

Difficulties experienced by individuals who care for palliative patients – a qualitative study informed by Jean Watson's theory of human caring

Ayşe Topuz¹, Sevil Güler², Oktay Bektaş²

¹Karamanoğlu Mehmetbey University, Karaman, Turkey

²Erciyes University, Kayseri, Turkey

Abstract

Introduction: Caregivers' difficulties with the caregiving process have a significant impact on how both they and the patients they care for are affected in a parallel manner. Jean Watson's theory of human caring supports this phenomenological qualitative research because it explains the relationship between caregivers' ability to provide care and the difficulties they face in doing so. This study aimed to determine difficulties experienced by individuals who care for palliative patients. The study was supported by Jean Watson's theory of human care.

Material and methods: In the study, the transcendental phenomenology model of the qualitative research method was used. The study group consisted of six individuals registered in the Palliative Treatment Unit and caring for inpatients. A semi-structured interview form was used in the study. The interviews were audio-recorded with the permission of the participants. After the audio recordings were written down, content analysis was made by creating code-category-themes. We tried to ensure validity and reliability throughout the study.

Results: The findings consisted of a theme, five categories, and thirty-one codes. As a result of the study, it was determined that the caregivers experienced psychological, physical, economic, social, and spatial difficulties during the caregiving process. In addition, somatic complaints, sleep disturbance, and problems related to lifestyle and family relationships were also identified.

Conclusions: It is recommended that nurses evaluate the caregivers at regular intervals, prepare and implement the necessary training, counseling, and supportive programs to reduce the difficulties they experience, and conduct future studies with larger groups.

Key words: palliative care, difficulties experienced, nurse, qualitative research.

Address for correspondence:

Assoc. Prof. Dr. Sevil Güler, Erciyes University, Kayseri, Turkey, e-mail: sevilbicer@erciyes.edu.tr

INTRODUCTION

Watson's theory of human caring was initially presented in 1979 and asserts that the experiences that allow the patient and the caregiver to get to know one another in a variety of ways form the foundation of care. Care is also a holistic approach that encompasses the aspects of the mind, body, and spirit [1–3]. At the core of Watson's theory, there are ten primary factors that determine the caring process [4]. Each of the ten caring factors can be placed in either the physical dimension or the expressive dimension of care [2]. The physical dimension focuses on individuals' physiological needs. The attractive factors in the physical dimension include the systematic use of scientific problem-solving methods, educational interventions, creating a supportive and safe environment, and addressing and meeting

physical needs. The attractive factors in the expressive dimension include the growth and development of a care-based value system, instilling hope by being sensitive and accepting one's own and others' emotions, and developing a relationship with the patient based on assistance and trust [5]. According to Watson, each caring factor is centered around the care interaction between the nurse and the patient and is based on human qualities such as kindness, love, and concern for others [1]. Therefore, if care is obstructed or cannot be provided due to internal or external factors, difficulties may arise. If these difficulties are not adequately addressed, the context of care may be affected, and caregivers may not be able to provide the desired care, leading to potential harmful internal consequences and problems that can be associated with such difficulties [6].

Caregivers' difficulties with the caregiving process have a significant impact on how both they and the patients they care for are affected in a parallel manner. Jean Watson's theory of human caring supports this phenomenological qualitative research because it explains the relationship between caregivers' ability to provide care and the difficulties they face in doing so [1]. Based on Jean Watson's theory of human caring, identifying the difficulties that caregivers may encounter in providing care will pave the way for approaches that can lead to the resolution of these issues. Additionally, overcoming the difficulties experienced by caregivers will positively impact their overall health and well-being. In this instance, it is anticipated that patients receiving palliative care may benefit from these increased well-being states as well. It is anticipated that this study will shed light on the difficulties faced by caregivers of palliative care patients, making their experiences more visible. This visibility has the potential to prevent the escalation of these difficulties and increase awareness in comprehensive approaches in all healthcare services, especially nursing, and contribute to the literature [7, 8].

Given all of this, the purpose of this phenomenological qualitative study was to identify the difficulties experienced by those who provide care for palliative patients. This study sought answers to the questions "What are the difficulties experienced by individuals who care for palliative patients throughout the caregiving process?", and "How are individuals who care for palliative patients affected throughout the caregiving process?"

MATERIAL AND METHODS

In this study, transcendental phenomenology, which is one of the models of qualitative research methods, was used [7, 8]. Data were collected using one-on-one, in-depth interviews with the individuals who provided care to palliative patients, as is the protocol for this research method [9].

Setting and participants

The participants of this study consisted of six individuals who provided care to patients registered in the Palliative Treatment Unit of a state hospital in the Central Anatolia Region of Turkey. In participant selection, purposeful sampling was utilized from the types of purposeful sampling techniques. The aim of purposeful sampling is to include intentionally chosen individuals who have experienced the phenomenon of interest, thus providing rich sources of information for the research. The purpose of purposeful sampling is not about population generalizability; instead, it deeply understands participants' experiences related to the phenomenon [10, 11]. The inclusion criteria for the study were as follows: (1) individuals aged 18 and over and (2) caring for a patient who had needed palliative care for at least six months (Table 1).

Data collection

In this research, interview was employed as the data collection tool. The Socio-Demographic

Table 1. Sociodemographic characteristics of the study participants

Participant	Age	Gender	Marital status	Number of children	Educational status	Degree of affinity with the patient	Caregiving duration	Other caregivers	Presence of chronic disease
Ece	60	Female	Married	3	Primary school	Spouse	2.5 years	No	No
Nur	41	Female	Married	1	Primary school	Her father	3 years	Nephew and brother	No
Gül	63	Female	Single	2	Primary school	No close	8 months	Another caregiver	Fibromyalgia, cholesterol
Eda	36	Female	Single	No	Primary school	Her grandfather	3 years	Aunt and uncle	Epilepsy
Ela	76	Female	Married	4	Primary school	Spouse	3 years	Groom and caretaker	No
Oya	24	Female	Single	No	High school	Her father	5 years	Mother and sister	Herniated disc, rheumatoid arthritis

Characteristics and Semi-Structured Interview Form about the Difficulties Experienced in the Caregiving Process were employed for the interview. The questions included in the interview were formulated with support from the literature [12–16]. Based on the expert opinions and pilot interview, necessary adjustments were made to the clarity, comprehensibility, accessibility, deficiencies, and details of the questions to ensure their alignment with the purpose. Examples of how the questions were finalized can be seen in the first version and the final version (Appendix 1) of all interview questions.

Data analysis and design

To evaluate the prepared socio-demographic and semi-structured interview form, a pilot interview was conducted by the researcher (A.T.) with three participants who provided care to patients registered in the Palliative Care Unit and were hospitalized there. During the pilot interview, the researcher could not obtain sufficient data from the participants regarding the sixth and seventh questions in the semi-structured interview form. Therefore, it was decided to cancel these questions (Appendix 1), and data collection commenced. The individuals who participated in the pilot interview were not included in the study.

To ensure clarity and confirm that the interview questions would capture data related to experienced difficulties, discussions with field experts were held to review the interview questions again [17]. The interview was conducted in a quiet, comfortable, non-threatening environment within the hospital to allow for the maximum disclosure of information [9]. The data were read by the researcher (A.T.) and filled out based on the responses provided by the patients. Simultaneously, the semi-structured interviews were audio-recorded, and the interviews lasted an average of 35–50 minutes. The interviews were concluded when data saturation was achieved.

Content analysis was used in this study [9]. The main procedural steps of the analysis are provided in Appendix 2.

Ethical considerations

In order to conduct the research, approval was obtained from the University's Social and Human Sciences Scientific Research Publication Ethics Committee (Approval No: 11-2023/178). The participants were asked to sign a voluntary permission form that had been authorized by the ethics committee. Participant confidentiality was ensured by using a unique pseudonym for each participant throughout data collection, analysis, and reporting of findings. Furthermore,

access to information and data was restricted to the researcher only throughout the research, and the data were secured using encryption on a protected device. Thus, the disclosure of participants' responses was limited, and the risk of potential harm to participants was minimized. All data related to the study will be stored for three years and then deleted.

Limitations

In this study, the care recipient patient group was limited to only palliative care patients. Another limitation was that the study consisted of transcendental phenomenological research. The aim of the study was to describe the difficulties experienced by individuals who care for palliative patients, which is why this qualitative research approach was chosen.

RESULTS

The findings are based on interviews with individual participants and cover circumstances or experiences during the caring process and reflect a compilation of data gathered through audio recordings and textual explanations. Personalized narratives give a framework for each participant's experience with the problems they encountered. The results consisted of one theme, five categories, and thirty-one codes (Table 2). Codes were generated based on participants' responses to open-ended questions under themes and categories, and direct quotations from the participants are provided below.

Findings related to the psychological difficulties category

The participants described the psychological difficulties they experienced during the caregiving process with ten different emotions (i.e., sadness, helplessness, longing, fear of death/loss, feeling depressed/exhausted, melancholy, fear of not being able to look, distress, hopelessness, introversion). All participants expressed that they were experiencing 'sadness and helplessness' as psychological difficulties. Some of the responses given by individuals providing care about the psychological difficulties they experienced are as follows:

- When I leave this place, a sense of fear of death engulfs me. ... When he's hungry, or when I can't manage, I often think about my helplessness. I feel really sad when I can't manage. The fear that I won't be able to take care of him starts to overwhelm me... More than anything else, I miss sitting down with my spouse and having a cup of coffee together.

Table 2. Experiences of individuals providing care to palliative patients

Code	Category
Sadness (Ece, Nur, Gül, Eda, Ela, Oya) Helplessness (Ece, Nur, Gül, Eda, Ela, Oya) Longing (Ece, Nur, Oya) Fear of death/loss (Ece, Oya) Feeling depressed/exhausted (Ece, Oya) Melancholy (Ece, Oya) Fear of not being able (Ece) Distress (Ece) Hopelessness (Ece) Introversion (Oya)	Category 1 Psychological difficulties
Pain (Ece, Nur, Gül, Eda, Ela, Oya) Neglect their own check-ups (Ece, Ela, Oya) Weakness (Ece, Ela, Oya) Fatigue (Ece, Ela) Sleep disturbance (Ece, Ela) Give up on self-care (Ece, Gül) Need someone (Ece, Oya) The patient's gender (Eda, Oya) Impairment of quality of life (Oya) Foot swelling (Ece) Rib injury (Gül) Herniated disc (Oya)	Category 2 Physical difficulties
Home care (Ece, Nur, Eda, Ela, Oya) Inability to meet the need for paid caregivers (Ece)	Category 3 Economic difficulties
Withdrawal from relationships (Ece, Gül, Ela, Oya) Unable to leave the patient (Ece, Gül, Oya) Decreased time for family/neglect of family (Ece, Ela) Struggles with shopping and household chores (Oya) Unable to continue education (Oya)	Category 4 Social difficulties
Uneasy with the individuals in the room (Gül) Not being able to take a bath in the hospital (Gül)	Category 5 Spatial difficulties

Does a person miss things? They do. ... I wish my spouse would wake up so I could take him home. ... I feel like I'm melancholy. I don't even want to daydream anymore. Because I know it won't happen (crying). Sometimes, I feel like I'm overwhelmed by and done (Ece);

- I felt emotionally shattered after my father. I closed myself off. ... I'm in a bad mood. I feel distressed and experience depression quite often (Oya).

Findings related to the physical difficulties category

The participants stated that they experienced difficulties such as pain in various body regions, weakness, rib injury, foot swelling, and herniated discs during the caregiving process:

- There are moments when I feel inadequate. Sometimes I lie down at night to sleep, yet I wake up fatigued... When I try to lift something, I struggle. Both my foot and ankle bones have undergone surgery. When I stand for an extended period of time, they swell and hurt. Of course, raising and lowering the patient causes pain in my feet, wrists, and waist (Ece);

- ... I cracked the cartilage tissue of two of my ribs on my right side while trying to lift my aunt without lowering these things (pointing to the bed railings) (Gül);
- ... I cared for him alone for two and a half years. I didn't have a herniated disc back then. It emerged afterwards. I have six platina in my back. It had such an impact on me that I was no longer able to care for my father (Oya);
- The participants expressed experiencing sleep disturbances during the caregiving process. One more thing errr... When a person is exhausted all day, it is normal for them to desire to sleep at night. But how can I sleep with my heart racing? ... One yearns for sleep. Even if I did sleep, I wouldn't be at peace... (Ela);
- The participants described the physical difficulties they experienced in the caregiving process related to their lifestyles as neglecting their own check-ups, giving up on self-care, impairment of quality of life, constantly needing someone, and the patient was male. They stated I had a gallstone that had to be removed, but how could I go to surgery when he was still here...? (Ela);

- ... When I care for my patient, I can't think about my own needs. I give up everything (Gül);
- ... Even the quality of my life decreased when my father was ill (crying). ... While I help with caring, I struggle a lot and do not handle hard work. My mum and sister are constantly there for me. I'm always in need of assistance (Oya);
- At the same time, the participants mentioned that they experienced challenges related to the gender of the patient during the caregiving process. Because he's a man and we're two women, we struggle a little when lifting him (Eda).

Findings related to the economic difficulties category

In this regard, Ece, who had been providing care for her spouse alone for two and a half years, expressed that she could not meet the need for paid caregivers:

- For example, I was able to employ a caregiver for roughly six months. My savings had run out... Hiring one is expensive (Ece);
- Also, other participants (except Gül) said that they experienced many financial difficulties regarding household expenses, especially caregiving costs, during the periods when they were providing home care;
- ... But, as I already stated, I wouldn't be able to handle it if I were at home. Everything, including medical items, is fairly pricey. ... Instead of wasting money on diapers, we may use our money to purchase wet wipes, food, and drinks for the patient (Oya);
- In fact, it's better here than at home. We might not be able to buy everything if we were at home. Everything is right here. Diapers are already infinite and many... We would have a lot of problems if we were at home. In any case, I'm not a working person (Nur).

Findings related to the social difficulties category

During the caregiving process, participants reported being withdrawn from relationships, having difficulties with shopping and home duties, and being unable to leave the patient:

- ... So, I mean, I only go out about every two to three months. If I don't need to, I won't even go out for an hour (Ece);
- I can't leave my father's side. ... I can't go to the market, I can't go shopping, and I never have any social life. ... My mother needs to go back and forth to the village all the time. I run the village while my mother is here. I go back and forth here every day (Oya);
- The change in participants' family ties is indicated by the code of decreasing time for family/neglect-

ing of family. My social life has been restricted, so it's completely over. I miss my children a lot. I can't always see my grandchildren (Ece);

- One of the participants, regarding the social difficulties experienced, explained that she was unable to continue her education during the caregiving process. I was going to go to university, but I couldn't go because of my father's state (Oya).

Findings related to the spatial difficulties category

During the interviews, one participant concerning spatial difficulties mentioned that she was uneasy with the others in the room. Other participants made no mention of any experienced difficulties in this respect:

- Our roommates have been here for almost three months. The woman is not at all clean. And they are always yelling. They never think that we are uncomfortable. Thank God we have this screen between us (Gül);
- I don't have any difficulties because of the hospital environment (Ela);
- The same participant explained spatially that she was unable to take a bath in the hospital related to her own care. I can never take a bath here. Because I don't think I will be clean (Gül).

DISCUSSION

When the findings obtained in the study are evaluated, it is notable that the provision of care is primarily undertaken by females. Many studies conducted with the relatives of patients requiring care have revealed that carers are predominantly female [14, 18–22]. In Turkish society, females are also more typically assigned to caregiving. When males adopt caregiving duties that have traditionally been considered female roles, it might lead to increasing difficulties owing to masculine stereotypes. Therefore, it is thought that males have difficulty meeting their needs.

In this study, the psychological difficulties experienced by the participants have been described as primarily sadness and helplessness, as well as longing, fear of death/loss, feeling depressed/exhausted, melancholy, fear of not being able to care, distress, hopelessness, and introversion. When looking at studies involving individuals providing care for a prolonged period, it has been explained that participants similarly experience negative emotions such as sadness, helplessness [14, 23], hopelessness, insolubility, anger [14], fear of loss, anxiety due to uncertainty, depression/burnout, inability to accept the situation, longing, and deterioration of mental well-being [22]. The establishment of a dependent

and close bond between the caregiver and the patient makes the caregiver feel heavily accountable. The perceived heavy responsibility turns the caregiver into the sole individual responsible for the patient's life. This situation leads the caregiver to experience intense emotions about the patient's life and negatively affects the caregiver's psychology.

When examining the physical difficulties experienced by individuals providing care during the caregiving process, it was found that they all expressed pain in various body regions as physical complaints. When examining the physical difficulties experienced by individuals providing care during the caregiving process, it was found that they all expressed experiencing pain in various body regions. At this point, it was determined that participants experienced lower back, neck, arm, shoulder, muscle, foot, and leg pains, and these health problems were approved and expressed by the participants to occur during the caregiving process. Additionally, participants also reported difficulties related to weakness, fatigue, rib injury, swelling in the feet, and herniated discs. It was found in related research that carers deal with physical difficulties and pains [14, 24–26]. It was also determined in previous research that caregivers frequently experience fatigue [26, 27]. Another difficulty experienced by caregivers is sleep disturbance. The participants stated that their patients also needed them at night. According to research, carers have trouble sleeping [14, 28], and some even report having restless nights and being forced to use sedatives to help them fall asleep [26, 29, 30]. Furthermore, caregivers expressed experiencing difficulties related to their lifestyles during the caregiving process, such as neglecting their own check-ups, giving up on self-care, impairment of quality of life, constantly needing someone else's assistance, and the patient's gender. In the study by Orak and Sezgin, it was found that the gender of the patient affected the physical health problems, psychological distress, and social and economic issues that arise during the caregiving process. Studies in the literature emphasize the significance of providing social support in enhancing the physical and psychological well-being of caregivers, as well as improving their quality of life. Therefore, any form of social support provided to caregivers plays a crucial role in improving their quality of life related to health. In this sense, the professional healthcare team should plan initiatives aimed at enhancing social support to improve the caregivers' quality of life [21].

One of the difficulties experienced by caregiving individuals also manifests in the economic domain. Regarding this, almost all participants stated that during the period of providing care at home, there were significant caregiving expenses in terms of the economy. Another issue mentioned is the in-

ability to meet the need for paid caregivers. It is believed that paid caregiving can create an economic burden and pose difficulties within the family. Similar findings indicating that caregivers experience economic difficulties during the caregiving process can be found in the literature [14, 22, 31]. These findings underscore the necessity of providing professional support to address the problems faced by caregivers, as well as the importance of institutional and home care services.

Another challenge in the caregiving process is social difficulties. In the conducted interviews, many participants indicated that due to caregiving, they withdrew themselves from social relationships, struggled with shopping and household chores, and were unable to leave the patient. In the study conducted by Kutlu *et al.*, the importance of socialization was emphasized, and the problems experienced by caregivers were clearly demonstrated [32]. Numerous other studies have also confirmed those conclusions [14, 22, 31, 33]. Another of the challenges carers encounter is changes in family relationships. In a study conducted by Turgut and Soylu in 2020, a caregiver family member expressed this situation as follows: *Our only life became the hospital. During this process, I started seeing my children's faces less. As a family, we were deprived of doing things together* [22]. Another research finding related to the social difficulties experienced is the inability to continue education during the caregiving process. Results from Turgut and Soylu also lend credence to this research conclusion. Caregivers may think that their privacy, leisure activities, and freedom have been lost or restricted and that they have had to make sacrifices. As a result, the likelihood of feeling abandoned in their caregiving role, experiencing a sense of isolation, and decreasing the perception of social support increases [22].

Finally, in the study's findings, it was observed that spatial difficulties in the caring process were also expressed. The experienced spatial difficulties were sharing the room with different patients and not being able to take a bath in the hospital due to hygiene. In the study by Çakır and Yaman, participants who expressed experiencing spatial difficulties described these difficulties as their homes being small and when a room was given to the elderly, there would not be enough room left for other family members [14].

CONCLUSIONS

The results of the present study indicated that the caregivers experienced psychological, physical, economic, social, and spatial difficulties during the caregiving process. In addition to these difficul-

ties, it has been observed that somatic complaints, sleep disturbance, and problems related to lifestyle and family relationships occur. Studies in the literature support the findings that caregivers experience psychological, physical, economic, social, and spatial difficulties during the caregiving process. When we return to Watson's theory of human care as two dimensions of care, these results support the theory. Thus, it explains the relationship between the care provided by individuals who give care for a long time and the experienced difficulties related to the barriers to this care. When these two elements are brought together, they serve to meet the needs of the caregiver and the patients under their care. In this context, foremost among the professional caregivers, nurses have also fulfilled their primary goal. In order to reduce the difficulties experienced by caregivers, they should be supported psychologically, physically, economically, socially and spatially. In addition, since the difficulties experienced by caregivers may change over time, it is recommended that they be evaluated at regular intervals by nurses and necessary training, consultancy and support programs be prepared and implemented to reduce the difficulties they encounter. Furthermore, in future research, it is recommended to conduct comprehensive studies investigating the difficulties experienced by caregivers, the influencing factors, and coping methods using different models, varying data collection tools, and analysis approaches.

ACKNOWLEDGMENTS

We would like to sincerely thank all of the caregivers who provided care to patients registered in the Palliative Treatment Unit who took the time last summer to respond to our survey. We know it was an extremely busy and challenging progress. We truly appreciate all of you taking the time to respond to the open-ended questions about the difficulties you experienced. Your honest, open, and extensive responses helped us understand more about the difficulties experienced. We are deeply grateful.

The authors declare no conflict of interest.

REFERENCES

1. Watson J. Caring theory as an ethical guide to administrative and clinical practices. *Nurs Adm Q* 2006; 30: 48-55.
2. Evangelista CB, Lopes MEL, Costa SFGD, et al. Nurses' performance in palliative care: spiritual care in the light of Theory of Human Caring. *Rev Bras Enferm* 2021;75: e20210029.
3. Rafael AR. Watson's philosophy, science, and theory of human caring as a conceptual framework for guiding community health nursing practice. *ANS Adv Nurs Sci* 2000; 23: 34-49.
4. Perkins JB. Watson's ten caritas processes with the lens of unitary human caring science. *Nurs Sci Q* 2021; 34: 157-167.
5. Ryan LA. The journey to integrate Watson's caring theory with clinical practice. *Int J Human Caring* 2005; 9: 26-30.
6. Dobrowolska B, Palese A. The caring concept, its behaviours and obstacles: perceptions from a qualitative study of undergraduate nursing students. *Nurs Inq* 2016; 23: 305-314.
7. Nam BH, English AS. Trauma-informed care: a transcendental phenomenology of the experiences of international faculty during the delta and omicron variant outbreaks in East China. *Int J Environ Res Public Health*. 2022; 19: 11057.
8. Neubauer BE, Witkop CT, Varpio L. How phenomenology can help us learn from the experiences of others. *Perspect Med Educ* 2019; 8: 90-97.
9. Creswell JW, Poth CN. *Qualitative inquiry and research design: choosing among five approaches*. 4rd ed. Sage Publications, Los Angeles 2018.
10. Creswell JW, Creswell JD. *Research design: qualitative, quantitative, and mixed methods approaches*. 5rd ed. CA Sage, Los Angeles 2018.
11. Gall M, Gall J, Borg R. *Educational research: an introduction*. Pearson Education, New York 2007.
12. Alam S, Hannon B, Zimmermann C. Palliative care for family caregivers. *J Clin Oncol* 2020; 38: 926-936.
13. Celik E, Aslan MS, Sengul Samanci N, et al. The relationship between symptom severity and caregiver burden in cancer patients under palliative care: a cross-sectional study. *J Palliat Care* 2022; 37: 48-54.
14. Çakır G, Yaman ÖM. Challenges and affecting elements of family members caring at home to elderly care. *J Med Soc Work* 2021; 18:104-124.
15. Duman Ö, Özdelikara A. The effect of views of patients relatives about palliative care on caregiver burden. *Kocaeli Univ J Health Sci* 2022; 8: 32-39.
16. Perpiñá-Galvañ J, Orts-Beneito N, Fernández-Alcántara M, García-Sanjuán S, García-Caro MP, Cabañero-Martínez MJ. Level of burden and health-related quality of life in caregivers of palliative care patients. *Int J Environ Res Public Health* 2019; 16: 4806.
17. Moustakas C. *Phenomenological research methods*. CA: Sage Publications, Thousand Oaks 1994.
18. Evaluation of the effects of home care for the elderly on caregiver families based on family theories. *J Soc Social Work* 2022; 33:577-604.
19. Eğici M, Can M, Toprak D, et al. Care burden and burnout status of caregivers whose patients are treated in palliative care centers. *J Acad Res Nurs* 2019; 5: 123-131.
20. Karakaya C, Işıkhan V. Evaluation of quality of life among caring family members of palliative care patients. *Soc Social Serv* 2020; 31: 1437-1458.
21. Orak OS, Sezgin S. Caregiver burden in family members of cancer patients. *J Psychiatr Nurs* 2015; 6: 33-39.
22. Turgut AŞ, Soyulu G. Palyatif bakım hasta yakınları ile nitel bir çalışma. *Toplum ve Sosyal Hizmet* 2020; 31: 460-476.
23. Lök N, Günbayı İ, Buldukoğlu K. Living with a person who has dementia: a study of phenomenology. *J Psychiatr Nurs* 2015; 6: 91-99.
24. Given BA, Sherwood P, Given CW. Support for caregivers of cancer patients: transition after active treatment. *Cancer Epidemiol Biomarkers Prev* 2011; 20: 2015-2021.
25. Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP. Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nurs* 2006; 29: 378-390.
26. Owoo B, Ninnoni JPK, Ampofo EA, Seidu AA. "I always find myself very tired and exhausted": the physical impact of caring; a descriptive phenomenological study of the experiences of prostate cancer caregivers in Cape Coast, Ghana. *PLoS One* 2022; 17: e0268627.
27. Yeşil T. Examining of the life quality and care burden of those who are looking after the patients suffering from chronic diseases. *Gümüşhane Univ J Health Sci* 2016; 5: 54-66.
28. Akyar AGİ, Akdemir PDN. Strains of caregivers of Alzheimer patients. *Hacettepe Univ Faculty Nurs J* 2009; 16: 32-49.
29. Carter PA. A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nurs* 2006; 29: 95-103.
30. Glajchen M. Physical well-being of oncology caregivers: an important quality-of-life domain. *Semin Oncol Nurs* 2012; 28: 226-235.
31. Atagün Mİ, Balaban ÖD, Atagün Z, Elagöz M, Özpolat AY. Caregiver burden in chronic diseases. *Curr Approach Psychiatr* 2011; 3: 513-552.
32. Kutlu İ, Demirel İ, Kazan G. Lives on alert: the problems and coping skills experienced by those who care for epileptic individuals. *J Acad Rev* 2021; 16: 189-211.
33. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 2008; 112: 2556-2568.

APPENDIX

Initial and final version of the interview questions

The initial version	The final version
<p>1. What are the psychological difficulties you have experienced during the caregiving process? Why?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • How do you feel when taking care of your patient? 	<p>1. What are the psychological difficulties you have experienced during the caregiving process? Why?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • How do you feel when you are with your patient? • How do you feel when taking care of your patient? • How do you think your patient's behaviors are affecting you?
<p>2. What are the physical difficulties you have experienced during the caregiving process?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • What difficulties do you generally experience while taking care of your patient? • How does taking care of your patient affect your personal care? • How/To what extent are you meeting your own needs while taking care of the patient? • How is your health? Can you tell me how the caregiving process has affected your health? 	<p>2. What are the physical difficulties you have experienced during the caregiving process? Why?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • What difficulties do you generally experience while taking care of your patient? • How do you evaluate the care you provide to your patient? • How does taking care of your patient affect your personal care? • How/To what extent are you meeting your own needs while taking care of the patient? • How is your health? Can you tell me how the caregiving process has affected your health? • What are the difficulties you have experienced regarding cleanliness/hygiene during the caregiving process?
<p>3. What are the economic difficulties you have experienced during the caregiving process? Why?</p>	<p>3. What are the economic difficulties you have experienced during the caregiving process? Why?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • How do you think your life has been economically affected or to what extent due to the care of your patient?
<p>4. What are the spatial difficulties you have experienced during the caregiving process? Why?</p>	<p>4. What are the spatial difficulties you have experienced during the caregiving process? Why?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • How does caregiving in a hospital environment affect you? What kind of difficulties are you experiencing? • How would you evaluate your hospital experience and your life here?
<p>5. What are the social difficulties you have experienced during the caregiving process? Why?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • How do you think your caregiving process affects your relationships with your family, relatives and friends? • How do you think your social life is affected by your patient's care? 	<p>5. Same way. No changes were made.</p>
<p>6. Can you tell me about your patient's personality traits?</p> <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • What are positive personality traits? How do these traits affect you? • What are negative personality traits? How do these traits affect you? 	<p>6. It was canceled.</p>
<ul style="list-style-type: none"> • 7. What significance does your patient have to you as a caregiver? <p>PROBING QUESTIONS</p> <ul style="list-style-type: none"> • What kind of relationship did you have with your patient before the illness? 	<p>7. It was canceled.</p>

STAGES OF ANALYSIS

Stage 1. Encountering the data

Initially, all interviews were transcribed verbatim and the data were organized in individual files for each participant, which were then compiled in electronic format (Moustakas, 1994). After transcribing all the interviews, the researcher (A.T.) verified the accuracy of each transcript.

Stage 2. Pre-coding the data

Subsequently, the transcripts were independently analyzed and organized according to codes and categories by A.T., S.G., and O.B. Direct quotations from each transcript were transformed into codes and categories by A.T. using MS Word, and then transferred into tables in rows and columns.

Stage 3. Organizing the emerging codes into meaningful categories

The initial categorical structure of the table was based on three of the interviews. The researchers had determined the categories from within the questions they had pre-established. Based on these identified categories, the analysis began with the direct quotations of participants who were anticipated to provide a diverse range of data to facilitate the analysis as much as possible (Ece, Gül, and Oya). These validated quotations were used to create the initial set of codes. If the existing codes did not fit the newly added direct quotations, their names in the table were changed. As a result, as new quotations were added, changes were made by redefining and reorganizing the content of existing codes and categories.

For instance, the first three excerpts that were chosen to fill in the content of the Physical Difficulties category created from the research question are provided below. From these direct quotations examined by researchers, the phrase used by Ece, '**don't sleep well**' and '**slept**' indicates sleep disturbance, the statement from Gül, '**the cartilage tissue of two of my ribs on the right side cracked**' indicates rib injury, and Oya's expression '**herniated disc**' were taken without alteration to determine the codes.

– I **don't sleep well**. Because my spouse keeps getting aspirations. For example, it happens from time to time, and I wake up every 10 minutes till dawn. We have been here for over two and a half years. I may have **slept** once or twice, resting peacefully from midnight until six a.m. At most, for half an hour. He has a cough, and I have to aspirate the phlegm (Ece).

– I was taking care of my father. I was the only one who was taking care of him. There was no one else looking after him. For the first three months, my mother took care of him. When some things in the village happened, she had to leave after that. I took care of him alone for two and a half years. I didn't have a **herniated disc**. It developed later. I have six plates on my back. I can't stand for a long time. I can't sit. I can't walk for an extended period. It affected me so much that I became unable to take care of my father, you know (Oya).

– Of course. Sometimes there's stiffness in Aunt's bones. At that point, she resists me unconsciously. I didn't expect her to resist so much one time. While trying to lift Aunt without lowering these (pointing to the bed rails), **the cartilage tissue of two of my ribs on the right side cracked** (Gül)."

Stage 4. Define the first category table

Participants							Category 1. Physical difficulties
Codes	Ece	Nur	Gül	Eda	Ela	Oya	
Pain	X	X	X	X	X	X	
Fatigue	X				X		
Foot swelling	X						
Rib injury			X				
Sleep disturbance	X				X		
Neglect their own check-ups	X				X	X	
Weakness	X				X	X	
Give up on self-care	X		X				
Herniated disc						X	
Impairment of quality of life						X	
Need someone	X					X	
The patient's gender				X		X	

Stage 5. Applying the initial theme to more data and making changes as needed

The theme of the research had been predicted to guide the analysis before the interview questions, which was likely. This theme was temporary, but as the analysis process progressed, it was re-evaluated and the predicted theme was confirmed.

Stage 6. Finalizing the table and applying it to the entire dataset

The transcripts were meticulously coded repeatedly by team members to ensure that no important data segment related to the research question(s) was left uncoded. As a result, thirty-one codes were generated and organized into five categories and one theme. The codes, categories, and themes that were established are presented in Table 3 of the findings section.