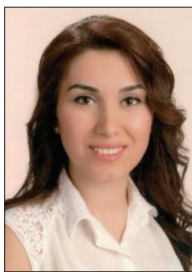


Experiences of Caregivers with Spouses Receiving Chemotherapy for Colorectal Cancer and their Expectations from Nursing Services

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ABSTRACT

Objective: The purpose of this study was to reveal experiences of caregivers whose spouses were receiving chemotherapy for colorectal cancer and their expectations from nursing services.

Methods: This is a qualitative study. The caregivers were interviewed at their home. Sampling criteria were volunteering to participate in the study, being able to understand Turkish, not having speech or hearing problems and offering care to spouses with primary colorectal cancer. The interviews continued until concepts likely to be responses to research questions repeatedly appeared. Fourteen caregivers with spouses receiving chemotherapy for colorectal cancer comprised the study sample. Data were collected with a descriptive characteristics form and a semi-structured interview at in-depth interviews after making appointments with the caregivers on the phone. The steps followed in the content analysis were coding data, an organization of codes and themes, description of findings and

evaluation of findings. **Results:** Experiences of the caregivers whose spouses were receiving chemotherapy for colorectal cancer and their expectations from nursing services were found to comprise the following themes “Facing the Disease,” “Difficulties Encountered,” “Continuing to Live,” and “Provision of Health Care Services.” **Conclusions:** The results of the study revealed that cancer and its treatment affected not only cancer patients but also their spouses offering care. Nurses giving care at oncology clinics, public health centers, and home can make care plans based on the four themes emerging in this study and can detect problems earlier and create appropriate solutions to them. They will contribute to the literature revealing needs of people offering care to oncology patients as well.

Key words: Colorectal cancer, nursing care, spouse caregivers

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Introduction

Colorectal cancer is the second most common type of cancer in Europe and the third most common cancer in Turkey.^[1] When patients diagnosed with this type of cancer start to receive treatment, they may experience severe pain, weight loss, vomiting, weakness, and loss of appetite. As a result, they may need considerable care.^[2,3]

Caregivers of patients with colorectal cancer have many responsibilities for provision of a medical, personal and safe environment, emotional, financial, and psychological support and all familial work.^[4-6] They are usually not ready for these new responsibilities. Preparedness is related to high perceived hope, low anxiety levels, and a balanced status of positive and negative effects.^[7] Caregivers usually fail to manage effects of care on them and suffer from emotional problems. It has been reported in the literature that they have psychological (increased tendency to cry, decreased frequency of laughing, increased tendency to talk, increased boredom, and depression in late stages), physiological (tiredness, decreased appetite, changes in defecation, and decreased sleeping), and sociological (decreased interest in social issues, decreased interpersonal relationships, and decreased involvement in social activities) problems and have a low quality of life.^[8-12] It is obvious that psychological and physical health status of patients and of their caregivers are interrelated and that anxiety levels of caregivers are related to their relationships with patients. As physical functions of patients with advanced stages of cancer are impaired, physical health of caregivers is disrupted, which may have a negative impact on the wellbeing of patients.^[13,14] Inability to fulfill increased needs of caregivers may lead to a lack of satisfaction in caregivers, which has a negative influence on care given.^[4] There is also evidence that caregivers have decreased physical activities and experience loss of efficiency at work due to their caregiving roles. They attribute this loss to long hours of caregiving, marital status, advanced stages of cancer, high levels of anxiety and depression, financial burden, disrupted the order of their daily life and health status.^[15] Erdogan and Yavuz reported that caregivers less frequently socialized and that their daily routines were affected by their caregiving roles.^[4] In Turkish culture, mainly family members shoulder the responsibility for giving care to their ill relatives. In general, this responsibility originating from culture automatically change patient relatives into caregivers.

Caregivers need information and emotional, social, and financial support from their families and friends. They also need to feel that they are not alone during the caregiving process. Caregivers may feel overburdened by increased needs of patients and may feel hopeless, weak, confused,

and annoyed and experience failure in the caregiving process.^[16-19] Health professionals provide caregiving family members with support so that they can easily accept their new roles and manage the caregiving process effectively. To offer them more effective support, in-depth interviews which allow them to express their feelings and needs should be performed.^[20] There have been very few studies about colorectal cancers and caregiving processes for colorectal cancer patients. There are studies about experiences of caregivers.^[13-16,21,22] As the incidence of colorectal cancers, patient care-related issues gain importance. Therefore, the aim of this study was to reveal experiences of individuals providing care for their spouses with colorectal cancer and their expectations from nursing services.

Methods

The study has a qualitative design. Purposeful sampling was used and 14 caregivers whose spouses were receiving chemotherapy for colorectal cancer were included in the sample. A preinterview was conducted with a caregiver to test whether questions could be understood easily and was appropriate for the purpose of the study. The study was performed between August and December in 2015. Face to face interviews were conducted in a silent, well-ventilated and well-lit room with a voice recorder after appointments with the caregivers were made through phone calls. The interviews continued until concepts likely to be responses to research questions repeatedly appeared. Conduction of interviews is the most appropriate technique to be implemented in illiterate individuals.^[23]

Sampling criteria were volunteering to participate in the study, being able to understand Turkish, not having speech or hearing problems and offering care to spouses with primary colorectal cancer. The interviews lasted 27 min on average.

Data collection tools

Data were collected with a descriptive characteristics form and a semi-structured interview. They were revised in accordance with suggestions from three experts experienced in qualitative research. The questions were directed toward revealing how caregivers felt when they heard about their spouses' diagnosis, what difficulties they encountered during the caregiving process, how they dealt with these difficulties and what their spouses expected from nurses during their treatment.

Evaluation of data

First, voice recordings were transcribed verbatim. Second, these transcriptions were evaluated with content analysis. The steps followed in the content analysis

were coding data, an organization of codes and themes, description of findings and evaluation of findings.^[23]

Validity and reliability of the study

The criteria recommended by Lincoln and Guba were taken into consideration to achieve validity and reliability of the study. They recommend the terms, credibility instead of internal validity, transferability instead of external validity, consistency instead of internal reliability, and confirmability instead of external reliability.^[24]

Credibility

All the interviews were recorded with a voice recorder and the researcher kept observation notes. Open-ended questions were used to collect in-depth data. Three investigators experienced in qualitative research first separately created and described themes and subthemes and then agreed upon them. Obtained data were also compared with those reported from other studies on different settings and samples.^[25]

Transferability

Data were reorganized in accordance with themes and subthemes described in detail. The themes and the subthemes were exemplified through direct quotes by depending on what the participants originally reported as much as possible.

Consistency

All the interviews were conducted by the same interviewer using the same semi-structured interview form

and the same voice recorder. Analyses were evaluated by three researchers.

Confirmability

All stages of the study were evaluated by the research advisor, who confirmed that comments, conclusions, and recommendations truly reflected crude data. Data collection tools, crude data, coding and all other research related material, are still preserved for confirmability.

Ethical approval was obtained from the non-Interventional Ethics Committee of Ondokuz Mayıs University (Decision Number 2014/12) and written, and oral informed consent was taken from all the participants. The study was supported by TUBITAK with the Research Grant Number of 114S001. So that written informed consent could be obtained from illiterate participants, their relatives who were literate were invited, and their written informed consent was obtained under the supervision of their relatives.

Results

The mean age of the participants was 54.78 years (minimum: 53 years; maximum: 81 years). About 85.7% of the participants were female. The mean duration of marriage was 47 ± 5.29 years, and all the participants had children. Thirteen point six percent of the participants did not have health insurance, and 60% of the participants were not literate. In addition, 50% of the caregivers took the responsibility for caregiving alone and the mean duration of caregiving was 2.06 ± 1.59 years. All

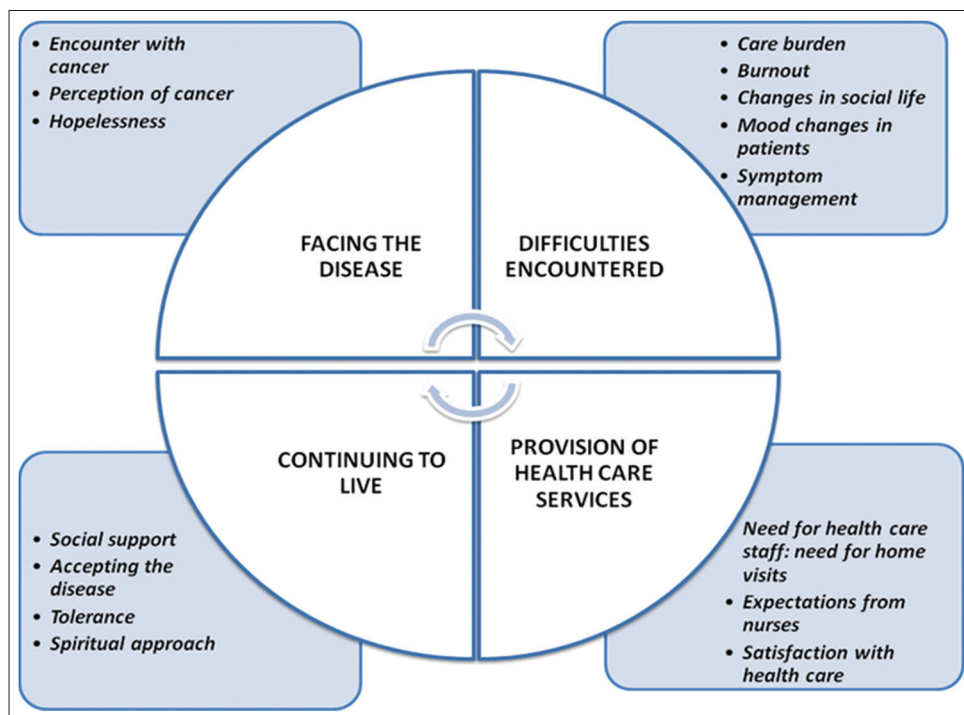


Figure 1: Themes and subthemes about experiences of the caregivers whose spouses were receiving chemotherapy for colorectal cancer and their expectations from nursing services

the caregivers participating in the study and the patients they provided care for were given information orally by the nurses when they first presented for chemotherapy.

Experiences of the caregivers whose spouses were receiving chemotherapy for colorectal cancer and their expectations from nursing services were categorized into four themes with their subthemes [Figure 1].

Facing the disease

The theme facing the disease had three subthemes: *“Encounter with cancer, perception of cancer, and hopelessness.”*

Encounter with cancer

The caregivers emphasized that they had difficulty in expressing their negative feelings and tried to hide their sadness when their spouses were diagnosed as cancer. *“I felt terrible. I was crying even while I was comforting him. I always cried. I hid my tears and he hid his tears, too.”*

Perception of cancer

The caregivers considered cancer as frightening. They underlined that the disease process was difficult for both themselves and their spouses. *“...The oncology clinic looks frightening... I felt as if it were a place for those with a terminal disease.”*

Hopelessness

The caregivers emphasized the bad times they experienced during the disease process. They admitted that they were hopeless and did whatever they were instructed by health professionals. *“She wrapped her arms around my neck. She cried a lot and begged us to save her. She cried and rejected her disease. We suffered a lot and had very bad times...”* *“I’m doing what I’m told to do. I have nothing else to do.”*

Difficulties encountered

The theme difficulties encountered was composed of five subthemes, i.e., *“care burden, burnout, changes in social life, mood changes in patients and symptom management.”*

Care burden

The caregivers commented that their spouses needed care like babies and that they had difficulties in the caregiving process. They explained that they had to take care of their spouses and do the household chores at the same time. *“...(Smiling) I’m doing my best to take care of him. He is just like a baby.”* *“It is not inevitable to have difficulty because I have to not only look after my spouse but also do the housework, feed the pets, take the kid to school...”*

Burnout

The caregivers mentioned that they had difficulty in continuing to give care and made great effort to fulfill their roles in the family. They added that their caregiving role had a negative impact on their health and their psychology and that their sleep patterns were disrupted. *“It is very difficult.*

I’ve really tried hard. I’ve devoted my life to him. I’ve given perfect care, but the disease has got worse and worse. I have failed... I’ve lost everything; my health and my psychology have become poor.”

Changes in social life

The caregivers could not leave home and always had to accompany their spouses. Therefore, they had difficulty in maintaining their prior social roles. One caregiver described this change as restriction of her freedom. *“I’m like a prisoner at home. My freedom is restricted. I used to do sports and go shopping, but now I can’t.”*

Mood changes in patients

The caregivers said that the patients were more impatient and annoyed after chemotherapy, which made them very upset. *“Now he is annoyed. He even doesn’t tolerate small mistakes and gets annoyed easily. He’s made me very upset. Sometimes he doesn’t want me to stay home. Sometimes he leaves home.”*

Symptom management

The patients were reported to experience many complications after chemotherapy such as pain, lack of appetite, nutrition problems, diarrhea, weakness, sleeplessness and sores in the mouth and throughout the body. One caregiver thought that her spouse was going to suffer from all complications, based on what she heard from other people, and that she and her spouse were very anxious about it. The caregivers also admitted that they could not do anything to cope with the complications and felt hopeless. *“I don’t know what to do when my husband doesn’t eat anything. I cook many dishes, but he doesn’t eat any of them,”* *“... When we came home from hospital, I put a bucket next to his bed... I thought he was going to vomit; actually it was not the case in practice.”*

Continuing to live

The theme continuing to live included *“social support, accepting the disease, tolerance and spiritual approach.”*

Social support

The caregivers reported that people visiting them boosted their morale and emphasized the role of familial support in coping with difficulties they faced during the treatment process. However, one caregiver mentioned that people visiting them had both positive and negative effects on her spouse. *“He (her husband) is afraid of being alone. He asks ‘are we alone again? Will we always be alone...’ To exemplify his feelings, he asks some visitors to stay with him when he sees them off.”*

Accepting the disease

The caregivers commented that the treatment of colorectal cancer was very difficult initially but later they got used to it and accepted it. *“... When this disease appeared first, it was frightening, but later I got used to it. I had to get used to live with it actually...”* *“... In the oncology clinic, we met many people whose*

relatives had cancer-their sons, daughters, spouses - We thought many people had cancer, which helped us to get used to it...

Tolerance

Some caregivers commented that they tended to fulfill whatever the patients asked for, treated them patiently and hid their feelings even when they got angry. However, some caregivers reported that they did not treat the patients differently or change their attitudes toward them. *"... Since he was ill, we have done things however he likes... We perform whatever he asks for in 80%–90% of the instances. We live this way."*

Spiritual approach

The caregivers believed that the disease was given by God and mentioned that they were able to struggle against difficulties thanks to their beliefs. They also prayed so that their spouses could get better and that they could continue their caregiving role. They commented that they benefited from praying as a kind of support. *"Thank God we have coped with many conditions, but I still continue to pray." "Fortunately, I can take care of him. He's my husband, my everything. God helps me when I run out of my energy."*

Provision of health-care services

The theme provision of health-care services included the subthemes, *"need for health care staff, expectations from nurses and satisfaction with health care."*

Need for health care staff: Need for home visits

The caregivers noted that health status of the patients worsened enough to require health care by health professionals at home. They also suggested that health professionals should visit patients and inform them at home regularly. They emphasized that home visits by health professionals could contribute to the patients' psychological wellbeing. *"Health professionals should carry out home visits, if possible. If they see what is done in home environments, they can provide appropriate guidance for us, which can be very useful. It gives us an opportunity to learn more about caregiving." "If health professionals have home visits, patients can tell them about their problems. Actually, it could be very useful. We had great difficulties at first. I wish they had visited us at those times."*

Expectations from nurses

The caregivers expected nurses to communicate with them, to have a positive attitude and to provide them with appropriate, timely information. *"We don't know what to ask the health staff. People have told us many worrying things... If somebody knowledgeable had told us what we might experience, we wouldn't have been affected this much."*

Satisfaction with health care

The caregivers reported that health-care professionals were friendly, which made them happy and helped them

maintain their wellbeing. They added that they did not have any problems and were satisfied with health care they received. *"Sometimes I think about health staff and ask myself how on earth they can't have any problems. They all always smile."*

Discussion

The results of the study revealed numerous difficulties experienced by the caregivers offering care to their spouses with colorectal cancer. As it has been reported in the literature as well, the high number of biopsychosocial difficulties encountered by people giving care to their family members with cancer cannot be overlooked.^[21,22,26-29]

Encounter with cancer was one of the subthemes emerging in the present study. In fact, the caregivers did not want their spouses to notice their sadness. It has been shown in the literature that people giving care to their spouses with cancer have emotional problems, anxiety and depression and that emotional support for these people would strengthen both the patients and the caregiving process.^[26,30] Psychological effects of cancer were found to lower the quality of life both in patients and their spouses as the disease process was prolonged.^[27]

The subtheme hopelessness revealed that the caregivers did not know what to do and needed support from health professionals, which is consistent with the results of a study by Totman *et al.*^[30] The caregivers also admitted that they felt hopeless when they felt lonely. This suggests that they could not cope with chemotherapy complications their spouses experienced at home. Research has also made it clear that people offering care to their family members with cancer have remarkable needs for knowledge and support.^[29,31] It seems that when health professionals provide caregivers with support at home, their coping skills can be improved.

The subtheme mood changes in patients showed that the caregivers experienced difficulty in continuing their caregiving role due to these changes and made great effort to adapt to them, which is compatible with the literature.^[30] In the present study, the patients were more impatient and annoyed after chemotherapy. These feelings of the patients can be attributed to cultures and underlying factors should be examined in detail in further studies.

One of the difficulties encountered was care burden in the current study, which is congruent with the results of the study by Totman *et al.*^[30] In their study, the caregivers considered the disease as an unexpected condition and admitted that they sometimes did not know what to do. They described care burden as a really difficult situation and asked themselves whether they could really do well.^[30] Similarly, in a study by Kim and Yi,^[29] burnout, experienced by caregivers, was found to be the most important factor lowering the quality of life. In Turkey, caregivers offering care to their ill family members

have an important role in home care and hospital care. Karabulutlu, from Turkey, emphasized in a study that coping strategies utilized by caregiving family members should be improved.^[28] To achieve this, knowledge/education, physiological and psychological needs of caregiving spouses and other family members should be satisfied.^[29]

Consistent with the present study, several other studies have shown that changes in social life have a negative impact on both patients and their spouses, which has become more marked as the caregiving process is lengthened.^[27,29,30,32,33] It should be kept in mind that people offering care to their spouses may suffer from social isolation and should be encouraged to share their experiences with their family and friends and people experiencing similar problems.

The subtheme tolerance revealed the caregivers' tendency to do whatever their spouses asked for, which is comparable to the literature.^[32] The subtheme social support made it clear that the caregivers were motivated by support from people around, especially family members. However, studies from other countries have shown that phone calls from family members and friends and visitors make caregiving difficult and cause tension and conflicts.^[30] Perceived social support, likely to affect the course of the disease, is closely related to culture. In Turkish culture, patients are prioritized and supported by family members and friends.

The results of this study also underlined positive effects of spirituality in coping with diseases. Experiences and difficulties varying with culture in cancer patients have been explored in several studies. Spirituality and fatalism are two important culture related concepts highlighted in the literature.^[22,34,35] Especially cancer patients have been observed to maintain their spirituality related behavior and experience an improvement in their health status more frequently than other patients.^[29,36-38] Recent studies have suggested evaluating intercultural variables in multicultural societies.^[22,29-34] Seemingly, support for cancer patients and their caregivers maintenance of their spiritual life at home and hospital can enhance their coping strategies and the quality of their life.

In the present study, the caregivers were found to expect health professionals to offer timely information about the caregiving process. Similarly, it has been shown by other studies that support from health professionals plays an important role in facilitation of caregivers' responsibility.^[27,30] In a study by Kim and Yi^[29] on needs of cancer patients and their caregivers, the patients most frequently expected health professionals to meet their knowledge and education needs. However, in a study by Sherman *et al.*, the caregivers argued that information provided by doctors during the treatment process was meaningless because they thought that it did not reflect the reality.^[32] In the literature, emphasis has been put on supportive roles of nurses directed toward detection

of side-effects of chemotherapy and improvement of coping with them as well as fulfilling information needs. The determination of cancer patients' expectations from nursing care and attitudes of nurses toward patients have also been reported to be important in terms of enhancement of healthcare offered.^[39,40] Therefore, it can be recommended that health professionals should not only offer information but also share caregivers' responsibility and help them to build their confidence in their caregiving skills.

Conclusion

The present study revealed coping difficulties experienced by spouses of cancer patients, their changing social and spiritual lives and social support needs. It also underlined knowledge, support and counseling needs of the spouses. It is clear that health professionals should fulfill knowledge needs of informal caregivers-spouses and other family members of cancer patients about all treatment processes including chemotherapy, maintain long-term counseling at home after discharge and improve coping skills of caregivers. To accomplish these goals, caregivers should be encouraged to share their caregiving responsibility with health professionals and family members and attend support groups including other caregivers offering care to similar patients. They should also be supported for maintaining their social and spiritual lives. These attempts will reinforce their coping skills, reduce their difficulties and help them to have a higher quality of life.

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Conflicts of interest

There are no conflicts of interest.

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