

RESEARCH ARTICLE

Experiences of Family Caregivers of Cancer Patients Receiving Chemotherapy

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Abstract

Background: Cancer is a disease which affects not only patients but also their families physically and emotionally. The purpose of this study was to determine the needs, challenges and ways of coping of caregivers of cancer patients. **Materials and Methods:** In the study, a phenomenological approach was used. Data were collected through semi-structured individual interviews. The study sample comprised 16 family members providing care for a cancer patient. **Results:** The study findings are grouped under four main themes: the impact of caregiving, masking feelings, experienced challenges and expectations, and coping. During the caregiving process, patient relatives are affected physiologically, psychologically and socially. It was determined that patient relatives hid their feelings and avoided talking about the disease for fear that they might upset the patient, and that they had difficulty in coping with the patient's reactions during the treatment process. Family members had difficulties arising from the health system, hospital conditions and treatment in addition to transportation and financial problems. Support is very important in coping, but it was determined that some of the relatives of patients did not receive adequate support. Patient relatives expect that health care professionals should provide them with more information about their patient's condition and the course of the disease that their patients should be dealt with by the physicians specialized in cancer, and that psychological support should be provided both for them and for their patient. **Conclusions:** During the caregiving process, family members are faced with many difficulties and they exhibit different coping behaviors which health care professionals should take into account.

Keywords: Cancer - caregivers - chemotherapy - coping - relatives - nursing

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Introduction

Cancer is a disease with high mortality and morbidity rates, and thus coping with it is difficult. It affects both patients and their families physically and emotionally. It is one of the main health problems, because it leads to deaths, affects people in all age groups throughout the world, makes the person dependent on others and affects both patients and their families adversely (Tamayo et al., 2010; Terakye, 2011). It is well known that due to cancer, not only patients' but also family members' daily living pattern is interrupted and that cancer patients' families suffer from stress more. Once the cancer diagnosis is established, family members should struggle with the challenges arising due to cancer and undertake the role of caregiving (Silveira et al., 2010; Tamayo et al., 2010; Terakye, 2011). Providing care for a loved one with a chronic or serious illness brings about heavy burdens (Terakye, 2011; Türkoğlu and Kılıç, 2012). According to the results of the report by the National Profile of Family Caregivers

in Canada, 2002, of the caregivers, 50% suffered physical health problems and 48% suffered mental health problems. In addition, of the family caregivers, 54% had financial difficulties and 66% had trouble in their working life due to their caregiver roles. In their study conducted to assess family caregivers' stress arising from their caregiver roles, Gopalan and Brannon (2006) determined that caregivers had not only physical problems such as hypertension and impaired immune system but also mental health problems such as depression or anxiety. Caregivers, due to their caregiver roles, also develop physical problems such as indigestion, changes in appetite, irregular eating habits, headaches, chronic fatigue, weight gain or loss, muscle pain, difficulty in concentration, and emotional symptoms such as restlessness, insomnia, decreased self-esteem and social isolation (Deeken et al., 2003; Dewar et al., 2004; Tsigaropoulos et al., 2009; Chang et al., 2013; Ogce et al., 2013; Stajduhar, 2013; Ugur et al., 2014).

Since cancer lasts for a long time, threatens life and prevents the patient from returning to work and social

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life, the caregiver's responsibilities increase, and roles within the family change (Tamayo et al., 2010; Terakye, 2011). Since family caregivers' usual daily life patterns are interrupted and they cannot return to their work and social life, they worry about themselves and their losses. They also suffer from depression, because they feel anxious, hopeless and helpless, and worry about the patient (Terakye, 2011).

Family caregivers not only deal with the challenges they face but also try to maintain their caregiver role and to keep the situation under control (Silveira et al., 2010). However, they quite often feel that they either are unprepared or lack knowledge to deal with this life-long crisis, or they do not have enough energy and resources to meet their patient's needs (Hilton et al., 2000; Haley, 2003; Lethborg et al., 2003). Understanding the difficulties experienced by cancer patients and their relatives and investigating their needs and expectations are important and essential to fully discover the impact of cancer.

For the development of rehabilitation and health care programs, it is essential to identify the needs of a cancer patient and his/her family at different stages of diagnosis and treatment of cancer (Schmid-Büchi et al., 2011). Identifying and understanding the needs will help nurses to focus on the care and to meet the priority needs (Schmid-Büchi et al., 2008).

In their study, Uğur and Fadiloğlu (2012) determined that caregivers were adversely affected by patients' suffering and depression. In the same study, it was also determined that caregivers had unmet information needs on the treatment of cancer (Uğur and Fadiloğlu, 2012). Health care professionals, especially nurses can have a positive impact on well-beings of caregivers (Eriksson and Lauri, 2000; Hudson et al., 2002; Bee et al., 2008; Pinkert et al., 2013). Meeting the needs of caregivers of cancer patients and providing enough support for them will help caregivers to perceive the burden of caregiving less, to cope with the symptoms better and to have decreased emotional stress levels and increased quality of life (Kurtz et al., 2005; Silveira et al., 2010).

As a result, studies have revealed that caregivers feel they are not adequately supported by healthcare professionals. In order for health care professionals to provide support for caregivers, it is important to understand the caregivers' difficulties, effects of coping and of caregiving on them, and their expectations. However, there are very few studies on difficulties, coping and needs of family caregivers of cancer patients. Therefore, it is considered that the findings of this present study will be of importance in determining the needs, problems and ways of coping of caregivers of cancer patients.

Materials and Methods

Study objectives

The purpose of this study is to determine the needs and challenges of caregivers of cancer patients receiving chemotherapy and their ways of coping.

Type of the study

In the present study, the phenomenological approach,

one of the qualitative research methods, was used. The phenomenological approach was preferred because it makes it possible to understand a concept or an event by investigating a person's experiences and perceptions related to that event (Yıldırım and Şimşek, 2005).

Settings and participants

This present study was conducted in Dokuz Eylül University Hospital Outpatient Chemotherapy Unit. In the study, the purposive sampling was used (Speziale and Carpenter, 2003). The study sample included relatives of the patients who received at least two cycles of chemotherapy. The participants had to volunteer to participate in the study and be able to communicate verbally. The process of determining the sample size continued until no new information emerged but the same information was repeated in interviews, and at the end, 16 people were included in the sample (Speziale and Carpenter, 2003).

The caregivers' ages ranged between 32 and 69 years, with a mean age of 52.93. Of them, 11 were female, 5 were male, 11 were primary school graduates, 3 were college graduates and 2 were illiterate. While, 14 of the participants had a middle-income status, 1 had decent income and 1 had low income. Of the caregivers, 8 provided care for their spouses, 3 for their parents, 2 for their children, 2 for their sisters and one for the uncle. Of the patients who were given care, 3 had colon cancer, 3 had breast cancer, 2 had lung cancer, 2 had larynx cancer, and 2 had stomach cancer. The other patients had other types of cancer (liver, bone, oral cavity cancer and leukemia).

Data collection

The data were collected through semi-structured individual interviews. The interviews were made by an experienced researcher (NG) who was trained in qualitative research methods. The interviews were conducted in the chemotherapy unit. An appropriate physical environment (quiet, safe) was created for the interviews. The interviews were audio-recorded.

The research questions were: How have you been affected by the caregiving process of your patient? How do you overcome difficulties you have had in this process?

Data analysis

Content analysis was used in the analysis of data, using the process described by Graneheim and Lundman (2004). To increase the reliability of the data analysis, the participants' statements were coded by the two authors separately. The codes were then compared and the differences discussed and re-evaluated until shared codes and categories had been created.

Ethical considerations

Ethical approval to conduct the study was obtained from the Ethical Committee of Dokuz Eylül University Institute of Health Sciences (decision numbered 2014/04-19 and dated 23.01.2014). The patients were informed about the purpose of the study both verbally and in written, and assured that they had the right to refuse to participate in the study before the interview.

Results

The findings of the study were grouped under four main themes: effects of caregiving, masking feelings, challenges experienced and expectations, and coping.

Main theme: Effects of caregiving

Effects of caregiving were placed into three categories: physiological, psychological and social effects.

Physiological effects: The participants stated that they suffered physical problems such as headaches, loss of appetite, weight loss, insomnia or fatigue related to grief and stress they had in the caregiving process. While some of the participants stated that their existing illnesses such as migraine or disc herniation worsened, others said that they developed illnesses such as hypertension, eczema, psoriasis.

"I know my headaches stem from my sadness". "Well, something happened to me, I have psoriasis, rheumatoid arthritis, I have a lot many problems, that is, my life is over".

Psychological effects: Participants stated that they experienced such feelings as distress, sadness, shock, anxiety, weakness, irritability, guiltiness, hopelessness, psychological suffering and fear of losing a loved one in the process of caregiving. One participant indicated that he was diagnosed with depression.

"Cancer is a word unfamiliar to us. So I was shocked, I was very much shocked and I couldn't pull myself together for a few months. It's been too heavy a burden for me... cancer, it is something devastating."

Social effects: Most of the participants stated that they had restricted social life due to their increased burden during the caregiving process and concerns that the patient might become infected. According to their statements, while some of the participants failed to adequately look after their children due to caregiving-related burden, some of them had to quit their jobs.

"In the meantime, I'm too worn out, I have no time for myself, I cannot go out, I cannot go anywhere."

One participant stated that she deliberately restricted the number of guests visiting her husband in order to prevent him from becoming depressed.

"I do not want anybody to visit us because they will ask my husband what happened to him. He was very strong. But because he is not anymore, everyone will say "Oh dear! What happened to you?" Then my husband feels bad."

Main theme: Masking feelings

The theme masking feelings is grouped in two categories: hiding one's feelings and having difficulty in coping with the way the patient expresses his/her emotions.

Hiding one's feelings from the patient: Most of the participants stated that they tried hard to hide their feelings in order to prevent the patient from becoming sad.

"...I cannot cry near him, I tell him that he is well (she cries)." "I behaved as if it were something not very serious. In fact, I was suffering inside. I did not show it to him."

One participant said that she did not show it when she was happy to avoid being misunderstood. She said, *"You cannot play or laugh with the kids or do similar things. You're holding back ... You have to act that way."*

Difficulty in coping with the way the patient express his/her emotions: Some respondents said that they avoided talking with the patients about cancer, and that they had difficulty in coping with the way the patient expressed his/her emotions.

"We talk about cancer but not in details. Because after a while, he gets emotional. I then change the subject. If I feel he is about to cry, or he might get worse... I do not want to see him like that. I want him to smile, to laugh. So, I always talk about joyful things."

Most of the respondents said that the patient experienced personality changes during the treatment process, and that they had difficulty in coping with these changes.

"Even if there is a trivial problem, he scolds you; he insults you. You become rather offended. But I attribute it to his being sick." "The other day, she said to me 'idiot', I felt very bad. She said 'get away from me, I'm gonna punch you in the face'. That saddened me, of course. But, well, that is because she is sick."

Main theme: Challenges experienced and expectations

Challenges experienced by the participants and their expectations which arise during the treatment process are placed into four categories: financial difficulties, transportation difficulties, difficulties arising from the health system, hospital conditions and personnel, and disease and treatment related difficulties.

Financial difficulties: Some of the participants said that they had financial difficulties in this process due to transportation costs and being discharged from work.

"You're having a tough time. In order not to wait two months to have diagnostic tests, you have to go to a private hospital. So, it is economically difficult."

Transportation difficulties: Some of the participants said that the hospital where their patient received treatment was far from their home, which was tiring for the patient to commute to and from the hospital and which caused difficulty in transporting the patient to and from the hospital. Therefore, some of the participants requested that their patient be hospitalized on the day when he/she received chemotherapy.

"Because commuting to and from the hospital takes a long time, it negatively affects you. Many people come from a remote place. They have no place to stay. So you can see people lying and resting in the park."

Difficulties arising from the health system, hospital conditions and personnel: Some of the participants complained that when they requested their patient to be referred to the university hospital where he/she

received treatment, authorities in the small government hospital located in the patient's place of residence raised difficulties.

"They hardly make referrals to the university hospital. I'm having trouble in receiving referrals. This wears me out. They know nothing about my son's condition and they do not want to refer him to the university hospital. But we're gonna struggle until we get referrals, but this is causing stress; it is wearing."

Some of the participants complained that they had to wait for the therapy for a long time due to the inadequate number of the nurses working in the chemotherapy unit, that they had trouble accessing the physician, that they were not adequately informed about the patient's condition, that the hospital was not comfortable enough, and that there were not enough wheelchairs or equipment for the convenience of the patients.

The participants requested that hospital conditions should be improved, that they should be provided more information about their patient's condition and the course of the disease by the health care professionals, that the patients should be followed by physicians specialized in cancer, and that both they themselves and the patients should be provided with psychological support.

"I wish I were told about my patient's condition, the course of the disease, how his illness is progressing... Being informed would relax me."

Disease and treatment related difficulties: Some of the participants said that they had trouble in dealing with the side effects of chemotherapy on the patient, the patient's compliance to the treatment and the patient's taking responsibility to fulfill his/her self-care. The participants also stated that they wanted the healthcare professionals to inform them about the side effects of chemotherapy more.

"When the colostomy bag was connected to the large intestine, there was no problem, but now it is connected to the small intestine and thus it fills up very quickly. I empty it, but she does not want to. It needs to be emptied frequently and she asks me to empty it. If I don't do it at that moment, she gets angry at me and says 'you deliberately don't want to empty it. But I'm having trouble emptying it'."

"Well, because I'm preventing her from doing certain things, because I ask her to wash her hands, to be clean, because I want her to wear health mask near a person with the flu, she sees me as her biggest enemy."

Main theme: Coping

The participants' coping with what they suffer during the course of the disease is divided into two categories: coping behaviors and factors affecting coping.

Coping behaviors: Most of the participants stated that they displayed such coping behaviors as crying, turning to God, rendering thanks to God and praying in this process.

"It is said that men do not cry, but in fact that is not true. Men cry but do not show it. Of course, you get sad. Is it possible not to get sad?" "I pray to God; I pray every night."

Some of the participants said that keeping themselves

busy by doing housework such as cleaning, or getting around, spending time with friends, doing handicrafts, watching television, playing computer games, spending time on the internet relieved them.

"... cooking, doing the dishes, housework. If I keep myself busy doing these, I don't think of the disease much. I get relieved this way."

One participant stated that she smoked to cope.

"I cannot sleep most of the time, especially at night. I very often get up and I smoke on the balcony. I smoke too much."

Factors affecting coping: Most of the respondents emphasized the importance of support from the family, friends and medical staff in coping. While some of the participants received enough support, the others did not.

"We're alone here, there is no one else. If I don't go out of here two months, no one cares where I am or how I am. Only two of us. We cry together; we cheer up together"

"I'm very happy to be here. I am pleased with the physicians, nurses, other employees... They love my son very much. They embrace him as their own child; they care about him; they take good care of him."

Some of the participants said that hoping or believing in that their patient would one day recover, the patient's showing signs of recovery or the patient's being happy positively affected their coping.

"You hope that this time he will recover. That's what supports us." "Of course, we got sad. But our patient's being strong, or his saying 'I will overcome this disease' reinforced us."

Some of the participants stated that other patients and their relatives were very supportive to them

"... Really, everyone here is like your relative ... you pour out your feelings by chatting with each other. When you are here, you don't get bored. Here, everybody supports each other."

Discussion

This qualitative study has shed light on the caregivers needs, challenges and ways of coping. In this study, four main themes were determined: effects of caregiving, masking feelings, challenges experienced and expectations, and coping. Due to cancer, not only patients' but also other family members' daily life is disrupted and they become more depressed (Lethborg et al., 2003; Tamayo et al., 2010). Therefore, caregivers suffer from physical and mental health problems (National Profile of Family Caregivers in Canada, 2002). A study conducted on the issue indicated that family caregivers suffered from anxiety and depression more than did patients (Schmid-Buchi et al., 2011). According to Huang et al.'s findings (1999), cancer is perceived as an untreatable and fatal disease, and patients and their relatives show reactions such as shock, sadness and hopelessness. Lethborg et al.'s study (2003) revealed that patients' relatives suffered from despair or fear of losing a loved one. Several other studies determined that caregivers developed physical problems such as changes in appetite, headaches, chronic fatigue, muscle pain, difficulty in concentration, and emotional

symptoms such as insomnia, restlessness, depression or anxiety (Deeken et al., 2003, Dew et al., 2004; Gopalan and Brannon, 2006; Tsigaropoulos et al., 2009). The results determined in this present study were similar to those of other studies in the literature: providing care to cancer patients led to physiological, psychological and social problems in caregivers. It was observed that in the caregiving process, caregivers suffered from grief- and stress-related disorders such as headaches, insomnia, that their existing illnesses were exacerbated and that they developed new diseases such as hypertension. It was also observed that caregivers showed psychological reactions of shock, anxiety, weakness, irritability and fear of losing a loved one. In the study, one of the participants was even diagnosed with depression. Therefore, it can be said that the findings of the study are in line with those in the literature and that caregiving poses a serious burden on caregivers.

In the study, it was determined that the family caregivers failed to adequately look after their children, had to lead a restricted social life, and had to quit their jobs. Similarly, several previous studies determined that social aspects of caregivers' lives were adversely affected (National Profile of Family Caregivers in Canada, 2002; Tsigaropoulos et al., 2009; Terakye, 2011; Shih et al., 2013; Stajduhar, 2013). Terakye (2011) stressed that caregivers' disrupted daily lives and unlikelihood of returning to work and social life played an important part in their developing emotional distress. Therefore, it is obvious that reducing the burden on caregivers and enabling them to maintain their social life as usual seem to have an important role in protecting their health.

In this present study, most of the relatives of the patients tried to hide their feelings for fear that they might sadden the patient. Some of the participants avoided talking about the disease and had difficulty in coping with reactions such as anger, irritability etc. shown by the patient during the treatment process. Similarly, in their study of cancer patients and their relatives, Lee and Bell (2011) observed that both patients and family caregivers hid their feelings from each other in order to look strong. In two other studies, it was determined that the relatives of patients wanted the patients to be happy, and they tried to display positive behaviors and create a positive atmosphere to keep the patient's morale high (Hilton et al., 2000; Lethborg et al., 2003). Liu et al. (2005) indicated that cancer patients received the greatest emotional support from their close family members, and that their optimistic attitudes and a positive atmosphere had a positive impact on the patients. In the same study, it was emphasized that the patients wanted to be in a good mood, to laugh and to have fun. Therefore, caregivers' hiding their feelings can meet patients' expectations of a positive atmosphere. However, this present study indicated that caregivers' not expressing, but hiding their feelings affected caregivers adversely. Thus, it would be useful to create an environment (i.e. a social support group) for caregivers in which they can share their feelings. However, this present study also revealed that family members' avoidance of talking about the disease may have been due to the fact that they did not know how to deal with the

patient's reactions. Thus, it is recommended that family caregivers should be supported and be given counseling by healthcare professionals on how to communicate with patients and how to cope with patients' ways of expressing their emotions.

It is known that caregivers experience financial difficulties (Hilton et al., 2000; National Profile of Family Caregivers in Canada, 2002; Tsigaropoulos et al., 2009; Stajduhar, 2013; Chindaprasirt et al., 2014). Tsigaropoulos et al. (2009) determined that patients' relatives had trouble in transporting their patients to the hospital. In this present study too, the patient's relatives were found to have transportation and financial difficulties during the treatment process similar to those in the literature. It was also determined that some of the participants had difficulties arising from the health system and hospital conditions. Other difficulties the patients' relatives had were as follows: difficulty in coping with the side effects of chemotherapy on the patient, the patient's unwillingness to take responsibility for his/ her self-care and the patient's leaving the whole responsibility on the caregivers' shoulders. It is known that caregivers have to fulfill nursing tasks at home (Bean et al., 2008). Schmid-Büchi et al. (2008) indicated that caregivers had difficulty in coping with the side effects of chemotherapy at home. Therefore, providing information about the treatment and possible side effects of the treatment for caregivers may help them overcome difficulties they face.

What the patients' relatives expected from the healthcare professionals in this present study related to challenges they face was as follows: they should be given more information, doctors who look after their patients should be specialized in cancer, and both they themselves and their patients should be provided with psychological support. Having a more comfortable environment and better conditions in the hospital was among their other expectations. Similarly, Pinkert et al. (2013) determined that caregivers wanted healthcare professionals to be specialized in their field and to have such qualifications that they could rely on them. Schmid-Büchi et al. (2011) determined that caregivers felt they were neither supported nor informed adequately by the staff. Hudson et al. (2002) reported that caregivers were generally not ready to provide appropriate care and that they needed more support and guidance provided by healthcare professionals. In another study, it was indicated that caregivers' adequately met needs would help them not to perceive caregiving as much burden as they previously did, to better cope with the symptoms and to have reduced stress levels (Kurtz et al., 2005). All these studies demonstrate that if family caregivers are to sufficiently cope with difficulties they face, their being informed and supported adequately by healthcare professionals is of critical importance.

Caregivers not only have to tackle the challenges they face but have to maintain their caregiving role as well (Silveira et al., 2010; Tamayo et al., 2010; Terakye, 2011). However, it is well known that they feel that they are unprepared and not knowledgeable enough to cope with this life-long crisis (Hilton et al., 2000; Haley, 2003; Lethborg et al., 2003). In this study, patients' relatives were determined to display the following coping behaviors some

being positive some being negative: crying, turning to God, rendering thanks to God, praying, keeping themselves busy by doing daily tasks, getting around, spending time with friends, doing handicrafts, watching television or smoking. In the literature, there are not many studies on how family caregivers of cancer patients cope with the problems they face. Thus, the findings of this study are thought to be of importance. Religious and spiritual beliefs play a significant role in the lives of Muslim population. Traumatic experiences such as diseases are believed as the way through which God tests us. Anger at God is an unacceptable emotion, and people try to make sense of this experience. Spirituality is an important psychological resource which improves coping, adaptation and quality of life (Harandy et al., 2010). This study revealed that religious and spiritual beliefs were an effective coping resource for the relatives of the patients.

In this present study, it was also determined that the support patients' relatives received from their family, friends, other patients' relatives and healthcare professionals was very helpful in coping with the difficulties they had, but that some of them did not receive adequate support. Likewise, Lethborg et al. (2003) determined that the support received from friends or family members was very important for caregivers, but that half of them considered that the support they received was insufficient. Eriksson and Lauri (2000) pointed out that caregivers needed to get information and emotional support from healthcare professionals, but they received less support than they needed. In the same study, it was also determined that the caregivers considered the staff's devoting enough time to them as the most important emotional support. Similarly, Hilton et al. (2000) determined that the patients' relatives did not know what to do or how to behave. They also determined that the patients' relatives needed support from healthcare professionals. Thus, it is important that healthcare professionals should allocate time to caregivers to listen to their problems and to identify their needs, and should provide them with necessary training and consulting. Healthcare professionals can also provide guidance for caregivers to recognize social support resources and to make use of them.

Caregivers of patients are adversely affected by the patient's suffering or undergoing depression (Uğur and Fadiloğlu, 2012). In this present study, different from the literature, it was determined that improvements in the patient's condition had a positive impact on caregivers. It was also determined that caregivers' coping with the difficulties they faced was positively affected by the following: hoping or believing in that the patient will recover, the patient's showing signs of recovery, the patient's being happy. Healthcare professionals are supposed to be realistic when informing the patient's relatives about the patient's condition and should refrain from giving false hopes. On the other hand, it should be kept in my mind that sharing improvements in the patient's condition with the family caregivers can affect their coping positively.

In conclusion, providing care for a loved one having a serious illness like cancer lays heavy burdens

on caregivers. During the caregiving process, family members suffer a lot many physiological, psychological and social problems. It was observed that many family members hid their feelings for fear that it might sadden the patient, avoided talking about the disease and had difficulty in coping with the patient's reactions such as anger, irritability etc. arising during the treatment process. Family members also had difficulties arising from the health system, hospital conditions and treatment in addition to transportation and financial problems.

In this present study, it was also determined that the support from their family, friends, other patients' relatives and healthcare professionals was very important for the patients' relatives in coping with the difficulties they had, but that some of them did not receive adequate support. Among the caregivers' expectations from the healthcare professionals were receiving more information, having doctors specialized in cancer look after their patients, and receiving psychological support both for themselves and for their patients. All these findings indicate that family caregivers need support more than estimated by healthcare professionals. Thus, healthcare professionals should pay attention to the needs of family caregivers and should support them.

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