ORIGINAL ARTICLE



Examination of family caregivers of advanced cancer patients within the scope of the cancer family caregiving experience model: An embedded mixed-methods design

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Abstract

Objective: This study aimed to examine the stressors and contextual factors that affect the quality of life (QoL) of caregivers of advanced cancer patients and to address their caregiving experiences.

Methods: The study had an embedded mixed-methods design and was conducted in the medical oncology unit of a training and research hospital in Turkey. In the quantitative phase, 125 patients with advanced cancer and their family caregivers were included. In the qualitative phase, 21 family caregivers were included. The analysis of quantitative data was carried out using SPSS 25.0 statistical program, and qualitative data were carried out using Collaizi's seven-step descriptive analysis approach. QoL was determined as the dependent variable and evaluated with Caregiver QoL Index-Cancer (CQOLC).

Results: The symptoms, care dependency of patients, and preparedness to the care of caregivers showed a direct impact on the CQOLC. Income level, employment status, and daily caregiving hours demonstrated a direct effect on the CQOLC. Four themes emerged from the interviews: Understanding the dynamics of the caregiving process, losing control of life during the caregiving process, limitation of socioeconomic freedom in the caregiving process, and the effort to hold on to life in the caregiving process.

Conclusion: The cancer family caregiving experience model is a useful model for evaluating the QoL of caregivers from a multidimensional perspective. Health care professionals should not forget that the QoL of family caregivers should be evaluated in multiple ways, and education programmes for family members should be structured.

KEYWORDS

cancer, caregiver, preparedness, quality of life, nurse

1 INTRODUCTION

Family caregivers play an important role in the care and treatment of advanced cancer patients since cancer requires long-term care and the care needs of the patients are high (Given et al., 2001). Family caregivers have complex tasks such as monitoring the symptoms,

coordinating the care, supporting the patient emotionally, arranging the environment to ensure the safety of the patient, problem solving, and decision making (Given et al., 2001). While the caregivers fulfil these complex roles, they may experience many difficulties due to sudden changes in the patient's health status, symptom burden

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experienced by the patient, the poor prognosis of the disease, and the loss of the patient (Hu et al., 2018; Wen et al., 2019). In addition, most the caregivers try to carry out their caregiver roles together with their other roles, and they may have difficulties in managing their responsibilities related to work and maintaining their social lives (Bevans & Sternberg, 2012; Kim et al., 2015).

Considering the effects of the caregiving process on family members, it is important to comprehensively consider the experiences of family members in this process. Several studies have highlighted the use of the cancer family caregiving experience model (CFCEM) to identify various factors associated with the caregiving experience (Peh et al., 2020; Stamataki et al., 2014). The CFCEM developed by Fletcher et al. assumes that cancer diagnosis initiates a stress process and that the quality of life (QoL) and care burden of family caregivers may be affected by various factors (Fletcher et al., 2012). The CFCEM consists of three basic components including stress process, contextual factors, and cancer trajectory that can affect the quality of life and care burden of family members (Fletcher et al., 2012; Stamataki et al., 2014). The stress process being the first component of the model consists of primary and secondary stressors. Primary stressors include the patient's symptom severity, care dependency, and the prognosis of the disease. Secondary stressors are related to family caregivers and include changes in plans, preparation for the care process, and fatigue level. The contextual factors of the model deal with the factors such as the gender, age, cultural characteristics, and personality of the caregivers that are thought to affect the caregiving experience (Fletcher et al., 2012; Stamataki et al., 2014). The cancer trajectory, which is the last known of the model, is a dynamic process and constitutes the experiences of family caregivers of cancer patients during this process.

The patient's symptom status and care dependency, which are among the primary stressors, affect the experiences of family caregivers. Advanced cancer patients have many symptoms such as pain, fatigue, weight loss, loss of appetite, nausea, vomiting, sleep disturbance, depression, anxiety, and hopelessness (Mandelblatt et al., 2020; Noel et al., 2021). Due to these multiple symptoms experienced, patients may need another person to meet their daily requirements (Lage et al., 2020). The patient's symptom severity, disease stage, and increase in care requirements enhance the duties and responsibilities of family caregivers. Therefore, family members with increased responsibilities in the caregiving process perceive the caregiving process as a burden, and their QoL decreases (Alvariza et al., 2020; Kang et al., 2013).

In addition, preparedness, one of the secondary stressors, can be considered as a protective factor against the negativities caused by this wearisome caregiving process (Henriksson & Årestedt, 2013). Preparedness to care is defined as how ready the family caregivers feel for their duties and responsibilities in the caregiving process, such as providing physical, emotional, social, and financial support (Archbold et al., 1990; Mason & Hodgkin, 2019). Preparedness to care plays an important role in reducing the physical and emotional burden of family caregivers, and increases positive emotions and experiences in the caregiving process (Henriksson & Årestedt, 2013; Maheshwari & Mahal, 2016). Preparedness to care increases the QoL of family caregivers by providing the opportunity to evaluate possible problems

faced in the caregiving process and to cope with these problems (Mazanec et al., 2018).

Contextual factors such as age, gender, education level, income level, and culture also affect the experiences of family caregivers. Studies conducted with family members caring for cancer patients reported that the elderly, women, unemployed, living in the same house with the patient, long-term caregivers, and those with high daily caregiving hours had higher care burden, and lower QoL (Erdoğan & Yavuz, 2014; Shahi et al., 2014). Cultural beliefs are closely related to the caregiving experience and are determinative of the meaning attributed to the disease and attitudes in the grief process (Hebert & Schulz, 2006; Pickett, 1993). However, no research was found that examines the experiences of family caregivers of advanced cancer patients within the framework of the cancer family caregiving experience model. Within the framework of the cancer family caregiving experience model, it is very important to reveal the experience of caregiving and the factors affecting the QoL of the family caregivers of patients with advanced cancer in Turkey in a multifaceted manner. This research dealing with the caregiving experience from a holistic perspective will guide the planning of individualised health education for caregivers. In addition, the study may be a guide for peer education, social support, and psychosocial interventions that can be done to improve the quality of life of caregivers. In particular, health care professionals should aware of the needs and experiences of caregivers and pay attention to this situation. Therefore, this study based on the CFCEM aimed to examine the stressors and contextual factors that affect the QoL of family caregivers of advanced cancer patients and to address their caregiving experiences within the care trajectory.

2 | METHODS

2.1 | Study design

The Standards for Reporting Qualitative Research (SPQR) was used as a guideline (Supporting Information S1). This study was designed with an embedded-mixed method design in which quantitative and qualitative data were combined in order to address the research questions more comprehensively. Quantitative and qualitative data are collected concurrently by researchers in embedded mixed methods. The main purpose of embedded mixed methods is that one of the quantitative or qualitative stages is at the forefront, while the other plays a supporting role (Palinkas et al., 2011). The essential aim of this model is to reveal the experiences of family caregivers in the caregiving process from a holistic perspective. In this study, while the qualitative stage was at the forefront, the quantitative stage played a supporting role.

This study based on the CFCEM included all three components of the model. Considering the stress process component, primary and secondary stressors were determined. Age, gender, cancer type, duration of cancer diagnosis, current treatment approach, symptom status, and care dependency levels of the cancer patient were specified within the scope of primary stressors. The level of preparedness for the care of family caregivers was investigated as the secondary stressors. Contextual factors are the second component of the model, which were the age, gender, education level, marital status, income level, employment status, degree of relationship to the patient, duration of caregiving, daily caregiving hours, living in the same house with the patient, previous caregiving history, education status about caregiving, and presence of chronic disease of family caregivers. The cancer trajectory being the last component of the model was revealed through in-depth interviews on the caregiving experience.

2.2 | Setting and participants

This study was conducted in the inpatient clinics and outpatient chemotherapy unit of the Medical Oncology department of a training and research hospital in Ankara, Turkey. The population of the study consisted of patients who were followed up with the diagnosis of stage III-IV solid cancer in the inpatient clinics and the outpatient chemotherapy unit of the Medical Oncology department a training and research hospital between September 2020 and July 2021 and family caregivers. Patients were included if they were more than 18 years old, were diagnosed with the diagnosis of stage III-IV solid cancer, had no psychiatric diagnosis and communication problems, and had a caregiver and accepted to participate to this study. Additionally, family caregivers were included if they were more than 18 years old, had no cognitive or communication problems, had provided care to a patient with advanced cancer during at least 3 months, and volunteered to participate to this study. The co-researcher, the third one (BO), who is a medical doctor (MD), directly assessed all potential participants in terms of inclusion criteria. Then, she sent the list of participants to the PI until the completion of the study. The PI checked participants for inclusion criteria in a room in the medical oncology department at the hospital.

2.3 | Sample size

A priori power analysis was used for the sample size of the quantitative phase of the study. The sample size was calculated in the G*Power program based on the correlation between the QoL and the preparedness to care of family caregivers (Fujinami et al., 2015). The sample size to be included in the study was calculated to be at least 111 based on 95% power, $\alpha = 0.05$, and the minimum effect size (0.3), and the correlation between the QoL and preparedness to care levels of 0.31. Accordingly, 214 patients were evaluated in terms of inclusion criteria between September 2020 and July 2021. A total of 58 cancer patients were excluded from the study because they did not have a diagnosis of stage III-IV solid cancer, and therefore, their family caregivers were not included in the study; 23 caregivers did not accept to participate in the study, and eight caregivers could not be included in the study because they gave care for less than 3 months. Therefore, the quantitative phase of this study was completed with 125 patients and their family caregivers.

Although there is no definite rule in determining the sample size in qualitative studies, it is emphasised in the in-depth interviews that

the research practice can be finished when data saturation is reached (Boddy, 2016; Gentles et al., 2015). In the qualitative phase of this study, 21 family caregivers were included in the individual interviews based on data saturation.

2.4 Data collection tools

2.4.1 | Semistructured interview guide

The interview guide was developed by the researchers, considering the guideline for in-depth interviews by Kvale (1996). This guideline consists of the following seven steps to structure in-depth interviews: Thematising, designing, interviewing, transcribing, analysing, verifying, and reporting (Guion et al., 2001). Based on these steps, the interview guide was designed to elucidate the experiences of family caregivers related to the caregiving of advanced cancer patients. Accordingly, the interview guide included open-ended questions focusing on the meaning of experiences of caregiving, the impact of caregiving on life, and coping mechanisms in the caregiving process. This guide was to ensure consistency with the questions that were asked and to facilitate the exploration of similar subjects and topics with the participants. This was necessary to generate comparable data to ensure consistency between interviews and to increase the reliability of the findings. All questions in the interview guide were reviewed for content by an independent qualitative expert who was not involved in its preparation and was revised by the researchers according to her comments. The form included follow-up questions exploring the caregiving experience: What does caregiving mean to you? What are the positive aspects of caregiving? What are the negative aspects of caregiving? How has been caregiving affected your life (health, relationships with other family members, social life, economic life)?

2.4.2 | Participant information form

The form developed by examining the literature consists of two parts (Fujinami et al., 2015; Lim et al., 2017). In the first part, there were five questions including the sociodemographic characteristics of the patients and the characteristics of the disease and treatment. The second part of the form included 14 questions about the sociodemographic characteristics of the family caregivers (such as age, gender, marital status, and degree of relationship to the patient) and caregiving-related characteristics (such as duration of caregiving, daily caregiving hour, and previous caregiving history).

2.4.3 | The Edmonton Symptom Assessment Scale (ESAS)

In the original form of the scale, there are nine questions including pain, shortness of breath, insomnia, fatigue, loss of appetite, nausea, well-being, anxiety, sadness, and other problems (Bruera et al., 1991).

The symptom severity is evaluated between zero (*no symptoms*) and 10 (*very severe symptom*). Each symptom in the scale is assessed in itself. The scale was adapted into Turkish, and items such as mouth sores, numbness in the hands, and changes in the skin and nails were added to the other problems section. In the study of adaptation to Turkish, it was determined that Cronbach's alpha coefficient was 0.83 and a total item correlation for each item ranged between 0.30 and 0.62 (Kurt & Unsar, 2011).

2.4.4 | Care Dependency Scale (CDS)

The scale consists of 17 items that evaluate the dependency in the following needs: Eating and drinking, continence, body posture, mobility, day and night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, worship, sense of rules and values, daily activities, recreational activities, and memory and learning ability (Dijkstra et al., 1999). Each item on the scale is rated on a 5-point Likert scale ranging from one (entirely dependent on others) to five (entirely independent). The total score varies between 17 to 85 points, with lower scores indicating an increase in care dependency. Cronbach's alpha coefficient was 0.97 in the Turkish validity and reliability study (Yönt et al., 2010).

2.4.5 | Preparedness for Caregiving Scale (PCS)

The scale consists of eight items, each responded to on a 5-point Likert-type scale ranging from zero (*not at all prepared*) to four (*very well prepared*) (Archbold et al., 1990). A total score ranging from zero to 32 is calculated by summing the responses for all items, with a higher score indicating more feelings of preparedness. The scale has shown good validity and reliability among caregivers of patients in palliative care. Cronbach's alpha coefficient was 0.92 and a total item correlation for each item ranged between 0.63 and 0.84 in the Turkish validity and reliability study (Karaman & Karadakovan, 2015).

2.4.6 | Caregiver QoL Index-Cancer (CQOLC)

The CQOLC consists of 35 items and four conceptual subdomains of QoL including physical functioning, emotional functioning, family functioning, and social functioning (Weitzner et al., 1999). Each item on the scale is rated on a 5-point Likert scale ranging from 0 (no at all) to 4 (very much). The subdomain scores of the CQOLC were obtained by summing the responses to the items involved in the sub-domain. The total CQOLC score is obtained by summing scores for all items and can range from 0 to 140. Higher scores on the CQOLC indicate better QoL. Cronbach's alpha coefficient was 0.88 for the total scale and subdomain Cronbach's alpha coefficient ranged from 0.73 to 083 in the Turkish validity and reliability study (Yakar & Pinar, 2013). The mean scores for the overall CQOLC and the respective domains were used as a cut-off point to form a binary outcome.

2.5 | Data collection procedure

In quantitative phase of the research, ESAS and CDS were applied to patients diagnosed with advanced cancer using the face-to-face interview technique by the first author. The family caregivers were filled Participant Information Form, PCS, and CQOLC by the first author using face-to-face interviews. After the quantitative data collection forms were completed, individual interviews guided by a semistructured interview form were conducted face-to-face with family caregivers who agreed to conduct in-depth individual interviews. In-depth individual interviews were conducted in a silent room located in the outpatient or inpatient units. The first author, who was a woman and research assistant with experience in qualitative descriptive research, conducted all interviews. The interviews were recorded on a voice recorder. Completing the quantitative data collection forms took approximately 15–20 min; individual interviews took at least 20 min, and a maximum of 50 min.

Interviews were conducted in Turkish. After the thematisation process was completed, a translation from Turkish to English was carried out. The translation was made by two expert academics who have advanced levels of English, and the translations were reviewed by professional editing service. Thus, this translation was double-checked.

2.6 | Ethical considerations

This study was conducted in accordance with the Helsinki Declaration. Ethical approval was obtained from the Non-Interventional Clinical Trials Ethics Committee of Hacettepe University (Number: GO20/517). The researchers explained the study aim and obtained verbal and written informed consent from all participants. The participants were allowed to withdraw from the study at any time without stating a reason and were not expected to pay for anything. Moreover, recordings of the interview were anonymously coded, randomly assessed, and hidden in an encrypted computer to ensure data security.

2.7 | Data analysis

We utilised a phenomenological analysis, based on Husserl's philosophy, to gain a better understanding of the meaning of the experiences of family caregivers related to the caregiving of advanced cancer patients (Husserl et al., 1995). According to Husserl's philosophy, descriptive phenomenological research defines and examines lived experience of individuals and its essence (Creswell & Báez, 2020). This analysis helps to study how individuals define a phenomenon, how they perceive it, and attribute a meaning to it Moreover, descriptive phenomenology is known to reveal poorly understood aspects of a phenomenon by uncovering the lived experience of individuals (Patton, 2014). The phenomenon of the present study was determined as "the experiences of family caregivers related to the caregiving of advanced cancer patients."

Considering the phenomenon in detail, Colaizzi's seven-step method was utilised for qualitative data analysis (Morrow et al., 2015). First, the first author carefully transcribed all audio recordings in Microsoft Word and repeatedly reviewed them to ensure their accuracy. After completion of transcription, the second co-author checked the transcripts by comparing them with audio recordings. MAXQDA software program (Version 20.0.6) was utilised to aid analysis of qualitative data. Each transcript was read and analysed independently by all authors. Second, all statements were reviewed in terms of their connection with the phenomenon. Third, meanings related to the phenomenon that resulted from an attentive consideration of important statements were identified. Fourth, the identified meanings were categorised into specific clusters of themes. Fifth, findings were merged for an exhaustive description of the phenomenon, and an inclusive description of the phenomenon was written. Sixth, the researchers condensed the exhaustive description to a short statement that included only aspects deemed to be prominent and essential to the structure of the phenomenon. Finally, patients were asked whether the fundamental structure of the finding captured their experience and feedback was obtained from all participants with member checking technique (Morrow et al., 2015).

The quantitative data of the study were analysed with the statistical program SPSS 25.0 (IBM SPSS Inc, Chicago, IL, USA). Compliance with the normal distribution was evaluated using the Kolmogorov Smirnov test, histogram, and Q-Q graph method. In addition, skewness and kurtosis values were checked for conformity with the normal distribution. Mean and standard deviation were used in the descriptive statistics of normally distributed data. In the descriptive statistics of categorical variables, number and frequency percentages are given. Regression analyses were performed to determine the determinants of the stress process and contextual factors on the QoL of family caregivers. Statistically significant in the study was that the *p* value was below 0.05.

3 | RESULTS

In this study, qualitative data played a prominent role, while quantitative data played a supporting role. Therefore, in the research findings, first qualitative findings followed by quantitative findings were included.

3.1 | Qualitative findings

The experiences of the family caregivers regarding the caregiving process within the scope of the cancer trajectory were examined through qualitative interviews. Interviews were held with 21 family members caregiving to advanced cancer patients (Table 1). As a result of indepth interviews, four themes were determined: (1) Understanding the dynamics of the caregiving process, (2) losing control of life during the caregiving process, (3) limiting socio-economic freedom in the

caregiving process, and (4) the effort to hold on to life in the caregiving process (Figure 1).

3.1.1 | Theme 1. Understanding the dynamics of the caregiving process

Subtheme 1: The multifaceted nature of caregiving

Family caregivers often described the caregiving process as a responsibility. According to family caregivers, giving care was a conscientious responsibility that required self-sacrifice, labour, and love.

Care is a matter of conscience. Care means sacrifice and love. If I explain in two words: love and sacrifice. (C15, 58 years, male, high QoL)

Some family caregivers perceived caregiving as a normal process in their daily lives. Moreover, the process of caregiving has become an essential part of their lives, such as breathing and eating.

To my mind, caregiving is something like normal breathing. Caregiving is as ordinary as breathing and eating. (C4, 27 years, male, high QoL)

According to the family caregivers with low QoL, it was within the scope of caregiving to support the patients when they cannot do it individually or when they need help. Most of the family caregivers stated that they meet the daily basic needs of patients such as going to the toilet, bathing, feeding, walking, hygiene, and transportation. In addition, family caregivers managed patients' hospital processes and medications.

I have to help my patient. I meet her need. When she cannot take a bath, I get it done. (C2, 66 years, male, low QoL)

I do not buy fast food from outside. Whenever I have the opportunity, I bring organic things from the villages. I am more careful with his diet. (C20, 49 years, female, low QoL)

In addition to the physical needs of the patients, some family caregivers emphasised that it was also important to support the patients psychologically during the caregiving process. Sharing the pain of the cancer patient and giving moral support by doing the activities patients missed and loved were an important part of giving care.

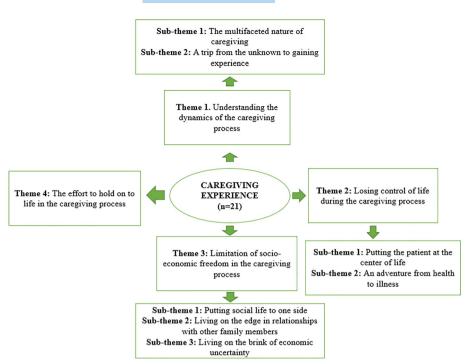
Care is perceived as just meeting physical needs, but I do not think so. Because they need psychological support. Mentally ... I provide my patient to breathe easily and make her do the missed things. This is care for them. (C6, 27 years, female, low QoL)

Caregivers	Age	Gender	Education level	Marital status	Income status	Employment status	Degree of relationship to the patient
C1	48	Male	High school	Married	Income more than expenditure	Yes	Child
C2	99	Male	Primary education	Married	Income equal to expense	o _N	Spouse
ຮ	63	Female	Primary education	Married	Income more than expenditure	No	Sister
C4	27	Male	University	Single	Income equal to expense	Yes	Brother
C5	69	Female	Primary education	Married	Income equal to expense	No	Spouse
90	27	Female	University	Single	Income equal to expense	o _N	Child
C7	61	Male	University	Married	Income equal to expense	Yes	Spouse
80	20	Female	Primary education	Married	Income equal to expense	o _N	Child
C9	46	Female	Primary education	Married	Income less than expenditure	No	Spouse
C10	33	Male	University	Married	Income equal to expense	Yes	Child
C11	45	Female	Primary education	Married	Income equal to expense	Yes	Child
C12	99	Male	Primary education	Married	Income equal to expense	No	Spouse
C13	52	Female	Primary education	Married	Income equal to expense	No	Mother
C14	59	Female	High school	Single	Income more than expenditure	o _N	Sister
C15	58	Male	High school	Married	Income equal to expense	No	Spouse
C16	32	Male	University	Married	Income equal to expense	Yes	Spouse
C17	92	Female	Primary education	Married	Income less than expenditure	No	Mother
C18	92	Male	Primary education	Married	Income less than expenditure	No	Father
C19	70	Female	Primary education	Married	Income less than expenditure	No	Spouse
C20	49	Female	Primary education	Married	Income equal to expense	No	Spouse
C21	31	Female	Primary education	Married	Income equal to expense	No	Spouse

TABLE 1 (Continued)

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Caregivers	Duration of caregiving (years)	Daily caregiving hour	Living in the same house with the patient	Previous caregiving history	Education status about caregiving	Presence of chronic disease	Quality of life
C1	2	12	Yes	ON	ON	No	76 point/low
C2	4	œ	Yes	Yes	o _N	Yes	71 point/low
C3		2	o _N	Yes	oN	Yes	69 point/low
C4	2	10	Yes	oN	o _N	o _N	81 point/high
C5	1	24	Yes	oN	Evet	Yes	55 point/low
90	2	12	Yes	oN	o _N	o _N	72 point/low
C7	3	24	Yes	ON	Evet	Yes	63 point/low
83	\leftarrow	9	No	oN	o _N	Yes	68 point/low
63	7	24	Yes	ON	ON	No	71 point/low
C10	2	œ	No	oN	o _N	o _N	61 point/low
C11	1	9	No	oN	oN	N _o	58 point/low
C12	7	18	Yes	oN	oN	Yes	65 point/low
C13	2	7	No	No	No	Yes	67 point/low
C14	2	24	Yes	oN	o _N	Yes	70 point/low
C15	2	12	Yes	ON	ON	No	83 point/high
C16	1	9	Yes	o _N	o _N	o _N	95 point/high
C17	2	20	Yes	No	ON	Yes	65 point/low
C18	\leftarrow	24	Yes	o _N	o _N	Yes	61 point/low
C19	8	18	Yes	Yes	No	Yes	58 point/low
C20	က	16	Yes	No	No	No	67 point/low
C21	1	14	Yes	٥N	٥N	°N	70 point/low



Subtheme 2: A trip from the unknown to gaining experience

Family caregivers with low QoL of advanced cancer patients emphasised that they feel themselves on the brink of obscurity in the caregiving process, as they do not know how to proceed and how to manage in the early stages of the caregiving process. Some family caregivers stated that they had difficulties in providing care to their advanced cancer patients due to the uncertainties in the disease and treatment process, and adapting to the hospital environment.

There is no cure. Doctors give poison, they kill cells. I do not know how the disease will proceed. I am in an uncertain situation. (C9, 46 years, female, low QoL)

For example, this is a big hospital. Since I do not go to hospitals all the time, I inevitably have a hard time finding any department. I stagger helplessly for three or five minutes. (C1, 48 years, male, low QoL)

In the caregiving process, family caregivers with low QoL often emphasised the importance of experience. Both the uncertainties in the caregiving process and the lack of previous caregiving experience made the caregiving process tiresome and complex for family caregivers. In this process, family caregivers stated that even the slightest changes in the patient's condition get into a panic and had difficulty in overcoming the changes. In addition, family caregivers liken themselves to a student who has just started school due to this difficult and uncertain process.

Of course, the disease is a process we do not know. There are changes in my mother that we have never seen before. Therefore, I'm panicking that I'm going to lose my mother. (C11, 45 years, female, low QoL)

I am like a student starting a new school. When I first started giving care, $\scriptstyle 1$ inevitably flustered. (C1, 48 years, male, low QoL)

Family members with low QoL who previously gave care emphasised that they had an easier time through this process. In addition, family caregivers who adapt to the life of their patients spend this process more comfortably by planning their hospital appointments and daily activities. In addition, some family caregivers also stated that they gained experience in dressing to wound and how the hospital works, even if they had a bad and difficult experience.

As I have previous experience, it is not very difficult. When my mother's serum is inserted, it takes one and a half to two hours. My mother sleeps under the influence of it. Those processes are my rest hours. I plan everything. (C6, 27 years, female, low QoL)

I meet the needs of my patient. Before, I did not know how to do dress a wound. But right now, I can dress a wound like a health care worker. (C1, 48 years, male, low QoL) I learn something, it gives me an experience. In other words, I learned about the hospital environment. (C16, 32 years, male, high QoL)

3.1.2 | Theme 2: Losing control of life during the caregiving process

Subtheme 1: Putting the patient at the centre of life

Family caregivers stated that they are completely devoted to caring and neglecting their own needs. During the caregiving process, family caregivers were more concerned about their patients than their own lives and worried about who would take care of their patients if they were unable to care.

Sometimes, I get very upset. Right now, If something happens to me, I do not know who will take care of him. I gave up everything and devoted all my time and everything to him. (C20, 49 years, female, low QoL)

All positive and negative emotions of family caregivers with low QoL were shaped according to the patient. An improvement in the patient's condition, a decrease in complaints such as pain, and even the patient's eating were a source of happiness, joy, and morale for family caregivers. Family caregivers perceived themselves and the patient as a whole and whether the patient is good or bad was directly reflected on them.

When she eats, the world is mine. Being with her makes me happy. (C14, 59 years, female, low QoL)

If my patient is in good spirits, I sleep well. But when he gets depressed and has pain, I cannot sleep either. I'm a little attached to it; If he's fine, I'm fine too. (C5, 69 years, female, low QoL)

Subtheme 2: An adventure from health to illness

Family caregivers with low QoL realised that the care process caused changes in their own health status. This study revealed that the family caregivers were physically worn out during the caregiving process and that their health status deteriorated. Some family caregivers complained of physical pain and fatigue from supporting their patient, moving, and the hospital environment. In addition, family caregivers emphasised that patients neglected their own chronic diseases while taking care of the hospital process, medications, and care, and did not go to regular health check-ups.

There is fatigue. Both physically and mentally. When I lift the patient, I bend down and my back hurts. There is mental fatigue. (C5, 69 years, female, low QoL)

I also have heart disease, asthma. After I had the angiography, the doctor said to come for a check-up in a month. I could not go. (C12, 66 years, male, low QoL)

In addition, family caregivers with low QoL stated that they experienced sleep problems due to changes in comfort due to the hospital environment, differences in sleeping hours, frequent waking up due to meeting the basic needs of the patient, and negative thoughts in the mind. Family caregivers dreamed of being able to sleep uninterruptedly for days if they had the opportunity.

You cannot sleep in hospitals. Sometimes, when you think about something, you lose your sleep. I cannot sleep when I'm obsessed. It's always spinning in my head. Sleep is gone. (C18, 65 years, male, low QoL)

I have not been able to sleep until morning since I came to the hospital. There is no comfort. If I have a chance, I'll probably sleep for 10 days without raising my head. (C7, 61 years, male, low QoL)

Family caregivers with low QoL mentioned that the caregiving process did not only wear them out physically but also that they had psychological difficulties. Some family caregivers complained that after they started caring for their cancer patients, they became angry more quickly and that there could be sudden changes in their emotions. Fear of loss created an emotional burden on family caregivers. Family caregivers mentioned that they had crying spells and expressed this as a lump in the throat.

When I cry, my head hurts. I feel like I cannot breathe. It's like they are putting a knot in my throat. (C3, 63 years, female, low QoL)

When I meet my father's needs and relax, I sit in the corner and cry. I am devastated when you see my father suffer. (C8, 50 years, female, low QoL)

3.1.3 | Theme 3: Limitation of socio-economic freedom in the caregiving process

Subtheme 1: Putting social life to one side

Family caregivers with low QoL stated that their lives passed between home and hospital during the caregiving process and that their habits of living had completely changed. Family caregivers emphasised that their social activities were reset and they even forgot to walk due to both care and home responsibilities. In addition, caregivers stated that they could no longer continue their favourite activities such as fishing and walking and that they forgot even the location of the market.

We would go on a picnic on the weekends, we would walk on the beach. I would go fishing. But now I have no activity. I tied it to the standard between home and hospital. (C10, 33 years, male, low QoL)

I forgot to walk. I had to go to the emergency bank. I forgot to walk. We were people who did not get on the bus but walked. Now we cannot walk at all, and neither can I. (C14, 59 years, female, low QoL)

I know neither a bazaar nor a market for three years. I am not going anywhere. I forgot the market, I forgot the door too. (C19. 70 years, female, low OoL)

Family caregivers with low QoL stated that they are bored with people who evaluate themselves from a judgmental point of view, they are tired of constantly telling people about the situation, and therefore they prefer to stay away from people.

They always tell me to take care of the wife. This is what upsets me the most. Tell me how it is to care well. Are they doing something different? (C2, 66 years, male, low QoL)

The environment usually affects me. I am always under pressure because they ask what happened. They wonder. (C6, 27 years, female, low QoL)

Subtheme 2: Living on the edge in relationships with other family members

The caregiving process caused unbalance in communication between family members, and while some could not tolerate each other in this process, others emphasised that they become more connected to each other. Some family caregivers with low QoL complained that they did not want to meet with their closest family members during this difficult process and they moved away. All family caregivers were experiencing sadness within themselves, and that they could no longer stand to see each other or that they had difficulty in tolerating each other.

My brother and I had a fight. We have become incapable of attracting each other. There was no problem between me and my brother, but now it has deteriorated. Now, I am aggressive. (C10, 33 years, male, low QoL)

We started to move away from this process. They're crying too, I'm crying too. That's why we try not to get together too much. (C13, 52 years, female, low QoL)

Although some family caregivers began to move away from each other during the caregiving process, some family members stated that they became close to each other in this process.

It connects us even more. It wasn't like this before. They were living their own life, I was living my own. But in the last two years, we have become more connected to each other. (C4, 27 years, male, high QoL)

Subtheme 3: Living on the brink of economic uncertainty

Family caregivers stated that they had to struggle with financial problems in this process. Travel expenses, especially in the process of going to and from the hospital, affected the lives of caregivers and put them in trouble.

We live outside the province. Since we are here for treatment, we come and go almost two or three times a week. This causes fuel costs. (C4, 27 years, male, high OoL)

We came here with the permission of the companion. That puts us in a difficult position. We come by bus. And sometimes we take a taxi. This is causing trouble. (C10, 33 years, male, low QoL)

The nutritional needs of advanced cancer patients brought along financial difficulties for family caregivers. Family caregivers wanted to contribute to the healing processes by feeding their patients with more nutritious, natural fruits and vegetables, and this situation forced them economically.

Our money is not enough to eat our fill. I'm juicing fruit. We buy fruit. All kinds of bananas, kiwis. He can eat them. He cannot eat anything else. (C19, 70 years, female, low QoL)

3.1.4 | Theme 4: The effort to hold on to life in the caregiving process

The family caregivers with low QoL struggled to hold on to life despite the negativities that they experienced during the caregiving process. Many caring family members have gained a spiritual understanding of the disease and the caregiving process, recognising that everything comes from God. For this reason, family caregivers accepted the caregiving process without complaining and believed that God would heal. Caregivers turned to religious activities such as praying, and reading the Qur'an in order to cope with this process.

I'm doing my prayer. I am reading my Quran. I pray a lot. I try to think well. (C3, 63 years, female, low QoL)

I say God is great. My God gives the healing; I say do not think too much. That's how I try to give consolation. (C17, 65 years, female, low QoL)

n Mean ± SD Primary stressors collected from patients Age of patients 57.76 ± 14.52 ≤55 years 79 63.2 Gender of patients 70 56.0 Female 70 56.0 Male 55 44.0 Cancer type Breast cancer 43 34.4 Colorectal cancer 26 20.8 Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 </th <th>caregiving experience model ($n = 125$)</th> <th></th> <th></th>	caregiving experience model ($n = 125$)		
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Age of patients 57.76 ± 14.52 ≤55 years 46 36.8 >55 years 79 63.2 Gender of patients 70 56.0 Female 70 56.0 Male 55 44.0 Cancer type 8 43 34.4 Colorectal cancer 26 20.8 34.4 Colorectal cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status 7es 12 9.6 No 113 90.4 Current treatment approach 2emotherapy 61 48.8 Radiotherapy 17 13.6 13.6 Immunotherapy 6 4.8 32.8 ESAS Pain 5.54 ± 1.99 5.85 ± 2.06 Nausea 3.55 ± 2.25 5.26 5.22 ± 2.25 Anxiety 4.81 ± 2.55 1.14 ± 2.19 1.15 1.15 1.15 1.15		—— Mean ± SD	%
Age of patients 57.76 ± 14.52 ≤55 years 46 36.8 >55 years 79 63.2 Gender of patients 70 56.0 Female 70 56.0 Male 55 44.0 Cancer type 8 43 34.4 Colorectal cancer 26 20.8 34.4 Colorectal cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status 7es 12 9.6 No 113 90.4 Current treatment approach 2emotherapy 61 48.8 Radiotherapy 17 13.6 13.6 Immunotherapy 6 4.8 32.8 ESAS Pain 5.54 ± 1.99 5.85 ± 2.06 Nausea 3.55 ± 2.25 5.26 5.22 ± 2.25 Anxiety 4.81 ± 2.55 1.14 ± 2.19 1.15 1.15 1.15 1.15	Primary stressors collected from patients		
>55 years 79 63.2 Gender of patients Female 70 56.0 Male 55 44.0 Cancer type Breast cancer 43 34.4 Colorectal cancer 26 20.8 Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers		57.76 ± 14.52	
Gender of patients Female 70 56.0 Male 55 44.0 Cancer type Breast cancer 43 34.4 Colorectal cancer 26 20.8 Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness	≤55 years	46	36.8
Female	>55 years	79	63.2
Male 55 44.0 Cancer type Breast cancer 43 34.4 Colorectal cancer 26 20.8 Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41	Gender of patients		
Cancer type Breast cancer 43 34.4 Colorectal cancer 26 20.8 Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach 61 48.8 Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41	Female	70	56.0
Breast cancer	Male	55	44.0
Colorectal cancer 26 20.8 Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS<	Cancer type		
Gastric cancer 18 14.4 Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status 7es 12 9.6 No 113 90.4 Current treatment approach 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08	Breast cancer	43	34.4
Other 38 30.4 Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status 7es 12 9.6 No 113 90.4 Current treatment approach 7ex 17ex 13.6 Chemotherapy 61 48.8 48.8 Radiotherapy 17ex 13.6 13.6 Immunotherapy 6 4.8 32.8 ESAS Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 5.54 ± 1.99 5.85 ± 2.06 5.85 ± 2.06 5.28 ± 2.25 5.28 ± 2.25 5.28 ± 2.25 5.28 ± 2.25 5.28 ± 2.25 5.28 ± 2.29 4.81 ± 2.55 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12 1.12	Colorectal cancer	26	20.8
Duration of cancer diagnosis 3.32 ± 2.49 ≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08	Gastric cancer	18	14.4
≤3 years 57 45.6 >3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Other	38	30.4
>3 years 68 54.4 Hospitalisation status Yes 12 9.6 No 113 90.4 Current treatment approach 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08	Duration of cancer diagnosis	3.32 ± 2.49	
Hospitalisation status Yes No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation ESAS Pain 5.54 \pm 1.99 Fatigue 5.85 \pm 2.06 Nausea 3.55 \pm 2.25 Sadness 5.28 \pm 2.29 Anxiety 4.81 \pm 2.55 Insomnia 5.14 \pm 2.19 Loss of appetite 5.03 \pm 2.12 Well-being 5.44 \pm 2.17 Shortness of breath 3.30 \pm 2.39 Changes in the skin and nails Mouth sores 2.78 \pm 2.23 Numbness in the hands 2.38 \pm 2.18 CDS Secondary stressors collected from family caregivers	≤3 years	57	45.6
Yes 12 9.6 No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	>3 years	68	54.4
No 113 90.4 Current treatment approach Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08	Hospitalisation status		
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Chemotherapy 61 48.8 Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESASPain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08	No	113	90.4
Radiotherapy 17 13.6 Immunotherapy 6 4.8 Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08	Current treatment approach		
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Symptom palpation 41 32.8 ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Radiotherapy	17	13.6
ESAS Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Immunotherapy	6	4.8
Pain 5.54 ± 1.99 Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Symptom palpation	41	32.8
Fatigue 5.85 ± 2.06 Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	ESAS		
Nausea 3.55 ± 2.25 Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Pain	5.54 ± 1.99	
Sadness 5.28 ± 2.29 Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Fatigue	5.85 ± 2.06	
Anxiety 4.81 ± 2.55 Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Nausea	3.55 ± 2.25	
Insomnia 5.14 ± 2.19 Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Sadness	5.28 ± 2.29	
Loss of appetite 5.03 ± 2.12 Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Anxiety	4.81 ± 2.55	
Well-being 5.44 ± 2.17 Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Insomnia	5.14 ± 2.19	
Shortness of breath 3.30 ± 2.39 Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Loss of appetite	5.03 ± 2.12	
Changes in the skin and nails 3.29 ± 2.41 Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Well-being	5.44 ± 2.17	
Mouth sores 2.78 ± 2.23 Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Shortness of breath	3.30 ± 2.39	
Numbness in the hands 2.38 ± 2.18 CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Changes in the skin and nails	3.29 ± 2.41	
CDS 65.07 ± 13.08 Secondary stressors collected from family caregivers	Mouth sores	2.78 ± 2.23	
Secondary stressors collected from family caregivers	Numbness in the hands	2.38 ± 2.18	
	CDS	65.07 ± 13.08	
PCS 22.82 ± 6.57	Secondary stressors collected from family ca	aregivers	
	PCS	22.82 ± 6.57	

Abbreviations: CDS, Care Dependency Scale; ESAS, Edmonton Symptom Assessment Scale; PCS, Preparedness for Caregiving Scale; SD, standard deviation.

TABLE 3 Characteristics of the contextual factors collected from family caregivers according to the cancer family caregiving experience model (n = 125)

model ($n = 125$)	, , , ,	.g 5/(p 6// 6// 6/
	n	%
Age (mean ± SD = 46.01 ± 10.88)		
≤45 years	65	52.0
>45 years	60	48.0
Gender		
Female	76	60.8
Male	49	39.2
Education level		
Primary education	66	52.8
High school	33	26.4
University	26	20.8
Marital status		
Married	115	92.0
Single	10	8.0
Income status		
Income less than expenditure	29	23.2
Income equal to expense	85	68.0
Income more than expenditure	11	8.8
Employment status		
Yes	49	39.2
No	76	60.8
Degree of relationship to the patient		
Spouse	53	42.4
Child	58	46.4
Mother/father	6	4.8
Brother/sister	8	6.4
Duration of caregiving (years) (mean ± SD	0 = 2.27 ± 1.35)	
≤2 years	81	64.8
>2 years	44	35.2
Daily caregiving hour (mean \pm SD $=$ 12.5	6 ± 5.70)	
≤12 h	79	63.2
>12 h	46	36.8
Living in the same house with the patient		
Yes	103	82.4
No	22	17.6
Previous caregiving history		
Yes	23	18.4
No	102	81.6
Education status about caregiving		
Yes	36	28.8
No	89	71.2
Presence of chronic disease		
Yes	49	39.2
No	76	60.8

Abbreviation: SD, standard deviation.

In this process, family caregivers with low QoL turned to various activities such as spending time on the phone, watching movies, playing games and reading books to relax and feel better. They emphasised that, family members can overcome negative situations with these various activities and they have developed a defence mechanism that will distract attention from this process.

When I have a little problem, for example, I take the phone or my computer. So, when I'm dealing with it, my head relaxes. (C14, 59 years, female, low QoL)

I read novels at home. Big novels. I want my mind to be scattered, I want to forget myself. (C20, 49 years, female, low QoL)

3.2 | Quantitative findings

3.2.1 | Characteristics of the stress process and contextual factors

When the primary stressors were examined, the mean age of the patients was mostly (63.2%) above 55 years of age. More than half of the patients (56%) were women; 34.4% of patients had a diagnosis of breast cancer, and 54.4% had been living with a diagnosis of cancer for at least 3 years. Only 9.6% of the patients are hospitalised. According to the ESAS subdomains scores, patients had the highest fatigue (5.85 \pm 2.06) and the lowest the numbness in hands (2.38 \pm 2.18). The mean CDS score of patients was 65.07 \pm 13.08. Considering the secondary stressors, the mean score of PCS of the family caregivers was 22.82 \pm 6.57 (Table 2).

When contextual factors are examined, 52% of family caregivers were under 45 years old. Most of the family caregivers were women (60.8%) and primary school graduates (52.8%). Moreover, most of the family caregivers were spouses (42.4%) or children (46.4%) of patients; 64.8% of the family caregivers provided care for patients 2 years or below; 63.2% of the caregivers provided care less than 12 h per day; 82.4% of family caregivers lived in the same house with their patients; most of them had no previous caregiving history (81.6%) and did not receive any training on caregiving (71.2%); 39.2% of family caregivers had at least one chronic disease (Table 3).

3.2.2 | Predictors of QoL

The total CQOLC score of family caregivers was 77.42 \pm 20.58 points. The variables related to the stress process contributed 70% to the CQOLC total scores of the family caregivers ($R^2=0.704$). According to the regression coefficients (B), as the pain, fatigue, nausea, sadness, anxiety, insomnia, and loss of appetite scores of the patients increased, the total CQOLC scores of the family caregivers decreased by 3.296, 4,595, 4,000, 3.647, 3.256, 2.967, and 3.496 points, respectively (p < 0.001). Moreover, the increase in scores of dyspnoea,

changes in the skin and nails, sores in the mouth, and numbness in the hands decreased the total CQOLC scores of the family caregivers by 2.821, 2.793, 3.449, and 2.899 points, respectively (p < 0.001). There was a significant relationship between feeling well-being scores and CQOLC total scores; family caregivers who feel well had higher total CQOLC scores (r = -0.399, p < 0.001). The improve in CDS scores of the patients increased the total CQOLC scores of the family caregivers by 0.621 points (p < 0.001). Age, gender of patients, cancer type, duration of cancer diagnosis, and hospitalisation status were not affected QoL of family caregivers (p > 0.05). The level of PCS in family caregivers, that is among the secondary stressors, improved the total CQOLC scores by 2.580 points (p < 0.001) (Table 4).

The variables related to contextual factors contributed to the total CQOLC scores of family caregivers by 23% ($R^2 = 0.233$). When these determinants are examined, family caregivers with lower income had 28,201 times less CQOLC total score than those with higher income levels (p < 0.001). Family caregivers who were not working had a total CQOLC score of 7.506 times less than those who worked (p = 0.047). Family caregivers who cared to patients for 12 h or less per day had a total CQOLC score of 8332 times higher than those who cared for their patients more than 12 h per day (p = 0.030). The age, gender, education status, marital status, degree of relationship to the patient, duration of caregiving, daily caregiving hours, living in the same house with the patient, previous caregiving history, education status about caregiving, presence of the chronic disease did not have a predictive effect on the CQOLC total scores of the family caregivers (p > 0.05) (Table 5).

4 | DISCUSSION

This study was examined the QoL with all its aspects on the basis of the cancer family caregiving experience model. In this study, symptom severity and care dependency, which are factors related to the stress process, were determined as predictors for the QoL of family caregivers. This study found that family caregivers of advanced cancer patients with high symptom severity and care dependency perceive a lower QoL. The literature emphasised that cancer patients experience fatigue, sleep problems, pain, and mental problems the most and that these disturbing symptoms also affect their family caregivers and reduce their QoL (Ellis et al., 2021; Wen et al., 2019). Seeing their loved ones suffer and depend on others due to symptoms causes great sadness in the family caregivers, and they may feel guilty for not being able to alleviate the symptoms of their patients, and this may be reflected in their QoL (Stamataki et al., 2014). In addition, the preparedness to care for the family caregivers can also affect the QoL. This study determined that the QoL of family members who felt ready for the caregiving process was higher. A study by Zale et al. (2018) conducted with family members of patients hospitalised in the intensive care unit was determined that family members who feel ready to care have higher physical, psychological, environmental, and social subdimensions of QoL (Zale et al., 2018). Family members who care for patients feel unprepared and inadequate because they do not have

 TABLE 4
 Regression analysis of the effect of the stress process on quality of life

					95% CI	
	В	SE	Test statistic	p value	Lower	Upper
Primary stressors						
Age of patients (reference value = >5	55 years)					
≤55 years	5.623	3.808	1.477	0.142	-1.915	13.16
Gender of patients (reference value =	= male)					
Female	5.171	3.713	1.393	0.166	-2.180	12.52
Cancer type (reference value $=$ other	-)					
Breast cancer	-3.620	5.878	-0.616	0.539	-15.259	8.01
Colorectal cancer	0.198	5.291	0.037	0.970	-10.277	10.67
Gastric cancer	5.949	4.574	1.300	0.196	-3.108	15.00
Duration of cancer diagnosis (referen	ce value = >3 years)					
≤3 years	5.263	3.693	1.425	0.157	-2.048	12.57
Hospitalisation status (reference valu	e = no)					
Yes	6.434	4.998	0.954	0.667	-1.762	11.51
Current treatment approach (reference	ce value = symptom	palpation)				
Chemotherapy	0.433	4.130	0.105	0.917	-7.744	8.60
Radiotherapy	-6.545	5.899	-1.110	0.269	-18.225	5.13
Immunotherapy	-16.780	9.687	-1.732	0.086	-35.960	2.3
ESAS						
Pain	-3.296	0.884	-3.730	<0.001	-5.046	-1.54
Fatigue	-4.595	0.801	-5.735	<0.001	-6.181	-3.0
Nausea	-4.000	0.755	-5.297	<0.001	-5.495	-2.50
Sadness	-3.647	0.746	-4.889	<0.001	-5.124	-2.1
Anxiety	-3.256	0.667	-4.883	<0.001	-4.576	-1.93
Insomnia	-2.967	0.809	-3.666	<0.001	-4.569	-1.36
Loss of appetite	-3.496	0.825	-4.238	<0.001	-5.129	-1.8
Well-being	-3.786	0.788	-4.803	<0.001	-5.346	-2.2
Shortness of breath	-2.821	0.736	-3.832	<0.001	-4.279	-1.36
Changes in the skin and nails	-2.793	0.742	-3.765	<0.001	-4.262	-1.3
Mouth sores	-3.449	0.776	-4.445	<0.001	-4.986	-1.93
Numbness in the hands	-2.899	0.813	-3.564	0.001	-4.509	-1.28
CDS	0.621	0.131	4.754	<0.001	0.362	0.8
Secondary stressors						
PCS	2.580	0.163	15.842	<0,001	2,258	2.90

Note: R = 0.839, $R^2 = 0.704$, F = 13.006, p < 0.001. Bold values are statistically significant (p < 0.05).

sufficient knowledge and skills due to the sudden emergence of this process (Tan et al., 2021).

The QoL of family caregivers is also affected by contextual factors including socio-economic variables. This study determined that variables such as age, gender, education level, marital status, degree of relationship to the patient, and presence of the chronic disease did not have an effect on the QoL of the family caregivers. When the literature is examined, it is seen that there are uncertainties about the effect of these factors on the QoL (Fletcher et al., 2012). In addition, these factors may not have been demonstrated the effects on QoL due to reasons such as the fact that the population of this study mostly

consists of married, primary school graduates, spouses, and children living in the same environment with the patient. On the contrary, income level, employment status, and daily caregiving hours are important predictors of QoL in this study. The QoL of family caregivers with a low income, unemployed, and long daily caregiving hours is lower. Low-income families have fewer financial resources, so they have difficulty dealing with the additional costs of caregiving (Ferrell et al., 2018). On the other hand, working family caregivers has the opportunity to take a break from their caregiving responsibility for a certain period of time during the day. Since family caregivers can maintain their own vital functions, it increases their satisfaction with life and their perceived

 TABLE 5
 Regression analysis of the impact of contextual factors on quality of life

					95% CI	
	В	SE	Test statistic	p value	Lower	Upper
Age of caregivers (reference value = >	45 years)					
≤45 years	1.059	3.715	0.285	0.776	-6.295	8.41
Gender of caregivers (reference value	= male)					
Female	-6.662	3.748	-1.778	0.078	-14.081	0.75
Education level (reference value = univ	versity)					
Primary education	-20.455	21.014	-0.973	0.332	-62.061	21.15
High school	-18.240	21.113	-0.864	0.389	-60.042	23.56
Marital status (reference value = marri	ed)					
Single	-2.958	6.810	-0.434	0.665	-16.439	10.52
Income status (reference value $=$ incor	ne more than exper	nditure)				
Income less than expenditure	-28.201	6.571	-4.291	0.000	-41.210	-15.19
Income equal to expense	-8.165	5.950	-1.372	0.173	-19.945	3.61
Employment status (reference value =	yes)					
No	-7.506	3.735	-2.010	0.047	-14.899	-0.11
Degree of relationship to the patient (r	reference value = sp	oouse)				
Child	-0.751	3.937	-0.191	0.849	-8.545	7.04
Mother/father	-6.423	8.887	-0.723	0.471	-24.020	11.17
Brother/sister	10.202	7.828	1.303	0.195	-5.298	25.70
Duration of caregiving (reference value	e = >2 years)					
≤2 years	5.199	3.871	1.343	0.182	-2.463	12.86
Daily caregiving hour (reference value	= >12 h)					
≤12 h	8.332	3.785	2.201	0.030	0.839	15.82
Living in the same house with the patie	ent (reference value	= yes)				
No	1.645	4.856	0.339	0.735	-7.967	11.25
Previous caregiving history (reference	value = yes)					
No	1.781	4.855	0.367	0.714	-7.830	11.39
Education status about caregiving (refe	erence value = yes)					
No	-2.071	4.084	-0.507	0.613	-10.156	6.01
Presence of chronic disease (reference	value = yes)					
No	3.845	3.794	1.014	0.313	-3.665	11.35

Note: R = 0.483, $R^2 = 0.233$, F = 2.366, p = 0.007. Bold values are statistically significant (p < 0.05).

QoL. The increase in the time spent by the family caregivers with the patient causes a decrease in the time that the caregivers spare for themselves and other daily work, and social activities, and this may be a reason for the decrease in the QoL (Ribé et al., 2018).

The caregiving experience of the family members of the advanced cancer patients was examined through in-depth interviews within the scope of the cancer trajectory. In this study, caregiving was defined by family members as a multifaceted situation that requires effort, sacrifice, and love, and also includes meeting both the physical and psychosocial needs of the patient, similar to the literature. In addition, a theory-building study conducted with family caregivers emphasised that caregiving was a new and multifaceted role and that their most obvious responsibility was to provide emotional support to the patient (McDonald et al., 2018). Some family caregivers stated that they had

negative experiences due to the uncertainties they experienced during the caregiving process and difficulties in adapting. Similarly, many studies stated that family caregivers experienced anxiety and had difficulties due to a lack of information about treatment and disease (Taylor et al., 2021). On the contrary, some family caregivers stated that this process taught them new information such as life planning, hospital operation, and dressing a wound. In addition, Leow and Chan (2017) stated that family members' knowledge and care skill levels increased, they became masters, and this is useful for managing similar situations that they may encounter in the future (Leow & Chan, 2017). The caregiving experience is a highly dynamic process that can have different effects on family members over time. For this reason, it can be encountered as a concept that can be emphasised as both uncertainty and experience by the caregiver family members.

One of the most striking findings of this study was that the family caregivers devoted themselves completely to their patients and stated that their well-being or badness is shaped by their patient's condition. In addition, family caregivers stated that they lived in social and economic limitations in addition to all these changes in their lives. Similar to our findings, McDonald et al. (2018) stated that family caregivers' lives revolved entirely around their patients, everything was overshadowed, and the most important thing in their lives was their patients (McDonald et al., 2018). Family members who focus on the patient's pain, problems, and needs in the best way are now worsening in their own health conditions, and also causes those who focus on the patient all the time in the day to ignore their own lives. New roles and responsibilities regarding caregiving take up all the energy and time of family members, leaving no opportunity for social life (Adelman et al., 2014; Tan et al., 2021). In addition to these, some family members in this study stated that they completely distanced themselves from people due to their judgmental and accusatory perspectives. Previous studies highlighted that the familial support felt during the responsibility of caregiving reduces the negative emotions in this process and provides convenience in coping (Ferrell et al., 2018; Mosher et al., 2017). On the contrary, the judgmental attitude of the people around the family caregivers causes feelings of guilt and sadness, and the caring family members prefer to distance themselves from the people around them.

Despite all the limitations that family caregivers used many different strategies to cope with the negativities during the care process. In this study, family caregivers stated that they turned to religious practices and distracting practices such as watching television and reading books in order to hold on to life during the caregiving process. The literature emphasised that family caregivers mostly went towards spiritual practices. Caregivers of cancer patients mostly used "praying, trusting in Allah and hope" coping methods (Fadıloğlu, 1996; Leow & Chan, 2017). In Turkish culture, individuals generally tend to see diseases as a natural event or destiny, and therefore they often turn to religious coping mechanisms (Fadıloğlu, 1996; Yıldız et al., 2016). In addition, previous studies stated that mind-distracting activities such as watching television and listening to music make family members forget their roles and responsibilities in the care process, and reduce negative thoughts (Yıldız et al., 2016). It is thought that doing activities that caregiver family members enjoy provides the opportunity to get away from negative feelings and thoughts, and provides an opportunity to breathe and rest.

CONCLUSION 5

The CFCEM is a useful model in evaluating the QoL of family caregivers from a multidimensional perspective. The QoL of family caregivers of advanced cancer patients decreases as the symptoms and care dependency of patients with primary stressors increase. The QoL of family caregivers of advanced cancer patients decreases as the level of preparedness to care, which is a secondary stressor, decreases. In terms of contextual factors, the QoL of family

caregivers with low income, unemployed, and long-term caregiving is lower. Caring for advanced cancer patients creates many limitations in the daily life of family members, including health, social, economic, and family relationships. Caregiving family members turn to spiritual and distracting practices to cope with the care process despite all the limitations they experience. All health care professionals should not forget that the cancer process affects family caregivers as well as patients and should comprehensively evaluate family members in this process. During the caregiving process, the information needs of family members should be met, and their level of preparedness should be increased by providing training and counselling for this process.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this paper.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

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