

## RESEARCH COMMUNICATION

# Impact of Home Education on Levels of Perceived Social Support for Caregivers of Cancer Patients

Birsel Canan Demirbag

### Abstract

**Background:** The healthcare needs of cancer patients are complex and persons involved in their caregiving process are faced with many issues that need to be addressed. The entire family and particularly the person taking on responsibility for patient care develop expectations from healthcare professionals, especially nurses. **Objective:** The study was conducted to evaluate the impact of a home education program provided to caregivers of cancer patients on the level of their perceived social support and problems in caregiving. **Interventions/Methods:** The caregivers of thirty seven cancer patients of 2,400 registered people in a family center were given an educational program in this descriptive and cross-sectional study twice a week for a month during the period of March 2011 – April 2011. **Results:** Of all caregivers, 56.8% were between the ages 36-40, 94.5% were female, 91.9% had received no education on caregiving, 81.0% stated that they mostly felt physically and mentally inadequate in their caregiving. Perceived Social Support from the family indicated a significant difference at  $8.05 \pm 4.38$  before and  $11.7 \pm 4.97$  after the education. A comparison of the mean scores of caregivers on emotional issues before and after the education revealed the following: spiritual distress scores were  $2.54 \pm 0.69$  before and  $2.44 \pm 0.43$  after the education; hopelessness scores,  $2.24 \pm 0.59$  before and  $2.23 \pm 0.38$  after the education; ineffective individual coping was  $3.89 \pm 1.42$  before and  $2.45 \pm 0.59$  after the education; competing needs in decision-making were  $3.54 \pm 0.69$  before and  $2.10 \pm 1.24$  after the education; depressive feeling were  $3.01 \pm 1.53$  before and  $2.02 \pm 0.99$  after the education ( $p < 0.05$ ). **Conclusions:** Positive effects of home education on levels of perceived social support and caregiving problems of caregivers of cancer patients were observed. Home educational programs for caregivers of cancer patients are important for both better understanding of the requirements of their patients and themselves.

**Keywords:** Cancer - caregivers - education - early intervention - family - health problems - home visit - social problems

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### Introduction

Cancer is a health issue that people of every age and in every country may have to deal with. Receiving a diagnosis of a life-threatening illness like cancer presents a serious psychological challenge for victims of the disease as well as the persons who look after these patients (Babaoğlu & Oz, 2003). Caregivers are described as individuals who take the responsibility of meeting the emotional and physical needs of persons who are unable to take on their own personal care (Scherbring, 2002). Studies have indicated that living with cancer generates reactions in both patients and caregivers beyond what may be deemed normal, sometimes manifesting as symptoms of psychiatric disorders (Babaoğlu & Oz, 2003). The basic principles in providing care in this disease are reducing the discomfort of the patient's symptoms and offering psychological support. It is also of the utmost importance to ensure the physical, emotional and social wellbeing of the cancer patient's caregiver (Hunt, 1991; Eng, 1993).

Many studies have uncovered emotional and social issues that are associated with feeling misunderstood, being unable to get adequate support from family members, and experiencing difficulties in communication (Smeenk et al., 1998). In a study of cancer patients and their families, Shyu (2000) found that 21-33% of patients and their family members had needs that had not been addressed during the cancer diagnosis and treatment process. It was seen that these needs were aggravated as the disease progressed. In research conducted by Flashkerud<sup>7</sup>, it was set forth that 70-80% of persons providing care for cancer patients were spouses, 20% were the patients' children and 10% were friends and other close acquaintances. Caregivers feel that they need more support in order to overcome the problems brought about by the illness. Healthcare providers have important responsibilities at this stage. Smeenk et al. (1998) reported in their study that 20 out of 25 of the interventions carried out by nurses attending to cancer patients and their families were of benefit. Cancer is a chronic disease that is full of ups and downs and

Department of Nursing, Faculty of Health Sciences, Karadeniz Technical University, Trabzon, Turkey \*For correspondence: [cdemirbag@gmail.com](mailto:cdemirbag@gmail.com)

rife with special needs and issues that have an impact on both patients and their caregivers (Flaskerud et al., 2000). The diagnosis of cancer is a traumatic experience for the individual and for the family. More than other diseases, cancer wreaks havoc over the balances in the lives of the cancer victim and his or her family, causing significant physical, psychological, economic and social distress. The implications of this impact increase the importance of developing the skills of caregiving. In many countries, there are healthcare programs geared to support cancer patients and their families. In Turkey, however, no state-subsidized program exists for cancer patients and their caregivers. Patients and caregivers are instead left to try to cope with their situation as best as they can on an individual level. Because of this, the care provided in this process becomes ultimately ineffective and inadequate due to myriad psychological, social and economic issues.

### Purpose

The psychological, physiological issues that confront cancer patients adversely affect family members as well. For this reason, family members also have a need for professional support. Besides having to learn to live with cancer, caregivers also experience psychological and physiological changes over the process of the illness and treatment. The healthcare needs of cancer patients are complex and persons involved in the caregiving process are faced with many issues that need to be addressed. The patient's entire family and particularly the person taking on the specific responsibility of caring for the patient develop expectations from healthcare professionals, and especially from nurses. This study was carried out for the purpose of evaluating the impact of home education provided to caregivers of cancer patients on the level of their perceived social support and the problems encountered in caregiving.

## Materials and Methods

Type of Research, the study was of single group pre-test/post-test pre-experimental design.

Location and Time of Research, the research was carried out at a family health center in a city in the Eastern Black Sea Region of Turkey during the period March 2011 – April 2011. This family center serves a total population of 2400. There were 37 cancer patients registered at the family health center.

Universe and Sample, the caregivers of the 37 cancer patients registered at the family health center made up the sample for the study.

Research Ethics, ethical and institutional permission was obtained for the study. The patients, their families and caregivers were informed about the content of the study, after which their written consent was obtained.

Patient Data Form, in order to collect information about the patients that were being cared for by the caregivers comprising the sample, a "Patient Data Form" drawn up by the researcher was used. This form contained data on the variables of the patient's age, gender, marital status, educational level, profession, social security status, working status, place of residence, symptoms, how long the patient had been afflicted with the disease, and the

people in the household with whom the patient was living.

Caregiver Data Form, in order to obtain information on the characteristics of the caregivers comprising the sample, a "Caregiver Data Form" drawn up by the researcher was used. This questionnaire contained data on the caregiver composed of the variables of the caregiver's age, gender, marital status, educational level, profession, social security, working status, the relation to the patient, whether the caregiver had any dependents, how long the caregiver had been attending to the patient, whether there were people from whom the caregiver received support, the physical, psychological, social issues that the caregiver faced since starting to take care of the patient, and how the caregiver answered the need to receive education on caring for the patient.

Scale of Perceived Social Support from Family and Friends (PSS/FR, PSS/FA), the Turkish version of the "Scale of Perceived Social Support" (abbreviated in Turkish as ASD-AL and ASD-AR), developed by Pracidona and Heller (1983) and adapted to the Turkish, tested for validity and reliability by Eskin (1993), was used in determining the caregivers' perceived social support scores. The scale is in the form of two independent scales. Each scale is made up of 20 items to which an answer is marked for "Yes," "No" or "I don't know." Each item indicating perceived social support is counted as "+1". The scores are in a range of 0-20. The option "I don't know" receives a score of 0. Scores of +10 indicate that social support is high, scores below +10 point to low perceived social support.

Questionnaire on Identifying Emotional and Social Issues: This form was created after a review of similar studies and pertinent literature. The Nursing Diagnoses List published in 1982 by the North America Nursing Diagnosis Association (NANDA) was used as a resource (Carpetino, 1999). In the scoring of the questionnaire, a "yes" response from the subjects was assigned 2 points, "no" was assigned 1 point. The questionnaire contains 12 sub-groups, 6 devoted to emotional issues and 6 to the social issues of caregivers of cancer patients. Comprising a total of 36 items, each issue was allotted three items, as follows,

Emotional issues,		
1-Spiritual distress		9, 10, 11
2-Despair		7, 8, 12
3-Anxiety-fear		1, 3, 13
4-Ineffective individual coping		4, 14, 18
5-Competing needs in decision-making		15, 16, 17
6-Depressive feelings		2, 5, 6
Social Issues,		
7-Feeling challenged in the role of caregiver		20, 21, 26
8-Inadequacy in carrying on daily activities		19, 23, 24
9-Change in Social Interaction		25, 29, 35
10-Change in Taking Part in Entertaining Activities		32, 33, 34
11- Change in Role Performance		22, 27, 28
12-Social isolation		30, 31, 36

In the evaluation of the questionnaire, the "yes" and "no" responses were first assessed as 2 points and 1 point,

respectively. Then, in order to identify each problem, the total scores of the previously grouped items were found. The responses of the 37 subjects were evaluated and points were obtained for each issue. In the statistical analysis, the scores that were thus obtained for the dependent variables were compared in terms of mean scores.

Data Collection and Intervention, the patients agreeing to participate in the study and their caregivers comprised the sample group. These patients and caregivers were provided information about the research. The implementation of the study involved use of the "Patient Data Form", "Caregiver Data Form", "Scale of Perceived Social Support from Family and Friends" and the "Questionnaire on Identifying Emotional and Social Issues." As part of the research, a visit was paid to the caregivers at the patients' homes. All of the questionnaires were implemented before the education took place. The education consisted of a program set up by the researcher that encompassed the topics of the meaning of cancer, the symptoms experienced by the cancer patient, stress and coping, individual coping, symptom management, planning for the care process, time management and, the importance of the contribution of family members in the care of the patient, all of these subjects being discussed face-to-face during the home visit. The home visits set up to provide the education were carried out twice a week; the duration of the program of visits was one month. Visiting times were limited to 1-2 hours. At the end of the visits, the caregivers were asked to fill out the same questionnaires. The patient's permission was obtained to have the data collection take place in a different room. The questionnaire was filled out in a period limited to 25 minutes, using the technique of face-to-face interviewing.

Evaluation of the data, the analysis of the data was carried out with the help of the Windows 16.0 Statistical Package for Social Sciences (SPSS). Figures and percentages, mean scores and the t significance test were used in the analysis.

## Results

The addresses of the caregivers were obtained from the family health centers where they were registered and home visits were paid to all caregivers without exception. Of the caregivers, 56.8% were between the ages 36-40, 94.5% were female, 29.7% were elementary school graduates, 75.7% were from the middle income bracket, 43.2% had 2 children, 37.8% were living in a household of four, 73% were living in rented homes, 40.5% were living in three-room houses, 86.5% did not have a private room in the house devoted to the patient, 91.9% had received no education on caregiving, 83.8% went to the hospital in emergencies, 59.5% were not acquainted with the symptoms of the patient, 94.62% did not have anyone helping in the caregiving process, 56.8% did not know whether they were adequate in their caregiving, 56.8% had expectations from the health team, 81.0% stated that they mostly felt physically and mentally inadequate in their caregiving, and 27.0% had been caring for the patient for a period of 1-3 years (Table 1).

A comparison of Perceived Social Support from Friends

**Table 1. Identifying Characteristics of Caregivers**

Characteristics of Caregivers		n	%
Age:	Between ages 25-30	2	5.4
	Between ages 31-35	3	8.1
	Between ages 36-40	21	56.8
	Age 41 and over	11	29.7
Gender:	Female	35	94.5
	Male	2	5.5
Education:	Literate	10	27.0
	Elementary school	11	29.7
	High School	9	24.3
	University	5	13.5
	Illiterate	2	5.4
Monthly Income:	Below TL 500-700 (low)	7	18.9
	TL 701-1000 (middle)	28	75.7
	TL 1001 and above (high)	2	5.4
No. of children of Caregiver			
	1	9	24.3
	2	16	43.2
	3	9	24.3
	4 and more	3	8.1
No. of people living in the house where patient is cared for			
	2	3	8.1
	3	8	21.6
	4	14	37.8
	5 and more	12	32.4
Status of Home in which Care is Given			
	Rented	27	73.0
	Owned	10	27.0
No. of rooms in the home where care is given			
	2	9	24.3
	3	15	40.5
	4	10	27.0
	5 and more	3	8.1
Whether or not Patient has Own Room			
	Yes	5	13.5
	No	32	86.5
Whether caregiver has received education on caregiving			
	Has received	3	8.1
	Hasn't received	34	91.9
Source of education: Relatives		3	8.1
Who the caregiver applies to in emergencies			
	Relatives	4	10.8
	Hospital	31	83.8
	No one	2	5.4
Is the caregiver familiar with the symptoms of the patient?			
	Yes	15	40.5
	No	22	59.5
Does the caregiver have anyone to help?			
	Yes	2	5.4
	No	35	94.6
Does the caregiver feel adequate in providing the care?			
	Yes	4	10.8
	No	12	32.4
	Doesn't know	21	56.8
Does the caregiver have expectations from the health team?			
	No	5	13.5
	Yes	21	56.8
	Doesn't know	11	29.7
Problems for the caregiver			
	My house isn't suitable	24	64.4
	I feel mentally and physically inadequate in caregiving.	30	81.0
	I need support, I'm having trouble in communicating with the patient	23	62.1
	I don't get enough sleep, tired	29	78.3
	I don't have any time for myself	33	89.1
	I have economic problems	28	75.6
Time the caregiver has been caring for the patient			
	1-6 months	5	13.5
	7-12 months	9	24.3
	1-3 years	10	27.0
	4-6 years	6	13.6
	7 years and more	7	21.6

**Table 2. Comparison (N = 37)**

Social Support	X±sd	t	p
Perceived Social Support from Friends and Family			
Friends:			
Before education	7.76±4.22	3.43	0.170
After education	9.75±4.61		
Family:			
Before education	8.05±4.38	4.77	0.000*
After education	11.68±4.97		
Mean Scores of Caregivers for Emotional Problems			
Emotional Issues;			
Spiritual distress:			
Before education	2.54±0.69	8,837	0.042
After education	2.44±0.43		
Hopelessness:			
Before education	2.24±0.59	1,666	0.104
After education	2.23±0.38		
Anxiety-fear:			
Before education	3.54±1.29	0.723	0.000*
After education	2.37±0.69		
Ineffective Individual Coping:			
Before education	3.89±1.42	0.88	0.000*
After education	2.45±0.59		
Competing needs in Decision-making:			
Before education	3.54±0.69	2,208	0.000*
After education	2.10±1.24		
Depressive Feelings:			
Before education	3.01±1.53	0.643	0.000*
After education	2.02±0.99		

**Table 3. Mean Scores of Caregivers for Social Issues**

Social Issues	X±sd	t	p
Difficulty in role of caregiver:			
Before education	3.81±1.24	1,333	0.000*
After education	1.94±0.67		
Inadequacy in daily activities:			
Before education	4.37±1.08	1,480	0.000*
After education	3.08±0.59		
Change in social interaction:			
Before education	3.64±0.94	8,837	0.000*
After education	2.55±0.69		
Change in Entertaining Activities:			
Before education	3.93±1.01	1,843	0.074
After education	3.08±0.59		
Change in Role Performance:			
Before education	3.78±0.75	1,390	0.173
After education	3.54±0.69		
Social isolation:			
Before education	3.35±1.11	1,351	0.185
After education	3.08±0.59		

and Family before and after the education displayed mean scores of 7.76 $\pm$ 4.22 before and of 9.75 $\pm$ 4.61 after the education, representing no significant difference ( $p>0.05$ ). When mean scores for Perceived Social Support from the Family were compared, these were seen to represent a significant difference at 8.05 $\pm$ 4.38 before and 11.68 $\pm$ 4.97 after the education ( $p<0.05$ ) (Table 2).

A comparison of the mean scores of caregivers on emotional issues before and after the education showed the greatest differences in the following categories: spiritual distress scores were 2.54 $\pm$ 0.69 before and 2.44 $\pm$ 0.43 after the education; hopelessness scores, 2.24 $\pm$ 0.59

before and 2.23 $\pm$ 0.38 after the education; ineffective individual coping was 3.89 $\pm$ 1.42 before and 2.45 $\pm$ 0.59 after the education; competing needs in decision-making were 3.54 $\pm$ 0.69 before and 2.10 $\pm$ 1.24 after the education; depressive feeling were 3.01 $\pm$ 1.53 before and 2.02 $\pm$ 0.99 after the education ( $p<0.05$ ) (Table 3).

In comparing the social issues mean scores of caregivers before and after the education, it was seen that the greatest differences manifested in the following categories: feeling challenged in taking on the role of caregiver displayed mean scores of 3.81 $\pm$ 1.24 before the education and of 1.94 $\pm$ 0.67 after the education; inadequacy in carrying out daily activities was 4.37 $\pm$ 1.08 before the education and 3.08 $\pm$ 0.59 after the education; social interaction was 3.64 $\pm$ 0.94 before the education and 2.55 $\pm$ 0.69 after the education ( $p<0.05$ ) (Table 4).

A significant difference was found before the education between the age of the caregiver and perceived support from family and friends ( $p<0.05$ ). Perceived family and friend support was observed to display lower scores in patients of 41 years of age and over. It was also determined that there was a significant difference between perceived family and friend support in terms of how long the caregiver had been caring for the patient; in periods of seven years and more, mean scores were seen to be low ( $p<0.05$ ). While no difference was found after the education between perceived friend and family support in terms of age and the period of sickness, a significant decline was however seen in the mean scores of perceived family support.

## Discussion

Cancer is a major condition that affects many people directly or indirectly. With the advances achieved in methods of treatment, the course of the disease has changed from being an acute and usually terminal illness to a chronic condition that often requires long-term treatment and home care (Kim & Given, 2008). For this reason, cancer appears before us as an illness that has an impact not only on the person receiving the diagnosis but also on all of the members of the patient's family. The cancer care that is usually provided by one of the family members involves a series of needs that must be addressed, among them, monitoring the treatment, coping with side effects, the need for emotional, financial and psychological support, personal care, and looking after medical equipment (Kim et al., 2006).

Caregivers who are family members have reported many issues with which they feel they must cope: conflicting social roles, stressful marital and family relations, restrictions placed on daily activities, anxiety and distress, personal health problems (Given et al., 2001).

Caregivers of cancer patients have been found to have emotional problems that can be identified as anxiety and fear, difficulties in providing care, being unable to cope, and depression (Given & Given, 2001). Many studies indicate that caregivers of cancer patients are most likely to experience emotional problems (Fadıloğlu, 1995; Given & Given, 2001). In the present study, the most common issue was the presence of depressive emotions, a result that is



consistent with the literature. In a study by Babaoğlu and Öz (2003), spouses taking on the care of cancer patients were seen to be most bothered by depressive emotions. Close to follow were ineffective personal coping and competing needs in decision-making. It has been asserted that the relationship between depressive feelings and perceived feelings of uncertainty have an impact on the capability to provide care (Macneil et al., 2010). Depression is one of the adverse outcomes of the caregiving process and one that leads to diminished quality of life, functional deterioration and increased mortality (Macneil et al., 2010). Many studies report that as the illness progresses, uncertainties about the future and the difficulties faced by caregivers in providing the needed caregiving bring about feelings of inadequacy that in turn lead to anxiety (Babaoğlu & Öz, 2003; Given & Given, 2001). The responsibility of having to care for a patient outside of the hospital, the physical care that needs to be provided, the problems encountered in the household and many other similar issues have been shown to be sources of depression (Given & Given, 2001). Caregivers are distressed by the problems they may encounter during the caregiving process and, accompanied by the fear of not being able to cope, these feelings lead to anxiety (Uğur, 2006).

In the present study, it might be suggested that the outcome of depression was a result of the fact that 94.5% of the caregivers in the sample were women. Stone et al. reported (1987) that 23% of all caregivers are women and that only 13% are husbands. Kellner et al. (1996) asserted that among caregivers, the spouses displaying the most depressive emotions were wives. In situations where long-term care was needed, 40-70% of the caregivers exhibited symptoms of depression and 50% actually received a diagnosis of depression (Bedard et al., 2004). It is for this reason and so that appropriate precautions can be taken that caregivers need to be informed about the burden that the caregiving process can place on their shoulders. There are many studies in the literature that point out that it is not only patients but caregivers too that need to be included in treatment programs and monitored in terms of their adaptation capabilities as well as from a psychiatric perspective (Zarit, 2004; Barg et al., 2000). In our study, the fact that there were significant differences in the levels of anxiety and fear, individual coping and competing needs in decision-making after the education compared to before indicates that being informed about the disease and the different aspects of patient care, becoming knowledgeable about symptom management at home, coping with stress, and planned living can have a positive impact on caregivers' lives.

As in our own culture, many societies consider the job of caregiving a woman's task, regarding this as a simple chore, which is a perspective that ultimately adds to the burden of the caregiver, pares down all feelings of self-confidence as the caregiving process progresses, creating many difficulties for the caregiver (Kim et al., 2007). Numerous studies have shown that supportive factors such as friends and family, organizational and educational programs have a positive impact on the role taken on by the caregiver of a cancer patient (Bloom, 1996; Eriksson & Lauri, 2000). The present study found that

facing challenges in caregiving and feelings of inadequacy in carrying out daily activities were the foremost social issues that plagued caregivers in their caregiving roles before the education. The significant differences seen after the education revealed that an educational program was indeed effective in this respect, which is an outcome that is consistent with the positive impact pointed to in the literature. At the same time, it was also found that the application of the caregiving plan taught in the program led to positive changes in the social interaction displayed by caregivers.

In their study, Skinner et al. (2000) reported that perceived support from both family and friends became diminished in chronic physical conditions but that the most prominent change was seen in the perception of support from friends. Again, Aras and Tel (2009) in a study, reported that patients' perception of family support was at a higher level than perceived support from friends. In the present study and consistent with the literature, the perceived social support from the family was also at a higher level than perceived support from friends. An examination of the scores on the scale of perceived social support from family and friends reveals that scores for perceived social support from the family show significant differences before and after the education. In a study by Parmelee (1983) on persons providing care to the elderly, it was shown that the social support received by caregivers reduced the effects produced by the stress of caregiving.

Although family members and relatives constitute the most effective social support system for caregivers, caregivers need support from both family and friends in order to develop an adequate perception of social support (Macneil et al., 2010). It has been reported that being surrounded by a network of close and devoted friends reduces feelings of loneliness and that maintaining satisfying friendships, contrary to family relationships, is dependent upon reciprocal interaction and support (Gülseren, 2002). In the present study, no significant difference was seen after the education in caregivers' perceived support from friends, a finding that can possibly be explained by the fact that due to the circumstances of the illness, caregivers perhaps had limited opportunities for reciprocal interaction that would serve to develop and expand friendships.

In conclusion, there is such profuse evidence in the literature pointing to the fact that cancer affects not only the individual with the disease but also caregivers, who are usually close family members, that the ramifications of this issue cannot be underestimated. When the various characteristics of the patient, the disease, and the caregiving process are considered, it might even be said that caregivers constitute a group that is even at relatively higher risk. This study has shown the positive effect of home education on levels of perceived social support and caregiving problems by caregivers of cancer patients. Influenced in large part by cultural factors as well, caregivers in Turkey must be supported with educational programs specifically devised for their needs and formulated after comprehensive and longitudinal research. It is important that health professionals evaluate the state of groups of individuals at risk who are forced to

provide home care and to provide them with the support they need. The responsibility that falls upon the shoulders of the health team and particularly public health nurses is to make sure that patients and their families are aware of the problems facing them and to guide them in seeking out the appropriate approach and behavior that will facilitate the caregiving process. More research in the future with larger sample groups in different societies and cultures, in different regions and in rural and urban areas, will be useful in better understanding the impact of various educational programs on caregivers of cancer patients.

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