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"What if I Die Before Him?" Concerns of Caregivers in Palliative Care

"Ya Ondan Önce Ölürsem?" Palyatif Bakımda Bakımverenlerin Endişeleri

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Abstract

Aim: Caregivers are family members who provide unpaid assistance to their ill spouses. In Turkey, family caregiving, engagement, and support are needed when patients are hospitalized. This study aims to better understand the feelings of caregivers behind their behaviors in a terrier palliative care setting.

Material and Method: This research is a cross-sectional qualitative study designed with phenomenology. Five family caregivers who volunteered to participate were interviewed face-to-face. Inclusion criteria were adult informal caregivers who currently provided care to the patient at home and in the hospital.

Results: The family caregivers consist of five spouses with a mean age of 44.8±4.80 years. Each caregiver is a female and the spouse of the patient. Of the patients diagnosis was Alzheimer's disease, dementia, gastric cancer, and stroke, respectively. The caregiving time was approximately 2.79±1.62 years. Four themes and eleven subthemes were indicated: Concerns about themselves: Overestimating their health care problems, Anxiety about staying strong; Consequences of the patient: Remembering the patient like a "hero"; Acceptance of the situation Fear of "finding him death" Challenges about caregiving Sacrificing from life Excessive responsibility Embarrassment from diaper care Lack of orientation for caregiving at first Coping strategies Devine providence Religious beliefs.

Conclusion: The findings of the study indicate that family caregivers have concerns about themselves and the consequences of their roles. Even if they try to cope with spirituality, healthcare providers can support them by recognizing their essential roles.

Keywords: Palliative care, family caregivers, concerns, spirituality

Öz

Giriş: Bakımverenler, hastalarına ücretsiz yardım sağlayan aile üyeleridir. Türkiye'de hastalar hastaneye yatırıldığında aile bakımı, katılım ve desteğe ihtiyaç duyulmaktadır. Bu çalışma, palyatif bakım ortamında bakımverenlerin davranışlarının ardındaki duygularını daha iyi anlamayı amaçlamaktadır.

Gereç ve Yöntem: Bu araştırma fenomenoloji ile tasarlanmış kesitsel nitel bir çalışmadır. Katılmak için gönüllü olan beş yüz yüze görüşme yapıldı. Dahil etme kriterleri, hastaya evde ve hastanede bakım sağlayan yetişkin refakatçiler olarak belirlendi.

Bulgular: Bakımverenlerin yaş ortalaması 44,8±4,80 yıl olan beş kadından oluşmaktadır. Hastaların tanısı sırasıyla Alzheimer hastalığı, demans, mide kanseri ve inme idi. Bakım süresi yaklaşık 2,79±1,62 yıldı. Dört tema ve on bir alt tema belirtildi: Kendileriyle ilgili endişeler: Sağlık sorunlarını abartmak, Güçlü kalma kaygısı; Hastaya bağlı sonuçlar: Hastayı kahraman gibi hatırlamak; Durumun kabulü "Onu ölü bulma" korkusu; Bakıcılıkla ilgili zorluklar Hayattan fedakarlık, Aşırı sorumluluk, Bebek bezi bakımından utanç, bakım vermeye başladığında oryantasyon eksikliği Başa çıkma stratejileri Dini inançlar.

Sonuç: Çalışmanın sonucunda, bakımverenlerin kendileri ve rollerindeki sonuçlar hakkında endişeleri olduğunu göstermektedir. Maneviyatla başa çıkmaya çalışsalar bile, sağlık hizmeti sağlayıcıları temel rollerini kabul ederek onlara destek olabilirler.

Anahtar Kelimeler: Palyatif bakım, bakımverenler, endişeler, spirtualizm

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INTRODUCTION

The International Association for Hospice and Palliative Care developed a new way of understanding palliative care in a consensus-based manner and caregivers added not only patients but also caregiver quality of health to the description.[1]

Family caregivers in palliative care are defined as 'individuals who may be friends, relatives, or partners actively engaged in providing care for a patient confronting a severe, life-threatening illness'.[2] However, caring often presents itself as an exhausting and emotionally taxing burden, creating a situation where caregivers can struggle to distinguish between their personal needs and their responsibilities in providing care.[3] In the public health systems recently, there has been a reduction in the number of hospital beds, accompanied by a rise in outpatient care. This change has highlighted the growing importance of family caregivers within this system.[2] In addition, the literature emphasizes the importance of addressing the requirements of family caregivers engaged in palliative care. This importance is particularly evident in terms of providing them with information and directing them to resources for respite, financial assistance, education, and psychosocial support.[4]

Healthcare planning is often apart from the unmet needs of family caregivers, and in most cases support for caregivers is suboptimal. For people who need palliative care, family caregivers are likely to provide a high level of care for the rest of the patient's life. This can cause uncertainty in time and process, which can result in enormous stress and an impact on the caregiver's health.[5]

In the literature, there are many studies about the burden of caregivers, depression and anxiety disorders, and financial problems.[6,7] Also, there are studies about caregivers' financial problems.[8,9] The expectations, confidence, pain management challenges, and problems of family caregivers were tried in various studies.[5,10-12]

To deliver patient- and family-centred care within palliative care services, it is crucial to thoroughly evaluate the needs and anticipations of family caregivers.[13] This study aims to better understand the feelings of caregivers behind their behaviors.

METHOD

Study Design

In terms of exploring the unmet needs of family caregivers and to better understand their caregiving experiences, the phenomenological design was chosen. The selection of this study approach was justified due to the unique and innovative nature of the research. It was considered the most suitable method to address the research question, which was designed to understand the needs and perspectives of family caregivers in depth.[14]

Recruitment of Participants

To share specific knowledge about a phenomenon, researchers use purposeful sampling to select individuals to participate in a study.[15] For this reason, family caregivers were selected from whom patients were hospitalized in a palliative care unit. The inclusion criteria were informal adult caregivers (18 years or over), who currently provided a combination of unpaid physical and emotional care to the patient at home in addition to the hospital.

Conduct of the Study

The interviews were carried out by a single researcher after the approval of the clinical ethics committee (01.09.2019 – 01.12.2019); in a semi-structured individual format, ensuring privacy, and lasting approximately between 30 minutes and 1 hour. The researcher used clarification, reflection, and requests for examples of interview techniques as a matter of phenomenological method.[15] At the beginning of the interviews, participants were asked to provide their consent for voice recording. Following the initiation of the audio recording upon obtaining verbal consent, the participants were asked to share their experiences with their patients. Following this initial phase, the interviews continued using a semi-structured format, with the following questions: 1. What obstacles do you come across in the process of caring for the patient? 2. How emotionally respond to your current situation? 3. What strategies do you employ to manage and overcome these challenges? To gain a deeper understanding of informal caregiver feelings and unmet needs in palliative caregiving, six semi-structured interviews were conducted. Of these interviews, five were selected based on the richness of our research objectives and according to the interpretative phenomenological analysis methodology guidelines.[16]

Data Analysis

The data interpretation process involved the use of content analysis techniques. During the analysis phase, the collected data were initially transcribed from interviews and then encoded using abbreviations formed by the initials of the respective caregivers of the participant's family, identified as K1, K2, K3, etc. Subsequently, the transcribed data was meticulously examined line by line, leading to the identification of emerging themes and categories. This study has been analyzed following the phenomenological procedures proposed by Moustakas.[14] First, we read the transcripts for general understanding and listed each statement about the experience. This resulted in a list of 108 important statements directly related to the experience. Then, by limiting the important overlapping expressions, we found the invariant components. Next, we create units of meaning from immutable structures, which is the process of creating meaning from important expressions of participants. Our goal in these first analysis steps was not to distort the original meaning but to distinguish the meaning by thinking over verbatim phrases. Then, we clustered and created themes from units of meaning.

Ethical considerations

The study protocol conformed to ethical guidelines of the 1975 Declaration of Helsinki, approved by the Erzincan Binali Yıldırım University Faculty of Medicine Clinical Ethic Committee date 30/05/2019 and number 06.

RESULTS

Socio-demographic status of the participants: The family caregivers consist of five spouses with a mean age of 44.8±4.80 years, the youngest being 38 and the oldest 50 years. Each caregiver is a female and daughter or granddaughter of the patient. Of the patients enrolled in the study, their diagnosis was Alzheimer's disease, dementia, gastric cancer, and stroke, respectively. Their mean age was 63.00±5.10 years. The caregiving time was approximately 2.79±1.62 years. All patients had a performance status of 3 or 4 according to the WHO performance stage. This includes patients who spend most of their waking hours in bed (more than 50%) or are entirely bedridden and have limited or no ability to self-care. Regarding the socio-demographic profile, the educational level of caregivers was primary to secondary school and the socioeconomic level was low to middle in a rural setting (**Table 1**).

The themes and subthemes of the study: Four themes and eleven subthemes were indicated by the phenomenological method (**Table 2**).

Table 2. Presentation of themes and sub themes

Themes	Sub-themes
Concerns about themselves	Overestimating their health care problems
	Anxiety about staying strong
Consequences of the patient	Remembering the patient like a "hero"
	Acceptance of "patient won't get well"
	Fear of "finding him death"
Challenges about caregiving	Sacrificing from life
	Excessive responsibility
	Embarrassment from diaper care
	Lack of orientation for caregiving at first
Coping strategies	Devine providence
	Religious beliefs

Concerns About Themselves

At the beginning of the intervention, all caregivers started claiming their health status. At first sight, they seemed to focus on their health care problems to take some attention from the surrounding as all the attention is on the patient. As the conversation progresses, it is understood that their healthcare problems started right after giving the care. An additional question was added to the intervention: 'Do you think that the reason for your health care problems is caregiving? All of them denied it, they were careful while choosing the words to not blame the patient or the patient's bedriven situation. The problem is: 'They want to be healthy; they want to stay strong to continue caring.'

"*I also have lupus. I assure you, I'm following the prescribed medications, just like my grandmother. When I see her and compare it to my situation, it is a blessing* '**K1**

"*…I underwent hernia surgery. I mean, they did not waste any time – as soon as I got there, they rushed me to the operating room. However, now they continue to advise me on self-care, but what choice do I have? I need to take care of myself...*" **K2**

Consequences of the Patient

All caregivers have obstacles concerning the consequences of the patient. Some of them worry about 'finding him dead', while others are upset that their patient will not get well. On the other hand, all caregivers needed to talk about their patient's life before the illness and they all agreed that she was a stunning person.

"*The children are quite anxious; the girls and my son watch her closely all the time, wondering if she is getting worse or not. We've developed this habit over time.*"**K3**

"*I am very sorry. Our patient is deteriorating before our eyes.*" **K1**

'*Also, why is my father like this?' We value him very much...*' **K5**

Challenges About Caregiving

All caregivers struggled with some issues, especially at the beginning of their patient's disease, due to the lack of orientation of caregivers. Some others claimed about diaper change problems and find it embarrassing. The others talked about the sacrificed life they had, late marriages, less social life, etc.

Table 1. Sociodemographic properties of participants

Code	Patient age Gender	Patient Diagnosis	Caregivers' age Gender	Spouse	Duration of caregiving	Caregivers diagnosis	Education level of caregivers	Economic status of caregivers
K1	63 Female	Alzheimer	38 Female	Granddaughter	2 years	Systemıc Lupus Erythematosus	Primary school	Low income
K2	55 Female	Dementia, hypertension	46 Female	Daughter	5 years	Breast Cancer	Secondary school	Middle income
K3	67 Male	Gastric cancer	48 Female	Daughter	1.75 years	Hypertension	Primary school	Low income
K4	68 Female	Stroke	50 Female	Daughter	1.2 years	Endometrıum Cancer	Secondary school	Middle income
K5	62 Male	Stroke	42 Female	Daughter	4 years	Lumbal Hernı	Primary school	Middle income

"My brother and I look after her like a baby, I kiss and hold her as well. We cannot predict how the patient would react if something were to happen to us. ' **K4**

'We initially had problems taking the drugs, but after they took us to the list of bedridden patients, we had no problem with the healthcare system.' **K3**

I change diapers two times a day, it was difficult at first, but now I am used to it. **K2**

Coping Strategies

They remain strong, and the underlying reason for it was both religious beliefs. They never feel guilty or blame the patient. Instead, they think it is a gift from God to show their religious beliefs.

'Whatever God decrees will come true. I believe in divine fate, but I hope everything turns out well for our mother. It is not an easy situation. ' **K4**

DISCUSSION

This study revealed an essential understanding of the concerns, feelings, and coupling strategies of family caregivers among the burden of palliative care. The study sample was similar to the literature where most of the family caregivers are daughters of patients who are married women of middle age and unemployed, where their economic status is low to middle.[17,18]

Palliative caregivers face the task of not only preparing for caregiving responsibilities but also anticipating the dying of the patient.[2] Although caregivers were often confident about how to care for physical needs, they had difficulties understanding the dying process.[12] In this study, it is stated that even family members have the anxiety of finding the death of the patient, and it became a habit to control it. Habit means a kind of acceptance that the patient won't suffer. Also, in a study where the core components of the well-being of caregivers were investigated, acceptance was mentioned, which means the capacity to allow things to happen naturally.[19]

Family caregivers (FCs) care for bedriven patients and they are at risk of physical and psychological issues that can result in healthcare problems.[20] On the other hand, FCs also had to struggle with their own physical and psychological health status.[21] In this study, the dominant topic was the caregiver's concerns for themselves. They try to give the best care to themselves as well as to the patient as possible because they have the anxiety of leaving the patient without care. Regarding anxiety, in another study conducted by an outpatient oncology clinic, FCs documented higher rates of anxiety and depression than individuals with cancer.[10] As their loved one's health deteriorates, caregivers discover it increasingly challenging to step away and have a break. Despite the genuine need for respite, caregivers paradoxically feel compelled to maximize their time with their loved one, recognizing its finite nature.[22] That's the underlying reason they worry about leaving them without care.

The entire process transforms a spousal or parent-child dynamic into that of a caregiver and care recipient, where caregivers suspend their own lives to care for their loved ones.[22] That means sacrificing your social and private life spontaneously (**Table 2**) that cannot even go out freely, feeling dependent and bound strongly.

Spirituality was the most common strategy and naturally preferred couping strategy.[20,23] Similar to this study, even though FCs have various concerns and challenges, they feel strong and blessed with spirituality. Although in the literature, the specific findings of spirituality in palliative care are underestimated.[23,24]

CONCLUSION

The findings of the study indicate that family caregivers have concerns about themselves and the consequences of their roles. Even if they try to cope with spirituality, healthcare providers can support them by recognizing their essential roles; understanding their experiences and needs. These strategies aim to assist caregivers in managing their own lives and in effectively caring for the patient without burden.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Erzincan Binali Yıldırım University Clinical Researches Ethics Committee (Date: 30/05/2019, Decision No: 06/04).

Informed Consent: All patients signed the free and informed consent form.

Referee Evaluation Process: Externally peer-reviewed.

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REFERENCES

1. Radbruch L, De Lima L, Knaul F, et al. Redefining Palliative Care-A New Consensus-Based Definition. J Pain Symptom Manage. 2020;60(4):754-64.
2. Karolinska Institutet. Holm M. Promoting preparedness for family caregiving – a randomised controlled intervention in palliative care. [cited 2023 Aug 16]. Available from: https://core.ac.uk/download/pdf/70343928.pdf
3. Sayin Kasar K, Yildirim Y, Bulut U. Comfort Level in Caregivers of Palliative Care Patients and Affecting Factors: What Should We Know? Omega (Westport). 2023;86(4):1461-72.
4. McKibben L, Brazil K, McLaughlin D, Hudson P. Determining the informational needs of family caregivers of people with intellectual disability who require palliative care: A qualitative study. Palliat Support Care. 2021;19(4):405-14.

5. Hart NH, Crawford-Williams F, Crichton M, et al. Unmet supportive care needs of people with advanced cancer and their caregivers: A systematic scoping review. Crit Rev Oncol Hematol. 2022; 176:103728.
6. Vrettos I, Voukelatou P, Panayiotou S, et al. Factors Affecting Caregivers' Burden in a Sample of Greek Family Caregivers Caring for Older Adults. J Gerontol Soc Work. 2023 ;66(5):694-707.
7. Fauziah W, Kato M, Shogenji M, Tsujiguchi H, Taniguchi Y. Factors Associated with Depression Among Family Caregivers of Patients With Stroke in Indonesia: A Cross-Sectional Study. J Nurs Res. 2022;30(5): e231.
8. Gardiner C, Taylor B, Goodwin H, Robinson J, Gott M. Employment and family caregiving in palliative care: An international qualitative study. Palliat Med. 2022;36(6):986-93.
9. Thomas Hebdon MC, Phan CT, Phillips C, et al. Ethical and Policy Implications of Financial Burden in Family Caregivers. Journal of Hospice and Palliative Nursing: JHPN: the Official Journal of the Hospice and Palliative Nurses Association. 2022 ;24(5): 226-32.
10. Thomas Hebdon MC, Phan CT, Phillips C, et al. Ethical and Policy Implications of Financial Burden in Family Caregivers. Journal of Hospice and Palliative Nursing: JHPN: the Official Journal of the Hospice and Palliative Nurses Association. 2022 ;24(5): E226-E232.
11. Vestphal TK, Gildberg FA, Jørgensen R, Rowaert S, Tingleff EB. Experiences of family caregivers in forensic mental health care-A qualitative evidence synthesis. J Psychiatr Ment Health Nurs. 2023;30(4):663-78.
12. Soroka JT, Froggatt K, Morris S. Family Caregivers' Confidence Caring for Relatives in Hospice Care at Home: An Exploratory Qualitative Study. Am J Hosp Palliat Care. 2018;35(12):1540-6.
13. Fernandes JB, Domingos J, Castro C, et al. Needs and expectations of family caregivers of cancer patients in palliative care: A study protocol. Front Psychol. 2023,13:1071711.
14. Greening N. Phenomenological Research Methodology. Scientific Research Journal (Scirj) 2019;7(5):88-92.
15. Penner JL, McClement SE. Using Phenomenology to Examine the Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer: Reflections of a Novice Researcher. International Journal of Qualitative Methods 2008;7(2):92–101.
16. Mason N, Hodgkin S. Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers. Health Soc Care Community. 2019;27(4):926-35.
17. Chi NC, Nakad L, Han S, et al. Family Caregivers' Challenges in Cancer Pain Management for Patients Receiving Palliative Care. Am J Hosp Palliat Care. 2023;40(1):43-51.
18. Niu A, Guo C, Zhong D, et al. Identifying the Unmet Supportive Care Needs, with Concomitant Influencing Factors, in Family Caregivers of Cancer Patients in China. Asia Pac J Oncol Nurs. 2021;8(3):276-86.
19. Robertson SB, Hjörleifsdóttir E, Sigurðardóttir Þ. Family caregivers' experiences of end-of-life care in the acute hospital setting. A qualitative study. Scand J Caring Sci. 2022;36(3):686-98.
20. Cheng Q, Xu B, Ng MSN, Zheng H, So WKW. Needs assessment instruments for family caregivers of cancer patients receiving palliative care: a systematic review. Support Care Cancer. 2022;30(10):8441-8453.
21. Harding R, Epiphaniou E, Hamilton D, et al. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. Support Care Cancer. 2012;20(9):1975-82.
22. Pepin E, Hébert J. Needs of caregivers of patients receiving in-home palliative and end-of-life care. Can Oncol Nurs J. 2020;30(2):147-52.
23. Williams L, Dewes O, Gott M. I heard it on the radio: supporting Pacific family carers through the development of culturally appropriate resources, a descriptive qualitative study. Progress in Palliative Care. 2020;29:1-4.
24. Selman LE, Brighton LJ, Sinclair S, et al. InSpirit Collaborative. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. Palliat Med. 2018;32(1):216-30.