10). The seeking of information from health-care providers and taking firm actions by patients become important coping strategies in the illness situation (11). Support has been found to reduce unfavorable psychological responses to stressful life events such as long-term disease (12–14). Much research has been conducted on the role of nurses in supporting recovery in patients (15–20).

Several studies have reported on the beneficial effects of social support in helping cancer patients

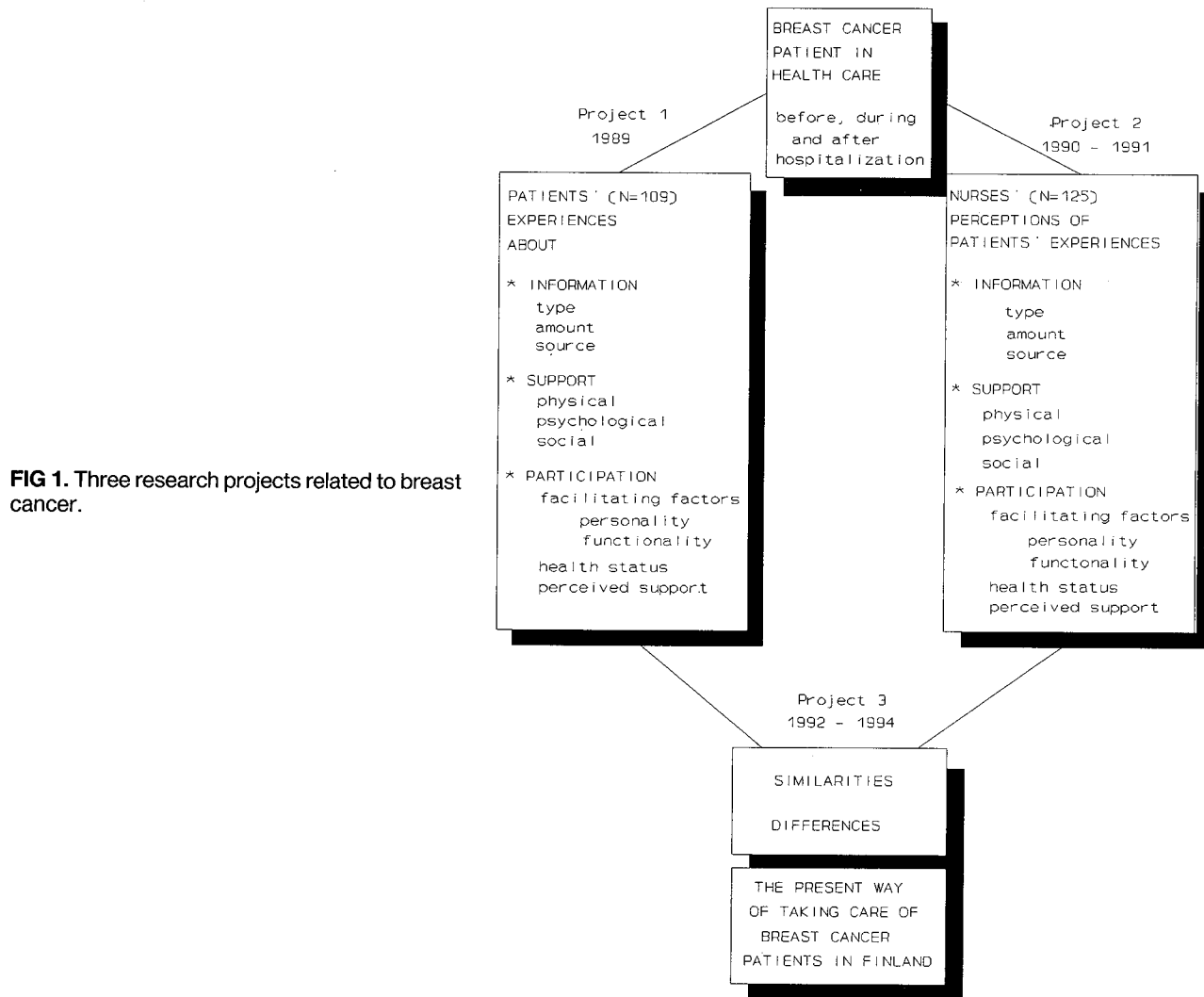
Tarja Suominen is Assistant Professor, Department of Nursing, University of Turku, Turku, Finland.

Helena Leino-Kilpi is Associate Professor, Department of Nursing, University of Turku, Turku, Finland.

Pekka Laippala is Associate Professor, Department of Public Health/Biometry Unit, University of Tampere, Tampere, Finland.

Address correspondence and reprint requests to Tarja Suominen, R.N., Lic.N.Sc., Department of Nursing, University of Turku, Uudenmaantie 43, 20720 Turku, Finland.

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adjust to their disease (21). A number of theoretical frameworks have been used in studies of the social support received by breast cancer patients. Funch and Marchall (22), Northouse (23), and Vachon (24) viewed social support systems as social networks and focused on the quantity of social relationships rather than on their functions. The effect of expressive support on patients' psychological well-being also has been the subject of many studies (24–28). However, such studies have not related support to the patients' reactions to the disease itself. Funch and Marchall (22) raised the issue about the effect of social support on survival. Spiegel et al. (28) found that membership of a support group was significantly related to survival. Lichtman et al. (29), Peters-Golden (30), and Taylor et al. (31) studied how expectations of support were met when a need for support was expressed.

Studies have looked at patient support from the viewpoint of the patients themselves (32) as well as their nurses (33). However, few studies have been conducted to compare the viewpoints of both patients and nurses. The purpose of the current article—as one part of the study project depicted in Fig. 1—was to discuss the physical, psychological, and social support of breast cancer patients as evaluated by the patients (project 1) and the nurses (project 2). Project 3 is not reported here.

METHODS

Instruments and Definition of Terms

Two questionnaires with multiple-choice and open-ended questions were developed on the basis of the research design (Fig. 1) and previous published

scientific literature and mailed to the subjects. Apart from questions on personal data, the patients were asked to evaluate their participation in their own treatment and the guidance that they had received in terms of information, support, and teaching of new skills. One category of questions asked breast cancer patients whether their evaluation of patient support provided before, during, and after their hospitalization. Figure 2 shows the subcategories of perceived support used in this study.

This study focused on the assessment of psychological and social support. Content validity for the questionnaire related to support was identified on the basis of literature reviews and empirical studies. Clinicians who provided support for patients were asked to review items in the questionnaire and judge that the items reflected the type of support to be measured. Physical support during hospitalization was measured by asking whether the patient felt that the unit in which she was treated was too large. The purpose

was to establish whether the physical environment of health care imposed any restrictions on the patient's opportunities for support, including the provision of information. However, the questions assessing the support received by relatives, as well as those concerning the support and help provided to patients, also dealt in part with physical aspects. The support received by relatives was evaluated on the basis of a question asking whether respondents felt that their relatives had received support from the staff. The content area of support provision was measured by asking whether the patient thought that she had received support from doctors, nurses, and others. Furthermore, patients were requested to answer one structured question measuring perceived provision of help.

Perceived psychological support during the patient's hospital stay was directly assessed by four questions: (a) Was the patient afraid of the health-care staff? (b) Did the nurses pay enough attention

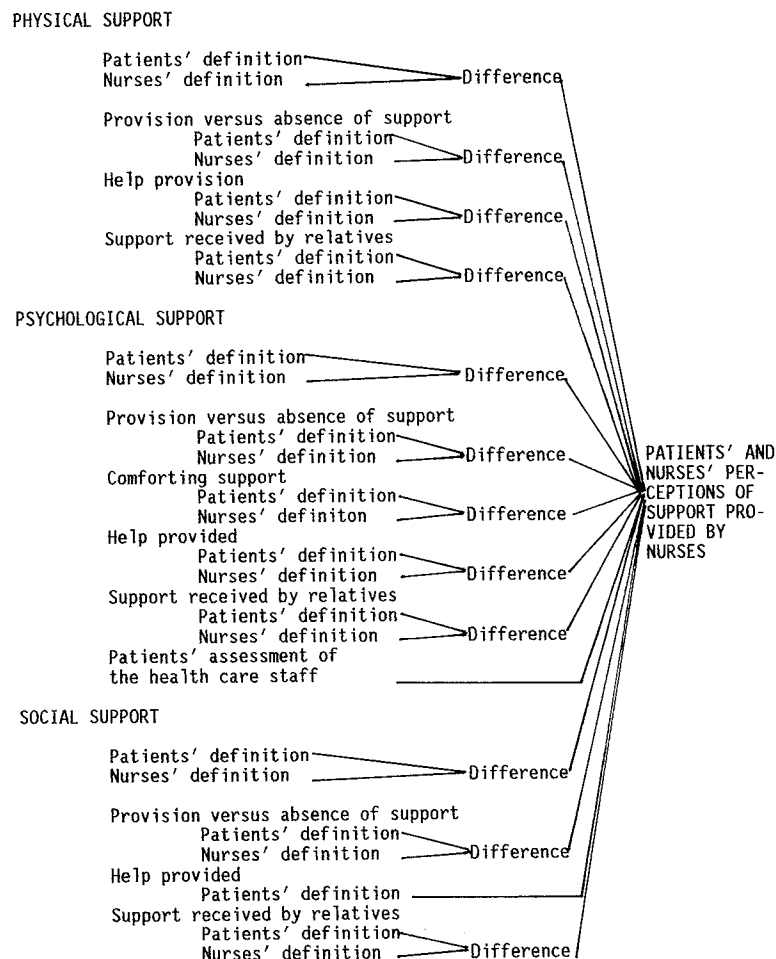


FIG 2. Conceptualization of patients' and nurses' perceptions of support.

to the patient? (c) Did the nurses provide the patient with opportunities for discussion? and (d) Were changes made in care if the patient found it disagreeable? In this content area there were five more specific questions about psychological support, asking whether nurses provided comfort and whether the patient felt that the health-care staff had a positive attitude toward patients. Furthermore, psychological support was assessed by questions about the provision versus absence of patient support, help provided for the patient, and support received by relatives. Comforting support was measured by six variables on the basis of questions dealing with comforting of patients, encouragement of patients, talking to patients, sharing experiences with patients, listening to patients, and treating patients individually. Patients were asked one additional question about their general experiences with nurses.

Social support during hospitalization was directly measured by variables based on the following questions: (a) Were relatives allowed to stay overnight at the hospital? (b) Were relatives allowed to visit the patient outside visiting hours? and (c) Did nurses encourage relatives to engage in discussions about the patient? There were also questions on whether nurses found the time to talk to the patient on her admission to the unit and, finally, whether nurses seemed to be preoccupied with their work. The questions about the provision of support and help as well as support received by relatives also covered social support.

As Fig. 2 shows, patient support during hospitalization was assessed from the viewpoints of physical, psychological, and social support. In each of these content areas, more detailed questions were asked on comforting support, provision versus absence of patient support, provision of help, and support received by relatives. Finally, the patient was asked to evaluate their perceptions of the health-care staff.

Setting and Sampling

This study was based on data collected from surgically treated breast cancer patients and nurses caring for cancer patients. The random sample of patients consisted of 140 Finnish women who were diagnosed with breast cancer within the preceding 3 years but not in the preceding 3 months. Of the selected subjects, 78% ($n = 109$) responded to the postal questionnaire in 1989. The youngest patient was 32 years of age and the oldest 78 years (47% of patients were ≤ 55 years of age and 30% were ≥ 61 years). Over half (55%) had discovered their disease themselves. All patients were surgically treated: 59%

had surgery only, and 29% had undergone both surgery and radiotherapy. Furthermore, 11% were treated with surgery, radiotherapy, and chemotherapy and 1% by surgery and chemotherapy. The cancer had recurred in 12% of the women.

A questionnaire was mailed in 1990 to 128 ward nurses and 48 nurses working in outpatient clinics who were primarily caring for breast cancer patients in one university hospital and six area hospitals. The hospitals were the same ones in which the patients had been treated. No systematic training had been provided to the nurses within the organizations concerned. The questionnaire was completed by 125 nurses (89 ward nurses and 36 nurses from outpatient clinics). The university hospital accounted for 35% and local hospitals for 65% of them. The majority of the nurses (62%) represented surgical wards; 12% represented radiological/oncological wards. Nurses from outpatient clinics accounted for 26% of all nurses. On average the nurses had been in the nursing job for 15 years and on a cancer unit for 12 years.

Statistical Analysis

Before the final analysis, the dimensions studied were reduced by combining several questions in an attempt to identify those questions that best measured patient support. Questions that were combined were then tested (χ^2) to confirm that they retrieved information as effectively as the original questions. The final statistical analysis of the data of both samples was based on log-linear modeling, which is a statistical multivariate technique appropriate for analysis of the dependence structure of categorical variables (34). In interpreting the relationships attained by cross-tabulation, it is important to bear in mind that a relationship of dependence between two variables does not necessarily imply a causal connection; rather, it sheds light on the nature of the relationship between the variables compared. The method is described in more detail in another report (35).

RESULTS

Patient Support Before Hospitalization

Both breast cancer patients and nurses reported that patient support before hospitalization was insufficient. Total lack of support was reported by 58% of the patients, and 63% of the nurses thought that patient support was poor. The nurses felt that patients primarily need social support, whereas patients reported that social support was most beneficial before the operation. One third of the patients felt that they

TABLE 1. Patients' report of comforting support provided to hospitalized patients with breast cancer (project 1)

Comforting support by nurses according to patients (n = 109)	None		Little		Unknown		Much		Very much	
	n	%	n	%	n	%	n	%	n	%
Comforting of patients	34	31	41	37	13	12	17	16	4	4
Encouragement of patients	24	22	37	34	13	12	25	23	10	9
Talking to patients	16	15	59	54	3	3	20	18	11	10
Sharing experiences with patients	32	29	36	33	15	14	20	18	6	6
Listening to patients	18	16	43	39	15	14	29	27	4	4
Treating patients individually	21	19	27	25	30	28	23	21	8	7

could best help themselves by relying on their own resources, i.e., positive attitude and personality, but only 3% of the nurses shared this belief.

Patient Support During Hospitalization

Patients felt that they received insufficient support during hospitalization. However, nurses reported that they were providing enough support. One specific area of concern in the analysis of psychological support was comforting support (Fig. 2). This is also depicted in Tables 1 and 2.

Tables 1 and 2 show that nurses described their activities in a more positive light than did patients. Nurses felt that they often offered encouragement to their breast cancer patients. Patients did not share this opinion. Patients felt that nurses did not talk to them, share experiences with them, listen to them, or treat them on an individual basis; most nurses disagreed with this assessment. However, about half of the nurses estimated that the level at which they offered support and shared experiences with breast cancer patients was insufficient.

Patients did not usually state whether they felt they would have been treated differently had they disagreed on how they should be cared for. One probable reason for this was a lack of courage. However, most nurses reported that such disagreement would not affect patient care, but nurses in outpatient

clinics were doubtful. Both breast cancer patients and nurses thought that nurses are preoccupied with their work routines. Patients expected nurses to have time for them when they were admitted to the unit. However, only half of the nurses felt that they had time for the patient at that time. Nevertheless, hospitalized patients generally had a positive opinion of the nurses. According to 79% of the patients, however, medical doctors and nurses did not provide support for patients' relatives, whereas 22% of the nurses reported that they were not providing support for the patients' relatives.

Patients and nurses were asked the same questions about the support-related knowledge of the patients. Breast cancer patients and nurses stressed different components of the concept of support. However, all study variables measured the same content area. Only the question about physical support was not significant in the nurses' opinion. This was assumed to be due to the poor operationalization of this content area. We arrived at the following interactions with data collected from patients when all the variables included in testing the investigated area (*, interaction; +, connection):

Social support (A)* psychological support (B)* comforting support (C)⁺

Support received by relatives (D)* comforting support (C)⁺

TABLE 2. Nurses' report of comforting support provided to hospitalized patients with breast cancer (project 2)

Comforting support by nurses according to nurses themselves (n = 125)	None		Little		Unknown		Much		Very much	
	n	%	n	%	n	%	n	%	n	%
Comforting of patients	4	3	48	38	21	17	47	38	5	4
Encouragement of patients	1	1	19	15	8	6	87	70	10	8
Talking to patients	0	0	22	18	9	7	80	64	14	11
Sharing experiences with patients	6	5	43	34	25	20	49	39	2	2
Listening to patients	0	0	15	12	5	4	89	71	16	13
Treating patients individually	0	0	5	4	8	6	82	66	30	24

Support received by relatives (D)* physical support (E)⁺

Provision versus absence of support (F)* comforting support (C)

In the reported model (ABC, DC, DE, FC), $G^2 = 24.22$, $df = 50$, and $p = 0.9992$. A high p value indicates a satisfactory model (34). The opinions of the nurses on patient support showed the following dependence structure:

Comforting support (C)* support received by relatives (D)* psychological support (B)⁺

Provision versus absence of support (F)* support received by relatives (D)⁺

Psychological support (B)* social support (A)⁺

Comforting support (C)* social support (A)

In this model (CDB, FD, BA, CA), $G^2 = 9.11$, $df = 19$, and $p = 0.9717$. However, we arrived at a second significant dependence structure of patients' opinions when we took into account that patients' opinions on support provision were affected by the way that nurses treated them and by the nurses' level of friendliness. The patients were also asked in this connection if they might have been helped more effectively. With these two additional variables, we arrived at the following model:

Psychological support (B)* patients' opinions about the health-care staff (G)⁺

Help provided (H)* physical support (E)

In this model (BG, HE), $G^2 = 9.48$, $df = 9$, and $p = 0.3944$.

In conclusion, multivariate analysis showed some associations. The data collected from patients showed that the psychological support received by a patient and her opinion about the health-care staff were related. Assessments of the physical support and help received by the patient in the hospital were interdependent. Patients who felt that they had received psychological support also had a favorable opinion of the health-care staff. Those breast cancer patients who still felt after hospitalization that they should have been helped more effectively in the hospital reported problems, especially in the physical area.

When support was analyzed by variables shared by patients and nurses, it was found that patients usually reported that they did not receive sufficient comforting support. Those who felt that they did not receive sufficient comforting and psychological support still felt that they received sufficient social support. However, those patients who reported that they re-

ceived no comforting support also felt that they were left without psychological and social support during their hospital stay.

Patients reported that the support received by relatives and perceived support from the health-care staff had equal effects on perceived comforting support. If patients felt that they did not receive comforting support, they also reported that they and their relatives had not received enough support. Furthermore, if patients felt that relatives were not well supported, they did not perceive the physical environment of the hospital as supportive.

Although nurses admitted that they provided insufficient psychological support for their patients, they thought that they provided sufficient comforting support. More than half of the nurses who thought that they did not provide psychological support estimated that they were good at supporting relatives. However, when nurses reported that breast cancer patients generally were not well supported by the health-care staff, relatives, friends, and other patients, they usually considered that neither were the relatives well supported. Interestingly, a totally new dependence structure was found in the patient data after addition, on the basis of a theoretical assumption, of variables based on two questions: (a) Did nurses treat patients favorably? and (b) Could patients have been helped better? The variables that measured (a) social support, (b) support received by relatives, (c) provision versus absence of support, and (d) comforting support lost their significance in this dependence structure. Accordingly, the issue as to whether nurses had a positive attitude toward their patients seemed to be important.

Patient Support After Hospitalization

According to their own reports, patients perceived that support provided after hospitalization came from relatives rather than friends. Of the nurses, 69% thought that patients are not well supported after hospitalization, whereas 58% of patients felt that they could have been supported and helped more effectively in their recovery after hospitalization via mental rehabilitation, being listened to, and more positive attitudes and social support. Nurses underscored the importance of occupational support, supporting persons, group therapy, follow-up examinations, and help consistently provided by the same doctor. Another central issue of support according to the nurses was the activities of cancer societies. Information received at the time of discharge from hospital was reported as the best form of help for the patient.

Nurses also pointed out that relatives should participate in the care of breast cancer patients and that individual care should be provided for these patients.

DISCUSSION

Patients found it difficult to define a role for health-care staff in patient support before hospitalization. Support was usually received from people other than the health-care staff. More than half of the nurses reported that breast cancer patients are not well supported before hospitalization. Although patients primarily expected informational support, nurses underscored the value of psychological and social support. Both patients and nurses reported that relatives are not well supported. According to patients, the involvement versus noninvolvement of relatives in their care had no bearing on their perceived support in the hospital.

Patients felt that they did not receive enough support and information during their illness. The need for information and psychological support seemed to be enormous. Nurses reported that they supported their patients more actively than indicated by many studies of patient groups (36). On the other hand, Northouse (5) and Northouse and Swain (4) have noted that nurses support patients sufficiently. In the present study, patients felt that they did not receive adequate support, whereas nurses were of the opposite opinion. One possible explanation for this discrepancy is that patients were mainly assessing social support, whereas nurses were evaluating support they provided as part of their work. However, the nurses' viewpoint is important because they base their care partly on their own assumptions.

The only significant issue on which patients and nurses agreed was whether patients were psychologically supported during hospitalization. Patients perceived that good recovery was not dependent on whether relatives were supported. Nurses attached much importance to the connection between the patient's recovery and the support received by her relatives. Nurses regarded social support as important, whereas patients did not include it in the list of the four most important factors of good recovery when support was assessed with the same variables among patients and nurses. It seemed to be important for patients that nurses had a positive attitude toward them and behaved in a friendly manner. This finding is consistent with the results of Forsyth et al. (17), Kaler (18) and Leino-Kilpi (20).

IMPLICATIONS FOR FURTHER RESEARCH

One goal of nursing is to provide support for patients. Patients and nurses seem to disagree on the most important forms of support, but further studies are needed to explore the underlying factors. In this effort we should focus on both methodological issues and specific research topics. The questionnaires used in this study need additional testing, and some items may not have been valid; that is, some items may not have included the different types of support. In addition, future studies need to measure nurses' and patients' perceptions within the same time frame.

Rigorous attention should be paid to the methodology of research in this field. The concept of support needs to be clearly defined and operationalized. What does the concept of support mean to the different parties involved, to patients, relatives, and health-care staff? What do patients expect from support? What kind of support do they expect at different stages of their illness? From whom do they expect to get support? How can we assess the resources the patients have themselves and how can we help, support, and teach patients to use strategies that support their recovery? Why do patients seek alternative forms of treatment? Do patients look outside the official health-care system and what are they looking for? What kind of support do relatives expect and, in particular, what kind of support do the children of breast cancer patients need? □

REFERENCES

1. Aaronson NK, Bartelink H, vanDongen JA, Dam J. Evaluation of breast concerning therapy: clinical methodological and psychological perspectives. *Eur J Surg Oncol* 1988;14:133-40.
2. Ganz PA, Schage CC, Polinsky ML, Heinrich RL, Flack VF. Rehabilitation needs and breast cancer: the first month after primary therapy. *Breast Cancer Res Treatment* 1987;10:243-53.
3. Krouse H, Krouse J. Cancer as crisis: the critical elements of adjustment. *Nurs Res* 1982;31:96-101.
4. Northouse LL, Swain MA. Adjustment of patients and husbands to the initial impact of breast cancer. *Nurs Res* 1987;36:221-5.
5. Northouse LL. The impact of breast cancer on patients and husbands to the initial impact of breast cancer. *Cancer Nurs* 1989;12:276-284.
6. Silberfarb PM, Maurer LH, Crouthamel CS. Psychosocial aspects of neoplastic disease: I: functional status of breast cancer patients during different treatment regimens. *Am J Psychiatry* 1980;137:450-5.
7. Cohen S, Willis TA. Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985;98:310-57.

8. Kessler RC, McLeod JD. Social support and mental health in community samples. In: Cohen S, Syme SL, eds. *Social support and health*. New York: Academic, 1985:219-40.
9. Lazarus R, Folkman S. *Stress, appraisal and coping*. New York: Springer, 1984.
10. Turner RJ. Direct, indirect, and moderating effects of social support on psychological distress and associated conditions. In: Kaplan HB, ed. *Psychosocial stress: trends in theory and research*. New York: Academic, 1983:105-55.
11. Hoskins C. Patterns of adjustment among breast cancer patients and partners. *Hoitotiede*. Turku, Finland: Pika Oy/Pro Nursing Society, 1991:140-56.
12. Dunkel-Schetter C. Social support and cancer: findings based on patient interviews and their implications. *J Soc Issues* 1984;40:77-98.
13. Wortman C. Social support and the cancer patient. *Cancer* 1984;53:2339-60.
14. Nelles WB, McCaffrey RJ, Blanchard CG, Ruckdeschel JC. Social supports and breast cancer: a review. *J Psychosoc Oncol* 1991;9:21-34.
15. DeBack V. Competencies of associate and professional nurses. In: *Looking beyond the entry issue: implications for education and service*. No. 41-2173. New York: National League for Nursing, 1986:43-51.
16. Dunn D. Assessing the development of clinical nursing skills. *Nurse Education Today* 1986;6:28-35.
17. Forsyth D, Delaney C, Maloney N, Kubesh D, Story D. Can caring behaviour be taught? *Nurs Outlook* 1989;29:284-90.
18. Kaler S, Levy D, Schall M. Stereotypes of professional roles. *Image* 1989;21:85-9.
19. Kieffer J. Selecting technical skills to teach for competency. *J Nurs Educ* 1984;23:198-203.
20. Leino-Kilpi H. Good nursing care. On what basis? *Ann Univ Turkuensis Ser. D. Medica-Odontologica* 49. Turku, Finland: Turku University, 1990.
21. Goldberg RJ, Cullen LO. Factors important to psychosocial adjustment to cancer: a review of the evidence. *Soc Sci Med* 1985;20:803-7.
22. Funch DP, Marshall J. The role of stress, social support and age in survival from breast cancer. *J Psychosomat Res* 1983;27:77-83.
23. Northouse LL. Mastectomy patients and the fear of cancer recurrence. *Cancer Nurs* 1981;June:213-20.
24. Vachon MLS. A comparison of the impact of breast cancer and bereavement: personality, social support and adaptation. In: Hobfall S, ed. *Stress, social support and women*. New York: Hemisphere, 1986:187-205.
25. Bloom J. Social support, accommodation to stress and adjustment to breast cancer. *Soc Sci Med* 1982;16:1329-38.
26. Bloom J, 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;19:831-7.
27. Smith EM, Redman R, Burns TL, Sagert KM. Perceptions of social support among patients with recently diagnosed breast, endometrial, and ovarian cancer: an exploratory study. *J Psychosoc Oncol* 1985;3:65-81.
28. Spiegel D, Bloom JR, Yalom I. Group support for patients with metastatic cancer. *Arch Gen Psychiatry* 1981;38:527-33.
29. Lichtman RR, Taylor SE, Wood JV. Social support and marital adjustment after breast cancer. *J Psychosoc Oncol* 1987;5:47-74.
30. Peters-Golden H. Breast cancer: varied perceptions of social support in the illness experience. *Soc Sci Med* 1982;16:483-91.
31. Taylor S, Falke R, Shoptaw S, Lichtman R. Social support, support groups, and the cancer patient. *J Consult Clin Psychol* 1986;54:608-15.
32. Suominen T. Breast cancer patient's opportunities to participate in their care. *Cancer Nurs* 1992;15:68-72.
33. Suominen T, Laippala P. Breast cancer patients: the support given by nurses. *Scand J Caring Sci* 1993;7:131-4.
34. Agresti A. *Categorical data analysis*. New York: Wiley, 1990.
35. Suominen T, Laippala P. An application of loglinear modeling in nursing research: nurses' perceptions about information that breast cancer patients' receive in hospital, 1995. (submitted for publication).
36. Anderson J. The nurse's role in cancer rehabilitation. Review of the literature. *Cancer Nurs* 1989;12:35-9.