

RESEARCH ARTICLE

Responsibilities and Difficulties of Caregivers of Cancer Patients in Home Care

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Abstract

Background: Having been known as a virulent disease in 1970s, cancer is now considered a chronic disease and 64% of cancer patients live for five years after diagnosis. Home care has gradually gained more importance and it is a great burden on the shoulders of caregivers. Caregivers have to undertake the responsibility of the cancer patient's home management, and organize care and arrange health care services according to the ever-changing condition of patients. Caregivers should be prepared for home care so they can provide accurate and complete care to patients. This descriptive study aims to investigate challenges that caregivers encounter in the home care of patients and the reasons for these challenges. **Materials and Methods:** The research group consisted of caregivers of outpatients in a daily treatment center in a university hospital. The research sampling consisted of 137 voluntary caregivers of patients who attended the Daily Treatment Center for control, chemotherapy or other supportive cares services between January-June, 2011. Data were collected with face-to-face interviews in the Daily Treatment Center. Ethics Committee approval was taken university hospital; caregivers and their patients were informed about the research and their approval was taken as well. **Results:** It was found that 54.01% of caregivers help patient's nutrition, 50.36% help medicine use, 26.28% help oral hygiene, 26.28% help to meet urinary needs and 51.82% help to change clothes, 69.34% of caregivers help to change bed sheets, 38.69% help the patient to communicate with their environment and 71.53% help to bring the patient to hospital or outside. **Conclusions:** This study, it was found that caregivers experience challenges due to following factors: patient nutrition, medicine use, oral and body hygiene, colostomy maintenance and stomach tube feeding, concern of dropping the patient, feeling incompetency in body temperature and fever control, fatigue, and lack of personal time.

Keywords: Responsibility - difficulties of caregivers - cancer patients - in home care

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Introduction

Having been known as a virulent disease in 1970s, cancer is now considered a chronic disease and 64% of cancer patients live for five years after diagnosis (Byar et al., 2006). As the number of cancer patients increases, new treatments methods are developed, symptoms are controlled, and psychological and physiological quality is improved; however, patients are directed to home care due to the lack of staff, accommodations and economic difficulties (Bektas and Akdemir, 2006; Romito et al., 2013). Home care has gradually gained more importance and it is a great burden on the shoulders of caregivers. Caregivers have to undertake the responsibility of the cancer patient's home management, and organize care and arrange health care services according to the ever-changing condition of patients. They help direct care activities such as physical care, symptom management, monitoring of changes etc. and also perform in-house activities such as shopping, child care, house care, cooking, laundry etc., as well as provide maintenance of care devices (infusion

pumps, intravenous fluid replacement, replacement of colostomy bag...), patient handling and ensuring patient safety (Wen and Gustafson, 2004; Stenberg et al., 2010; Hazelwood, 2012; Chang et al., 2013). However, it is reported in the literature that caregivers are not prepared sufficiently before the patient is discharged (Altun, 1998; Wen and Gustafson, 2004; Karabuga, 2009; Serfelova et al., 2012). The period after discharge is important for the management of the symptoms of cancer patients. Hendrix et al. (2006) found that emergency service is frequently used within the first and second weeks after the discharge of cancer patients. Chamber et al. (2001) investigated integration strategies of caregivers. Accordingly, it was found that caregivers do not receive any formal training about patient handling, medical treatment methods, protection from pressure ulcers, catheter maintenance, nasogastric nourishing, incontinency management; they try to do their best, acquire necessary information and skills through making mistakes, observation and conducting research from friends and neighbors. Given et al. (2001) report that caregivers experience challenges

in pain management, patient mobilization, daily life activities, communication with health personnel, symptom management, home medicine treatment, the management of emotional reactions of the patients and often feel helpless and useless, especially when they cannot control the patient's pains. Caregivers should be prepared for home care so they can provide accurate and complete care to patients (Given et al., 2001; Hendrix and Ray, 2006). Nurses should define the responsibilities of caregivers based on the patient's prognosis and dependency needs, and challenges and requirements encountered while fulfilling these responsibilities, in addition to planning and applying the necessary practices to meet these requirements (Wen and Gustafson, 2004; Stenberg et al., 2010; Chang et al., 2013). For these reason, this study investigated the challenges that caregivers encounter while providing home care to patients and the reasons for these challenges.

Materials and Methods

Descriptive study aims to investigate challenges that caregivers encounter in the home care of patients and the reasons for these challenges. The research group consisted of caregivers of outpatients in a daily treatment center in a university hospital. According to hospital data, service was given to 12,320 cancer patients in the Daily Treatment Center in 2009. The research sampling consisted of 137 voluntary caregivers of patients who attended the Daily Treatment Center for control, chemotherapy or other supportive cares services between January-June, 2011. The caregivers, aged 18 and older, spoke Turkish, lived in the same house with their patients, and had given care for more than three months. They were at least primary school graduates and did not receive financial compensation for their caregiving service.

Data collection tools

The "Caregiver's description form" and "Identification form regarding challenges that caregivers encounter in home care and the reasons for these challenges," which were prepared after the literature review, were used to collect data. The caregiver's description form consists of descriptive data. The form includes questions about the caregiver's age, gender, educational background, marital status, number of children, employment, health insurance, caregiving period, relationship degree with the patient, whether s/he resides with the patient or not. The Identification form regarding challenges that caregivers encountered in home care and the reasons for these challenges was prepared after the literature review (Altun, 1998; Wen and Gustafson, 2004; Sapountzi-Krepa et al., 2008; Serfelova et al., 2012). The form consists of questions about nutrition and urinary needs of the patient, body hygiene, changing clothes and bed sheets, transporting the patient to hospital, patient handling, conducting financial transactions, giving medicine treatment, follow-through treatment required when the patient had fever or pain, and challenges encountered during these practices.

Data collection

Data were collected with face-to-face interviews in the Daily Treatment Center. During the data collection process, the researcher determined caregivers who complied with the sampling criteria; caregivers were informed about the aim of the research and the voluntary ones were included in the study.

Data analysis

The SPSS package program was used to analyze data. Socio-demographic data of caregivers, challenging daily life activities for caregivers, and the reasons for these challenges, were distributed in figures and percentages.

Research ethics

Ethics Committee approval was taken from Dokuz Eylul University; caregivers and their patients were informed about the research and their approval was taken as well. No financial support was received from any institution or agency to conduct this research.

Results

The participants' demographic information is as follows: 70.80% of caregivers were female, 31.40% were in the 40-50 age group, 42.30% were primary school graduates, 81.80% were married, and 70% were unemployed. In addition, 96.30% had health insurance, 57.70% gave care for one year, 49.60% were the spouse of the patient, 70.80% had no chronic disease, and 56.93% did not receive any help during caregiving process (Table 1).

It was found that 54.01% of caregivers help patient's

Table 1. Descriptive Characteristics of Caregivers

		Figure (%)
Gender	Female	97 (70.80)
	Male	40 (29.20)
Age	39 and younger	27 (19.70)
	40-50	43 (31.40)
	51-61	41 (29.90)
	62 and older	26 (19.00)
Educational background	Primary education	58 (42.30)
	High school	38 (27.70)
	University and over	41 (29.90)
Marital Status	Married	112 (81.80)
	Single	25 (18.20)
Employment	Employed	41 (30.00)
	unemployed	96 (70.00)
Health insurance	Available	132 (96.30)
	Not available	5 (3.70)
Caregiving period	3-12 months	79 (57.70)
	2-3 years	20 (14.60)
	3-5 years	18 (13.10)
	5 years and more	20 (14.60)
Relationship degree with the patient	Parents	35 (25.50)
	Spouse	68 (49.60)
	Child	25 (18.30)
	Sibling/relatives	9 (6.60)
Presence of chronic disease	Yes	40 (29.2)
	No	97 (70.8)
Receiving support during caregiving process	Yes	59 (43.07)
	No	78 (56.93)

nutrition, 50.36% help medicine use, 26.28% help oral hygiene, 26.28% help to meet urinary needs and 51.82% help to change clothes. It was found that 69.34% of caregivers help to change bed sheets, 36.69% help the patient to communicate with their environment, and 71.53% help to bring the patient to hospital or outside. It was found that 75.91% help to shop for patient and house needs, and 59.12% help financial transactions of patients. In addition to all these practices, 48.18% of caregivers provide help when the patient have hyperthermia and 50.36% help when the patient has pain.

Analyzing the challenges that caregivers encounter in performing daily care activities for patients; it was found that the reason for these challenges is patient's loss of appetite in 19% of caregivers; patient's problem in swallowing medicines in 15.94%; and patient's nausea and vomiting in 10.14%. It was found that 22.22% of caregivers have difficulty in dealing with the oral hygiene of patients because patients do not want to use mouth care solutions. It was found that 8.20% of caregivers who provide body hygiene to patients have concerns about dropping the patient and 19.67% have difficulty dealing with body hygiene. It was found that 19.44% of caregivers who meet urinary needs of patients feel the risk of dropping the patient due to their physical mobility restriction, 11.11% feel this risk due to the patient's colostomy bag and 8.33% feel the risk due to the mobility restriction of the patient. It was found that 9.86% of caregivers who help to change clothes of patients have difficulty due to the pain and mobility restriction of the patient (2.82%); 7.37% get tired while changing bed sheets and creating a suitable living area for the patient. It was found that 11.32% of caregivers who support patient's communication do not have sufficient consultancy service from health personnel. It was found that 6.12% of caregivers who provide support for out-of-home activities have difficulty due to the mobility restriction and risk of

falling of the patients (17.35%). It was found that 5.77% of caregivers who shop for patients and house needs have concerns about the patient's being alone at home. It was found that 2.47% of caregivers who provide help for the financial transactions of house and patient complain about the lack of time for themselves. It was found that 22.73% of caregivers have difficulty in bringing the fever of the patient down and 31.88% have difficulty in pain control (Table 2).

Discussion

The home care of cancer patient requires extra effort and management. In this study, which investigated challenges encountered by caregivers in performing daily life activities of cancer patients and the reasons for these challenges, it was found that many needs of cancer patients are met by caregivers and caregivers report some difficulties during this process.

In this study, it was found that the daily life activities of patients performed by caregivers consist of shopping for the patient and house, creating suitable living areas to accommodate patient mobility, helping with financial transactions of the house and the patient, and supporting patient nutrition. In addition to all these activities, it was found that caregivers are also responsible for controlling the body temperature and pain of the patient. The research findings are similar to the results of Altun's (1998) study. Altun's (1998) reported that patients' primary daily life activities that are performed by caregivers are as follow: bringing the patient to treatment/control, taking the patient for a walk (90.15%), shopping for the patient and house (77.27%), helping with the patient's nutrition and cooking for the patient (68.94%), giving medicines (66.67%), and cleaning and tidying the environment where the patient lives (66.66%). However, the range of daily life activities of patients that are supported by caregivers is not similar to

Table 2. Help of Caregivers for Daily Life Activities (DLA) of Patients and the Reasons for the Challenges Encountered During This Process

DLA for which caregivers provide help	Figure (%)*	Reasons of challenges	Figure (%)**
Nutrition (including cooking)	74 (54.01)	Patient's loss of appetite	26 (19.00)
		Patient's nausea and vomit	3 (2.20)
		Patient's nasogastric tube feeding	3 (2.20)
Medicine use	69 (50.36)	Patient's challenge in swallowing medicines	11 (15.94)
Oralhygiene	36 (26.28)	Patient's nausea and vomit	7 (10.14)
		Patient's unwillingness to use solutions	8 (22.22)
Body hygiene	61 (44.53)	Patient's risk of falling	5 (8.20)
		Tiredness of caregiver	12 (19.67)
Meeting urinary needs	36 (26.28)	Patient's physical mobility restriction	7 (19.44)
		Patient's risk of fall	3 (8.33)
		Presence of colostomy in patient	4 (11.11)
Changing clothes	71 (51.82)	Presence of pain in patient	7 (9.86)
		Patient's physical mobility restriction	2 (2.82)
Providing suitable resting environment ^a	95 (69.34)	Tiredness of caregiver	7 (7.37)
Communication	53 (38.69)	Insufficient information taken from health personnel	6 (11.32)
Taking the patient out, bring her/him to hospital, patient handling	98 (71.53)	Patient's physical mobility restriction	6 (6.12)
		Patient's risk of fall	17 (17.35)
Shopping	104 (75.91)	Patient's being alone at home	6 (5.77)
Help for financial transactions	81 (59.12)	Caregiver's lack of time for her/himself	2 (2.47)
Control of patient's body temperature	66 (48.18)	Non-efficiency of caregiver's practices	15 (22.73)
Control of patient's pain	69 (50.36)	Non-efficiency of caregiver's practices	22 (31.88)

*Percentages were calculated by n: 137; **Percentages were calculated according to providing help for DLA; ^a(tidying up the room, preparing the bed, changing bed sheets)

the findings of some other studies (Spountzki et al., 2008). This is because of the fact that caregivers generally consist of family members in Turkey and they have to manage other responsibilities within house as well. Therefore, the order of priority's changes in activities supported by caregivers. For example, in the study of Spountzki et al. (2008), body hygiene and helping the patient's nutrition are primarily performed; in the present research, these activities are not prior to others. This finding support the fact that caregivers also need help. In this study, it was found that 56.93% of caregivers do not receive any assistance. In the literature, it was reported that caregivers who are directly responsible for patient care should receive support from external institutions regarding household management (Chamber et al., 2001).

To provide support for the daily life activities of patients brings along a range of problems as well (Stajduhar, 2013). In this study, the challenges encountered by caregivers while supporting the daily life activities of patients can be examined under three titles; namely, patients, health system and caregivers. The reasons for these challenges are the patients' loss of appetite, hardship in swallowing medicines, rejection to the use mouth care solutions, and the risk of falling due to mobility restriction. A few caregivers reported that they have difficulty in changing the patients' clothes due to a nasogastric tube or colostomy, and the pain of patients. The findings are similar to the results seen throughout the literature. Given et al. (2001) found that caregivers need to be informed about the disease, treatment, management of symptoms and emotional problems of patients, the prognosis of the disease, household management, developing problem solving strategies, providing financial support and supporting the patient's mobility. Hendrix et al. (2006) found that planned and practical training given to the caregiver for the home care of cancer patients reduces challenges and stress. In this study, the finding that caregivers find it difficult to change the adaptor of the patient's colostomy bag (11.11%) is similar to the result of the research conducted by Jansma et al. (2005).

In this study, it was found that caregivers have difficulty changing the clothes of patients due to their pain. Hendrix et al. (2006) emphasized that caregivers are in need of help regarding medicine management and patient's clothing; follow-up, consultancy and training programs before and after patient discharge are important in order to reduce the problems encountered during this process. In the literature, it is reported that caregivers should be supported regarding pain control, medicine management, medicine dosage, pain assessment, and the management of side-effects of medicines (Given et al., 2001; Silver and Wellman, 2002; Todd et al., 2002; Jansma et al., 2005; Sapountzi-Krepa et al., 2008; Adams et al., 2009; Hendrix et al., 2009; Meeker et al., 2011; Stajduhar, 2013).

In this study, the reasons for the challenges encountered by caregivers were determined as follow: fatigue, concern about leaving the patient alone at home, and feeling incompetent in pain and fever control. These findings are compatible with the literature. Chamber et al. (2001) reported that caregivers are in need of information and support about emergencies and challenging caregiving

requirements. In the literature, it was emphasized that caregivers have difficulties performing their duties due to concern, fear, fatigue, and unwillingness to leave the patient alone due to the fear of finding the patient worse or deceased (Altun, 1998; Roberts et al., 2002; Ugur, 2006; Northouse et al., 2012; Serfelova, 2012). Nurses should offer solution focused recommendations for the problems encountered by caregivers in addition to defining high-risk health problems, and improving the health of individual, family and society. In this way, the caregiver will perform their duty consciously; be able to deal with symptoms as well as their own life quality. These changes will lead to an improvement in the care provided by caretakers (Honea et al., 2008).

In this study, system-sourced challenges were found to be as follows: the lack of consultancy given from health personnel and the patients' risk of falling due to long hospital processes. In a guideline for caregivers prepared by the American Cancer Association, it is emphasized that cancer patients are in a high-risk group for falling these patients slip and fall especially when they are moved from their bed and given a bath. Furthermore, it is encouraged that caregivers should help patients to walk, make patients sit on the edge of their beds for a couple of minutes before handling them, ask about dizziness; railings should be placed in places like baths/toilets, carpets should be removed, the necessary precautions should be taken to wear nonslip shoes or sandals, and hospital system-sourced problems should be solved (www.cancer.org). In order to reduce insufficient information related problems, health personnel should detect the needs of caregivers at home and provide consultancy service about the disease, prognosis of the disease, medicine treatment and needs for caregiving (Given et al., 2001; Hendrix and Ray, 2006; Serfelova, 2012).

In the literature, it is emphasized that caregiving is influenced by cultural structures (Robison et al., 2009) and that caregiving is a responsibility traditionally fulfilled by female members of the family (Todd et al., 2002; Adams et al., 2009; Serfelova, 2012). According to Turkish general customs, families and relatives of people in need of care prefer caregiving in their own social environment (www.manevibakim.com). The changing processes in the 21st century have improved the status of women in business life and steered women out of the house and turned the traditional family structure into a more nuclear oriented one. Because of all these aforementioned changes, and despite the fact that the home care rates of the elderly and people in need of care has decreased, these people generally continue to receive caregiving services from their family members in their own social environment. Our study support abovementioned findings and it was found that 70.80% of caregivers are females and 49.60% are caring for their spouses.

To conclude; in this study, it was found that caregivers experience challenges due to following factors: patient nutrition, medicine use, oral and body hygiene, colostomy maintenance and stomach tube feeding, concern of dropping the patient, feeling incompetency in body temperature and fever control, fatigue, and lack of personal time. In this scope, health professionals should

define the physiological, social and emotional needs of caregivers, prepare caregivers for home care and symptom management before patient discharge, and plan and apply suitable practices for caregivers so as to improve their integration with their new role (Given et al., 2001; Hendrix and Ray, 2006; Meeker et al., 2011; Serfelova, 2012). Furthermore, it should be remembered that caregivers can develop integration strategies based on environmental and cultural factors.

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