Types and sources of social support among cancer patients; are there differences with respect to gender

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ABSTRACT

The uncertainties and fears experienced by an individual diagnosed with cancer are likely to result in an enhanced need for social support. Social support is beneficial to cancer patients in adjusting to the stress of the disease, but those who have cancer may be especially likely to experience difficulties in obtaining adequate support. Types and sources of social support available to people afflicted with cancer related to reproductive organs and breast were assessed in this study, focusing on gender differences with respect to social support. Two hundred and eighteen respondents completed the Norbeck Social Support Questionnaire. Significant differences were found with respect to gender and being married, age, having grandchildren and being employed. Statistically significant differences were also found with respect to emotional support and frequency of contact with network members. Females scored higher emotional support, as well as higher total function support than the males, even though the females were more likely to be single, divorced or widowed. This contests the statements about the marital relationship as the most powerful life support source and the significant factor for cancer survival. It seems that there might be other affecting factors that make the cancer patient perceive and experience social support, perhaps a gender factor.

Health care providers must take into consideration that there are differences in how human beings act and perceive things with respect to gender.

Key words: cancer patients, gender, social support, sources of social support.

INTRODUCTION

In 1997 a total of about 43 000 cancer incidences were reported to the Swedish Cancer Registry. The most common form of cancer for men in Sweden is prostate cancer, with 5 920 cases a year, and for women, breast cancer, with 5 821 cases a year[1] . Cancer is one of the most common causes of death in Sweden today, second only to cardiovascular disease[2] . It is calculated that one third of the present population will develop at least one form of cancer during their lifetime[3-5]. Approximately 50 % of all cancer patients have a survival time exceeding five years and may live with cancer as a chronic disease[4,6]. Cancer, however, is to be considered by most people, as a life-threatening disease for which there is a poor prognosis. Statistics cannot reveal the physiological, psychological and sociological impact of cancer and the loss of productive years across all segments of the life span[5,7]. The treatment of cancer is often complex and extended, which may cause irreparable damage to physical, mental or social functioning. There is also a lifelong fear of recurrence or being taken ill with a new form of cancer[4,8]. This fear or uncertainty is common in both acute and chronic illness during all phases of the disease and is a great source of stress for patients and their families[10-12]. Social support has a positive influence on recovery, and adequate social support can protect people in crisis from a variety of pathological states as well reducing the amount of medication required[13].

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Social support

The literature provides various definitions of social support, and the term is used widely, often referring to mechanisms by which interpersonal relationships protect people from negative stress effects. Despite the different meanings of the term, social support has been claimed to have a positive outcome on physical health and mental well being[14]. An operational definition of the variable, a definition widely used by researches, states that social support encompasses three types of support: affect, affirmation and aid[15-16]. The dynamics of support have been studied using two conceptual models: one structural, the other functional. A structural model describes an individual's network of relationships, whereas a functional model features an individual's perceptions of the types and qualities of relationships[13,17]. Influenced by this definition and these models, an instrument was developed, measuring three components of social support, (affect, affirmation, aid) functional network properties (number, duration, and frequency), and recent losses of network members[18-19]. According to this instrument people have a greater likelihood of a positive outcome if they have adequate social support or have benefited from a successful intervention. Aspects affecting how much social support that is needed and/or available include both demographic variables and individual differences, such as self-esteem and social competence[20]. In the normative data[19], which consisted of 136 healthy employees, family or relatives are reported by the greatest number of respondents as a source of support, followed by friends. The highest mean number of people listed in the network was friends; the second highest was family and relatives. The average network size was about 12 people. Emotional support and feelings of intimacy have been shown to be critical components of the health-protective effects of social support throughout the adult life cycle. The marital relationship is among the most powerful normative life course supportive relationship[21].

Social support and cancer

The uncertainties and fears experienced by an individual diagnosed with cancer are likely to result in an enhanced need for social support. Social support is beneficial to cancer patients in adjusting to the stress of the disease, but those who have cancer may be especially likely to experience difficulties in obtaining adequate support[22]. Social support may provide distress, if significant others react with fear or feelings of aversion towards the cancer patient[23]. The frequent mention of communication problems is particularly noted in the cancer literature. The causes of these communication problems are complex; significant others often feel threatened and uncomfortable about the individual's disease. The individual with cancer often interprets these behaviours as evidence of rejection. Cancer could undermine one of the strongest resources people have in coping with the disease, their social relationship/network[14]. One measure of the potential for social support is the number of people in a persons' network who may provide support and aid[24]. The network size, the number of individuals with whom the individual has direct contact, does not confirm evidence of more support. Small networks characterised by close relationships have generally been regarded as the most supportive in time of crisis[25]. Cancer patients reported in a study[26], that primary sources of support were manifested by patients' overall preference for tangible aid from family, modelling from friends who had cancer, and open communication from health professionals. Family and friends were equally preferred sources for dealing with affective reactions to the stressfulness of cancer[26]. Another study about cancer patients and their perception of social support showed that support was dependent on the source. Particular actions were perceived to be helpful from some but not from others in the network. The cancer patients reported that the most helpful type of emotional support received was from spouse, family and friends. These patients also mentioned that informal and tangible support were the most helpful types of support provided by these same individuals[27]. It appears that the experience of cancer represents a paradoxical circumstance; social support is potentially a strong resource for adjusting to cancer, yet reaction to the disease can interfere with the provision of support.

Social support and chronic illness/sever illness

Common aspects of social support, provided to women with chronic disease have been identified[28-29]. They include the family, access to a supportive spouse, interactions specific to self-care regimes, social exchange outside the family, social contact, the number of persons in the network, and leisure activities. In these studies of women with chronic illness, it was found that the women received more functional support from their partners than from any other sources. It was also found that family provided more affective support than others did and friends provided more affirmative support than family or others[28-29]. The size of the social network ranged from 3 to 24 people, with a mean of about 13[28]. Another study assessing the relationship of social support in the indicators with 7-year survival among women with breast cancer supported the view that social support may have an effect on longer survival[30]. Social support is a key factor in adjustment to breast cancer, according to another study in this area[31]. Marital support was clearly conceptualised as the perceived degree of satisfaction with a spouse's response to emotional and interactional needs during the

different phases of breast cancer. The need for support outside the marital relationship also increased over time, as it was noted that cancer is a chronic disease, with ongoing demands[31].

In a study of patients waiting for a cardiac transplantation, including 27 men and 4 women, social support was grouped in three main types: affect, affirmation, and aid[32]. Families and friends provided all types of support; hence families provided most affective and aid support. Family and friends were the most commonly identified sources of support, followed by health care professionals. The size of the social network ranged from 3 to 27 people, perhaps reflecting differences in support requirements and the availability of different types of support[32]. Head injured adults reported that they had positive feelings toward support perceived from families and friends, but were less positive about supports received from their peers. Results from this study also showed that the younger the respondents, and/or the younger age at time of injury, the greater the support received, especially from family members[33].

Social support and gender

Are there any gender differences with respect to social support? In one study, describing and comparing the social network and the size and composition of women and men's social network[24], the following findings were reported: the conflicted social networks of women were larger and comprised of more family member's[24]. Demographic factors, such as age and socio-economic status, were not significantly related to the size of these women's social network. But younger men, and men of higher socio-economic status, showed significantly larger social networks than other men[24].A study focusing on gender differences in psychosocial adjustment to cancer [34] found that there was no significant difference by gender in the level of distress experienced. Hence women made a more positive adjustment and social support seemed to affect these differences[34]. Results confirming this, i.e. no significant differences between men and women, were shown in a study about the psychological well being of adults with acute leukaemia in remission. There were no significant mean differences between men and women on the demographic variables or any of the other variables of concern[35]. In another study focusing upon gender differences[36], only a few gender differences in coping were found. Men (fathers) used more active problem focusing, whereas women (mothers) used more social-support seeking -on all measurements[36].

Although many studies concerning the impact of cancer on individuals' psychosocial well being and social support have focused on women, few have focused on men or on a comparison by gender.

The aim of the present study was to identify the types and sources of social support available to people afflicted with cancer related to reproductive organs, including breast cancer. The focus in this study was to investigate whether there are differences with respect to gender and the social support/network.

MATERIAL AND METHODS

Criteria were set to establish the research population; the respondents had to be (i) adults; (ii) diagnosed with a cancer related to reproductive organs, including breast cancer, during the period 1990-1995: and (iii) registered as patients at a County Hospital, in southern Sweden.

The total population 1990-1995 included approximately 2300 patients with the following types of cancer diagnosis: breast, prostate, testicle, and uterus cancer. The aim of the sample was to reach a stratified sample of 1:10 in each group of cancer diagnoses, giving about 230 patients.

Sample

The sample of 242 individuals, 123 (50.8 %) females and 119 (49.2 %) males, ranged in age from 26 to 82, with a mean age of 64. The sample consisted of a total of 123 women, with breast cancer (n= 112), uterus cancer (n= 9) and with cancer both in their breast and their uterus (n= 2), and a total of 119 men, with prostate cancer (n= 109) and testicle cancer (n= 10). The average duration of illness was five years for the sample (n=242).

The Questionnaire

The questionnaire used in present study was the Norbeck Social Support Questionnaire (NSSQ), which is a self-reported instrument designed to measure multiple dimensions of perceived social support (14-15). Using a Likert scale, respondents rated each member of the network on three sub-scales of social support, (affect, affirmation, aid), functional network properties (number, duration, and frequency), and recent losses of network members. Respondents identified by given name or initial those people in their social networks whom they perceived as providers of support. The NSSQ consisted of a total of nine items. The first six items were about social support, and items seven and eight were about functional network properties. The last item was about recent losses. Since the individual's convoy may change over time, this last item is a variable of secondary interest in the study of social support. The items were scored by the value assigned

by the respondents on a 1-5 scale. The designer of the instrument adjusted the six first items, changing the value from a 1-5 scale to a 0-4 scale, to ensure that 0 and not 1 would mean "not at all"[37].

Back-translation[38-39] was used to translate the NSSQ into Swedish and then back to English to establish equivalence. There are three specific steps for back-translation[38-39], which were followed step by step. The researchers obtained permission from the designer of the instrument to translate the instrument into Swedish.

Test-retest Pearson Correlation was calculated for the sub-scales[18] and showed the following figures: affect .89, affirmation .88, aid .86, total function .90, and total network .92. In the revised instructions[37] two of the original sub-scales, affect and affirmation, are combined into a single sub-scale, emotional support. In the present study, the NSSQ alpha coefficients were computed to assess the internal consistency of the sub-scales for this sample; the alpha coefficient was .93.

Procedure

The cancer registry in southern Sweden identified the patients and sent this information to the researchers, who forwarded it and written information about the study to the physicians responsible. Those physicians had to make a final judgement regarding the patients' health-status, as to whether they could participate in the study or not. Reasons for excluding patients were depression, psychological instability, dementia, aggravated disease, or not speaking Swedish. The questionnaire was introduced to the respondents using an information letter, where the respondents were invited to participate in the study. The respondents were informed about the aim of the study, confidentiality, selection procedures, and permissions received. They were also given a telephone number, which they could use if they had questions. The response rate for answering the NSSQ became 90 % (n= 218). Some questionnaires were returned unfilled regarding the NSSQ with comments like "I cannot manage to answer the questionnaire" or "I do not want to grade my relatives and friends".

The regional Ethical Committee approved the study. Permission was also given by the Swedish Data Inspection Board to identify patients in the cancer registry and to compute the data.

Statistical method

The statistical package used is SPSS/PC +[40] Descriptive and analytic statistics were used. All results are reported as means ±standard deviation of the mean (SD). For comparison of means of two independent groups, Student's t-test and ANOVA were used. The Pearson's χ^2 test for categorical data was used to assess whether there was a significant association at the 5% significance level, between gender and each of the measures assessing social support and functional network properties as well as demographic data.

RESULT

Table I presents the socio-demographic, independent background variables. Females were different in several ways in comparison with their male counterparts. They were younger and more likely to be single, divorced or widowed. More than half of the females (51.2 %) were employees compared to only one tenth of their male counterparts (10. %). A statistically significant difference was shown with respect to gender and being married ($p<0.05$). There was no significant difference according to gender and having children, whereas there was a significant difference with respect to gender and having grandchildren ($p<0.005$). There was also a significant difference with respect to gender and age ($p<0.005$), as was also the case for occupation and gender ($p<0.005$). The average duration of illness was 5.0 for the women and 4.9 for the men, and no significant difference was shown.

Table I. Demographic characteristics of a sample of 123 female and 119 male respondents in the study about social support and gender differences.

Characteristics	Female			Male		
	Mean	SD	Range	Mean	SD	Range
Age in Years	58.96	11.51	26-82	69.76	10.37	28-81
Marital status:		%			%	
Single		09.76			04.20	
Married		64.48			83.19	
Divorced/separated		08.94			05.04	
Widowed		13.82			07.56	
Children		90.20			87.30	
Grandchildren		54.40			73.90	
Occupation:						
Employees		51.21			10.08	
Retired		39.83			89.92	
Unemployed,						
on sick leave etc.		08.96			00.00	
Type of cancer:						
Uterus		07.32				
Breast		91.05				
Breast/uterus		01.63				
Prostate					91.60	
Testicle					08.40	

Except for the loss items and numbers in the network the mean values reflect the ratings on each item for the entire network list (Table II). The mean support is a function of both quality of support and the number of people listed in the network. Females scored higher emotional support than males and this difference was significant ($p<0.05$).

Table II. Means and standard deviations of scores for female and male respondents on the NSSQ.

	Female (n=116)		Male (n=102)	
NSSQ Subscales	Mean	SD	Mean	SD
Emotional support [a]	107.8	59.3	91.8	58.6
Aid[a]	55.1	31.7	49.4	33.4
Total Function	162.9	87.8	140.4	87.9
Network size	8.5	4.4	7.4	4.4
Duration[b]	41.6	21.6	36.0	21.6
Frequency of contact[c]	31.8	16.2	27.4	16.0
Total Network	81.9	41.9	70.9	41.6
Recent losses[d]	.2	.4	.2	.4
Loss Quantity[e]	.6	1.7	.6	1.9
Loss Quality	1.4	.9	1.6	.8
Total Loss	1.8	3.5	1.6	3.3

[a] Based on average ratings for network members on a 5-point scale, ranging from 0 (not at all) to 4 (a great deal)

[b] Based on average ratings for network members on a 5-point scale, ranging from 1 (less than 6 months) to 5 (more than 5 years)

[c] Based on average ratings for network members on a 5-point scale, ranging from 1 (once a year or less) to 5 (daily).

[d] Score represents dummy coding of 0 = No and 1 = Yes.

[e] Number of categories checked; 9 possible. Based on a 5-point rating scale ranging from 0 (not at all) to 4 (a great deal).

No significant difference was found with respect to the sub-scale, aid, even if the females scored higher values than males. Looking at the total function scores; the females scored higher than the males. Social support strength is represented by total function on the NSSQ. This score is the summation of the sub-scales, emotional support and aid, scores. No significant difference was found, even though the value was near the line (p 0.063). The average network size for the respondents is 8.0 and with females scoring 0.5 higher than this figure and males scoring about 0.6 lowers. No significant difference was shown.

Duration is the variable, which inform us about the duration of the respondents' relationships with network members. Once again the females scored higher values than the males, and this was also quite near a significant difference (p 0.057). For the variable, frequency of contact with network members, even here the females scored higher than the males, and this difference was significant ($p< 0.05$). The sum of these two variables and network size is the total network score, which gives us higher scores for females than for males, in accordance with figures shown above. Thus, the difference is almost significant (p 0.054).No significant difference was found for any of the loss variables or at the total loss score with respect to gender.

Table III. Multivariate analysis of variance of total function support, by network sources.

	Females (n=116)		Males (n= 102).	
Source	M	SD	M	SD
Spouse	3.7	.5	3.7	.4
Family	3.3	.7	3.3	.7
Friends	3.2	.7	3.0	.6
Work associates	3.0	.6	2.4	.7
Neighbours	2.9	.5	2.8	.6
Health care providers	2.2	.9	2.4	.8
Counsellors	3.0	.5	1.5	.0
Priest	2.9	.9	3.3	.9
Other [a]	3.0	.8	2.5	1.2

[a] Other sources included member of different societies etc; member of a choir, member of the parish church, member of the sports club; domestic animal i.e. the dog.

The respondents answering the NSSQ (n=218) listed a total of 1 719 people in their networks. Spouses were listed totalled 175 and had the highest total support score perceived, followed by family and friends with a frequency of 838 and 392, respectively. The next source of support, with a frequency above 100, was work associates, listed with a frequency of 128. The remaining sources had a frequency lower than 100, down to five (counsellors).

Table III presents the sources of social support available for the respondents and the score of total function support. Both females and males reported the highest score for spouses, followed by family. No significant difference was found with respect to gender and available sources (spouses and family) and total support scores. After these sources came friends, work associates and neighbours; significant differences was found with respect to gender and friends ($p< 0.002$), as was the case with respect to gender and work associates ($p< 0.000$). Health care providers were ranked in sixths place. Males scored the health care providers higher than did the females. After that followed counsellors, priests and other sources of support; no significant difference was found with respect to these sources and gender. The value for counsellors and gender, however, was near the borderline (p 0.064).

DISCUSSION

According to Norbeck[20], support given and received generally occurs within the network of ongoing relationships. Therefore, assessment of established relationships with respect to commitment and closeness is

crucial to determine the adequacy of a person's social support network.

The network size for the respondents was small: approximately four family members and two friends. There were no differences with respect to gender and network size. The average network size was eight people, which is less than reported in the normative data study[19], or in the study about chronic disease[27]. It was notable that there were no considerable differences between the network size of females and males. This is in contrast with another study[41], where an examination of gender differences in studies indicated that females identify a larger number of members in their network than male's[41]. Even if females had higher emotional support scores, it was not linked with a larger network. These figures are in accordance with the normative data study[19], and the statement by Caplan[25]; small networks characterised by close relationships has generally been regarded as the most supportive in time of crisis. The network seemed to be characterised by close relationships, both females and males listed as mentioned above, family members and friends as first priority.

The duration of the respondents' relationships with network members gave high figures, showing us that the network members were well known and "familiar" to the respondents. The females scored a little bit higher than the males, but no significant difference was shown, even if the value was a border-liner.

According to the variable, frequency of contact with network members, the females scored higher than the males, and this difference was significant. This could be due to the fact that females have a tendency to maintain social contact and social support, and because of the female character; women talk naturally about feelings and what they perceive. It could also be due to the age of the women, who were younger, and the fact that they were employees. These aspects can be an explanation of the figures about significant differences in frequency of contact, but also of the scores in Table III.

Females scored higher on total function support with respect to the sources of friends, work associates, neighbours, counsellors and others, whereas males scored higher on sources such as spouse, family, health care providers and priest. It seems as though men, especially older men, have a tendency to rely more on their partner and family than on other network members, even if the priest in some cases was an important source of social support.

Females scored lower total function support than males with respect to the spouse as a source of support, which seems to contradict what Primomo et al.[28] and Hoskins et al.[31] found, and the notion of the marital relationship as the most powerful normative life course supportive relationship[21]. There was conformity to the Hoskins et al study[31] with respect to the fact that support outside the marital relationship increased over time, as it was noted that cancer is a chronic disease. The respondents in the present study had had their cancer diagnosis for an average of five years, and could therefore experience the disease as chronic. Priority given to spouse, family and friends as sources of support is consistent with findings from previous studies of social support and chronic illness[28-29,32-33] and studies of social support and cancer[26-27]. It was notable that health care providers were scored quite low, being given the lowest figure throughout for total function support, even though the males scored them somewhat higher. The health care providers were ranked sixth. These results are in contrast to what patients waiting for a cardiac transplantation reported[32], where patients identified sources of support and health care professionals as the third most common source. This could be due to the fact that these cardiac patients are cared for in the hospital; the cancer patients in the present study are treated at home and live with their cancer as a chronic disease, making their appointment with the physician once or twice a year. It could also be due to the fact that the majority of the sample in the cardiac study was men.

Another interesting aspect is that males scored the total function support perceived by health care providers higher than the females did. In fact, the males scored the health care providers' equivalent to the family, whereas the females scored the health care providers with the lowest score given to any source of support. The reason for this can only be speculated about. Perhaps it could be that men felt cared for, and about, when they were in focus at these annual appointments, even if it was just once or twice a year. Or, could it be that the males perceived support since there was an open communication with the health care providers about the disease and its treatment, perhaps a more active problem-focusing communication? The women on the other hand wanted more social-support seeking communication. This social-support seeking communication might focus more on the women's feelings about the disease and what feelings the disease causes them. If so, it is consistent with findings from previous research on social support and gender[34,36].

Much of the data relating to social support has relied exclusively on female samples. The omission of males from

such studies may be of significance, since it is supposed that genders influence the relationship between support variables and mental health/ well being. In the present study significant differences were found with respect to emotional support and frequency of contact, as well as total function support and sources of support. Females scored higher than males, which is consistent with findings from previous studies of social support and gender[34,36]. In these studies the females made a more positive adjustment to the cancer disease; and males were more actively problem-focused, whereas females sought more social support.

CONCLUSION

Females scored higher emotional support, as well as higher total function support than the males, even though the females were more likely to be single, divorced or widowed. This contests the statements about the marital relationship as the most powerful life support source and the significant factor for cancer survival. It seems that there might be other affecting factors that make the cancer patient perceive and experience social support, perhaps a gender factor.

It is important that the health care providers take into consideration that there are differences in how human beings act and perceive things, with respect to gender. If we as health care providers are to support cancer patients, we must know how to receive them and recognise their individual needs. We also have to understand the importance of providing support, not only to the cancer patient, but also to the whole family.

Several findings generated from the results of this study show the need for further testing and further research about gender differences.

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