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PERSPECTIVES IN PALLIATIVE & HOME CARE

EDITORIAL / EDİTÖRDEN

Dear Readers,

We are delighted to present the latest issue of the Perspectives in Palliative & Home Care journal to you. Perspectives in Palliative & Home Care (PPHC) is an open-access, free, interdisciplinary journal that publishes articles in the fields of palliative and home care based on the principles of independent, unbiased, and double-blind peer review. Our journal reflects the interdisciplinary approach that forms the foundation of palliative and home care, addressing a wide range of specialties.

In this issue, we present three original research articles and one review article to our readers. The first original research article examines the psychosocial support experiences of patients with Hodgkin lymphoma undergoing chemotherapy using a phenomenological qualitative research design. The second study investigates the relationships among spirituality, psychological well-being, and care burden among family members providing home care to hemodialysis patients. The third research article evaluates care dependency and quality of life among patients receiving outpatient chemotherapy, as well as the burden on their caregivers. The review article in this issue discusses sarcopenia and nursing care-a critical topic in the palliative care process-from a comprehensive perspective.This issue also includes a case report detailing the palliative care process for a patient diagnosed with Chiari malformation. The review article comprehensively discusses how focusing on the individual needs of elderly patients forms the foundation of geriatric palliative care practices.

We would like to thank all our authors for contributing to the literature on palliative and home care by sharing their scientific work in the Perspectives in Palliative & Home Care journal, our reviewers for their meticulous evaluation of the articles submitted to our journal, and our editorial board members for their dedicated work throughout this process.

We look forward to seeing you in our next issue...

With our respect

Editors

Professor Rukuye AYLAZ, PhD

Associate Prof. Zeliha CENGİZ, PhD

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PERSPECTIVES IN PALLIATIVE & HOME CARE

Değerli Okurlarımız,

Perspectives in Palliative & Home Care Dergisi'nin yeni sayısı ile sizlerle buluşmanın mutluluğunu yaşıyoruz. *Perspectives in Palliative & Home Care* (PPHC); palyatif ve evde bakım alanlarında bağımsız, önyargısız ve çift-kör hakemlik ilkeleri çerçevesinde yayın yapan, açık erişimli, ücretsiz ve disiplinler arası bir dergidir. Dergimiz, palyatif ve evde bakımın temelini oluşturan disiplinler arası yaklaşımı yansıtarak farklı uzmanlık alanlarına hitap etmektedir.

Bu sayımızda üç özgün araştırma makalesi ve bir derleme makalesi okurlarımızla buluşmaktadır. Özgün araştırma makalelerinin ilki, kemoterapi alan Hodgkin lenfoma hastalarının psikososyal destek deneyimlerini fenomenolojik nitel bir araştırma tasarımıyla ele almaktadır. İkinci çalışma, hemodiyaliz hastalarına evde bakım veren aile bireylerinde maneviyat, psikolojik iyi oluş ve bakım yükü arasındaki ilişkileri incelemektedir. Üçüncü araştırma makalesi ise ayaktan kemoterapi alan hastaların bakım bağımlılığı ve yaşam kalitesi ile bakım verenlerin yükünü değerlendirmektedir. Bu sayımızdaki derleme makalesi ise palyatif bakım sürecinde kritik bir konu olan sarkopeni ve hemşirelik bakımını kapsamlı bir bakış açısıyla tartışmaktadır.

Bilimsel çalışmalarını *Perspectives in Palliative & Home Care* Dergisi ile paylaşarak palyatif ve evde bakım literatürüne katkı sağlayan tüm yazarlarımıza, dergimize gönderilen makaleleri titizlikle değerlendiren hakemlerimize ve bu süreçte özveriyle çalışan yayın kurulu üyelerimize teşekkür ederiz.

Bir sonraki sayımızda görüşmek dileğiyle...

Saygılarımızla,

Editörler

Prof. Dr. Rukuye AYLAZ

Doç. Dr. Zeliha CENGİZ

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Perspectives in Palliative & Home Care

Research Article/Araştırma Makalesi

Psychosocial Support Experiences of Patients with Hodgkin Lymphoma Receiving Chemotherapy: A Phenomenological Qualitative Study

Kemoterapi Alan Hodgkin Lenfoma Hastalarının Psikososyal Destek Deneyimleri: Fenomenolojik Bir Nitel Araştırma

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ABSTRACT

Background/ Objective: Hodgkin lymphoma is one of the hematological malignancies that affects not only individuals' physical health but also their psychological well-being and social lives. Although psychosocial support is a fundamental component of cancer care, qualitative evidence regarding how patients with Hodgkin lymphoma undergoing chemotherapy experience such support remains limited. This study was conducted to explore the psychosocial support experiences of patients with Hodgkin lymphoma undergoing chemotherapy.

Material and Methods: The study was conducted using a phenomenological qualitative research design. Data were collected through semi-structured individual interviews with 16 patients with Hodgkin lymphoma undergoing chemotherapy at a university hospital in Türkiye. The interviews were audio-recorded, transcribed verbatim, and analyzed using Braun and Clarke's thematic analysis approach.

Results: The analysis of the data yielded three overarching themes and nine subthemes. The first theme, "The Psychosocial Burden of Life Following Diagnosis," captured participants' experiences of shock and uncertainty, altered body image, and social isolation. The second theme, "Sources of Psychosocial Empowerment," encompassed support received from family, healthcare professionals, and peers. The third theme, "Regaining Strength and Reconstructing Meaning in Life," reflected participants' experiences of developing effective coping strategies, reassessing life priorities, and fostering hope for the future.

Conclusion: Psychosocial support plays a pivotal role in facilitating patients' adaptation to the chemotherapy process and strengthening the psychological resilience of individuals with Hodgkin lymphoma. Integrating family-centered approaches, nurse-led psychosocial support interventions, and structured peer support programs into routine oncology care is recommended to enhance comprehensive patient care.

Keywords: Hodgkin disease; psychosocial support; qualitative research; nursing.

ÖZ

Giriş/Amaç: Hodgkin lenfoma, bireylerin yalnızca fiziksel sağlığını değil, psikolojik ve sosyal yaşamlarını da etkileyen hematolojik malignitelerden biridir. Psikososyal destek, kanser bakımının önemli bir bileşeni olmasına rağmen, kemoterapi sürecindeki Hodgkin lenfoma hastalarının bu desteği nasıl deneyimlediğine ilişkin nitel kanıtlar sınırlıdır. Bu araştırma, kemoterapi tedavisi alan Hodgkin lenfoma hastalarının psikososyal destek deneyimlerini incelemek amacıyla yapılmıştır.

Gereç ve Yöntem: Araştırma fenomenolojik nitel araştırma deseninde yürütülmüştür. Veriler, Türkiye'de bir üniversite hastanesinde kemoterapi tedavisi alan 16 Hodgkin lenfoma hastası ile gerçekleştirilen yarı yapılandırılmış bireysel görüşmeler yoluyla toplanmıştır. Ses kayıtları yazıya aktarılmış ve Braun ve Clarke'ın tematik analiz yaklaşımı doğrultusunda analiz edilmiştir.

Bulgular: Verilerin analizi sonucunda üç ana tema ve dokuz alt tema belirlenmiştir. "Tanıyla Değişen Yaşamın Psikososyal Yükü" teması; şok ve belirsizlik, değişen beden algısı ve sosyal izolasyon deneyimlerini içermektedir. "Güç Veren Destek Kaynakları" teması; aile desteği, sağlık profesyonellerinin desteği ve akran desteğini kapsamaktadır. "Yeniden Güçlenme ve Yaşamı Anlamlandırma" teması ise baş etme stratejileri geliştirme, yaşam önceliklerini yeniden değerlendirme ve geleceğe yönelik umut duygularını içermektedir.

Sonuç: Psikososyal destek, Hodgkin lenfoma hastalarının kemoterapi sürecine uyum sağlamalarında ve psikolojik dayanıklılıklarını güçlendirmelerinde önemli bir role sahiptir. Onkoloji bakımında aile merkezli yaklaşımların, hemşire liderliğinde psikososyal destek programlarının ve akran destek uygulamalarının yaygınlaştırılması önerilmektedir.

Anahtar Kelimeler: Hodgkin lenfoma; psikososyal destek; nitel araştırma; hemşirelik.

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1. Introduction

Hodgkin lymphoma (HL) is a hematological malignancy of the lymphatic system and one of the most common cancers affecting young adults. Although advances in chemotherapy, targeted therapies, and supportive care have improved survival (American Cancer Society, 2025; NCI, 2025), patients continue to experience substantial physical, psychological, social, and emotional challenges (Ansell, 2024).

A cancer diagnosis is often perceived as a major life crisis characterized by uncertainty, fear of death, anxiety about the future, and loss of control (WHO, 2024). These challenges may be greater in HL because it commonly occurs during young adulthood, disrupting education, employment, family life, and social roles (Boland et al., 2022). Chemotherapy further contributes to psychosocial distress through fatigue, nausea, pain, infection risk, alopecia, altered body image, social isolation, perceived stigma, and emotional vulnerability (Rosenthal, 2022).

Psychosocial support is a core component of cancer care that promotes psychological well-being through emotional, informational, and practical support from family, friends, peers, and healthcare professionals (Milzer et al., 2023). Adequate support is associated with lower anxiety and depression, better treatment adherence, greater hope, and improved quality of life, whereas inadequate support contributes to psychological distress and poorer treatment experiences (NCCN, 2025; Zingler et al., 2025; Clothier et al., 2025).

Nurses play a key role in providing psychosocial support through continuous patient contact, empathetic communication, emotional support, education, and coping enhancement (Oncology Nursing Society, 2024). However, little is known about how patients with HL experience psychosocial support, which sources they perceive as most meaningful, and how these needs evolve during chemotherapy (Boland et al., 2022; Rosenthal, 2022). Although quantitative studies have examined quality of life, symptom burden, and psychological adjustment, qualitative evidence on psychosocial support experiences during chemotherapy remains scarce, particularly regarding support from family, peers, nurses, and other healthcare professionals.

Therefore, this study aimed to explore the psychosocial support experiences of patients with Hodgkin lymphoma undergoing chemotherapy. The findings may strengthen psychosocial oncology nursing care and inform patient-centered supportive care. The study addressed the following research question: “How do patients with Hodgkin lymphoma undergoing chemotherapy experience psychosocial support throughout their treatment journey?”

2. Methods

Study Design

This qualitative phenomenological study explored the psychosocial support experiences of patients with Hodgkin lymphoma undergoing chemotherapy. A phenomenological approach was used to examine participants’ lived experiences and the meanings they attributed to psychosocial support throughout chemotherapy. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Supplementary File 1).

Study Setting and Data Collection Period

The study was conducted in the outpatient day chemotherapy unit of a university hospital in southern Türkiye, where ambulatory chemotherapy is provided for patients with hematological malignancies. Data were collected between June and July 2026 through face-to-face, individual, in-depth interviews conducted in private settings.

Participants and Sampling

Participants were patients with Hodgkin lymphoma receiving treatment at the hospital’s Hematology Clinic. Purposive sampling was used to recruit adults (≥18 years) who had completed at least one chemotherapy cycle, were able to communicate in Turkish, and provided informed consent. Individuals with cognitive impairment or severe physical or psychiatric conditions affecting participation were excluded. Data collection and analysis were conducted concurrently. Saturation was achieved after 14 interviews, and two additional interviews confirmed no new codes, categories, or themes, resulting in a final sample of 16 participants. Data saturation was determined through concurrent data collection and analysis, with no new codes or concepts emerging during the final interviews. Two additional interviews confirmed thematic redundancy.

Data Collection Instruments

Data were collected using a researcher-developed Personal Information Form and Semi-Structured Interview Guide based on the literature. The Personal Information Form included sociodemographic and clinical characteristics. The interview guide explored experiences following diagnosis and during chemotherapy, sources of psychosocial support, perceptions of nursing care, and coping strategies. It was reviewed by experts in oncology nursing and

qualitative research to ensure content validity and clarity. Minor revisions were made based on expert feedback to improve clarity, comprehensiveness, and the logical sequence of interview questions prior to data collection.

Data Collection Procedure

Face-to-face, individual, in-depth interviews lasting approximately 20–30 minutes were audio-recorded with participants' informed consent. The researcher used probing questions to encourage detailed responses, while field notes documented nonverbal behaviors, emotional responses, and contextual observations. Interviews were transcribed verbatim for thematic analysis. Field notes were reviewed alongside interview transcripts during analysis to enrich contextual interpretation and support theme development.

Data Analysis

Data were analyzed using Braun and Clarke's six-phase thematic analysis. Interviews were transcribed verbatim, checked against the recordings, and repeatedly read for familiarization. Meaningful units were identified through line-by-line coding, and related codes were grouped into potential themes and subthemes. These were iteratively reviewed, refined, defined, and named to ensure coherence and distinctiveness. Initially, transcripts were coded line by line. Similar codes were then grouped into categories, which were subsequently refined into subthemes and overarching themes through iterative comparison and team discussions. The researchers coded the data independently and resolved differences through discussion and consensus. Representative quotations were used to support the findings. The analysis resulted in three overarching themes and nine subthemes. Any discrepancies were resolved through iterative discussion until consensus was achieved, ensuring consistency and credibility of the analytical process.

Trustworthiness

Trustworthiness was established according to Lincoln and Guba's criteria of credibility, transferability, dependability, and confirmability. Credibility was supported through rapport-building, probing questions, and repeated review of transcripts and interpretations. Transferability was enhanced by detailed descriptions of the participants, setting, data collection, and analysis.

Dependability was ensured through systematic documentation, an audit trail, and independent coding followed by consensus. Confirmability was strengthened through reflexivity, representative quotations, and transparent documentation to ensure that interpretations remained grounded in participants' accounts. Prior to data collection, the research team discussed and documented their pre-existing assumptions regarding psychosocial support experiences. These reflections were revisited throughout analysis to ensure that interpretations remained grounded in participants' narratives. In addition, an audit trail documenting analytical decisions was maintained throughout the study, and regular peer debriefing sessions were conducted to enhance analytical rigor and confirmability.

Ethical Considerations

Ethical approval was obtained from Akdeniz University Medical Scientific Research Ethics Committee (Approval No.: TBAEK-490; Date: 04.06.2026), and institutional permission was granted by the healthcare institution where the study was conducted. The research adhered to the principles of the Declaration of Helsinki.

Before participation, all participants received detailed information about the study, including its purpose, interview procedures, audio recording, confidentiality, and the use of data for research purposes. Written and verbal informed consent were obtained prior to data collection. Participants were informed that participation was voluntary, that they could withdraw at any time without consequence, and that their decision would not affect their treatment or healthcare.

To ensure confidentiality, interviews were conducted in private settings, and all recordings, transcripts, and research data were stored in password-protected files accessible only to the research team. Participants were anonymized using identification codes (e.g., P1, P2, P3), and all data were managed and reported in accordance with internationally accepted principles of research integrity and publication ethics.

3. Result

Participant Characteristics

A total of 16 patients with Hodgkin lymphoma undergoing active chemotherapy participated in the study. Participants were aged 22–44 years (mean: 32.8 ± 8.7 years). Most were female (56.3%, n=9), single (56.3%, n=9), had completed higher education (75.0%, n=12), and were not actively employed (56.3%, n=9). Most had been diagnosed within the previous six months (68.8%, n=11), had completed three or more chemotherapy cycles (68.8%, n=11), and had received chemotherapy-related education (75.0%, n=12). Nearly all participants lived with their families (93.8%, n=15). Family members were the primary source of psychosocial support (68.8%,

n=11), followed by friends (56.3%, n=9), whereas only 31.3% (n=5) had received professional psychological support.

Table 1. Sociodemographic and Disease-Related Characteristics of the Participants (N=16)

Characteristics	n	%
Age group (years)		
18–25	4	25.0
26–35	6	37.5
36–45	4	25.0
46–55	2	12.5
Mean age (years), mean ± SD	32.8 ± 8.7	
Gender		
Female	9	56.3
Male	7	43.7
Marital status		
Single	9	56.3
Married	7	43.7
Educational level		
High school	4	25.0
College/University	1	62.5
Master's/Doctoral degree	2	12.5
Occupation		
Student	4	25.0
Government employee/Worker	5	31.3
Self-employed	3	18.7
Homemaker	2	12.5
Other	2	12.5
Employment status		
Employed full-time	5	31.3
Employed part-time	2	12.5
Unemployed	9	56.2
Health insurance		
Yes	1	100.0
No	0	0.0
Perceived income level		
Income less than expenses	5	31.3
Income equal to expenses	9	56.2
Income greater than expenses	2	12.5
Self-rated health status		
Good	3	18.7
Fair	1	62.5
Poor	3	18.8
Time since diagnosis		
0–3 months	5	31.3
4–6 months	6	37.5
7–12 months	4	25.0
>12 months	1	6.2
Total number of chemotherapy cycles received		
1–2 cycles	4	25.0
3–4 cycles	6	37.5
5–6 cycles	5	31.3
≥7 cycles	1	6.2
Received education about chemotherapy		
Yes	1	75.0
No	4	25.0
Received psychological support		
Yes	5	31.3
No	1	68.7
People living with the participant*		
Living with parents	7	43.8
Living with spouse	6	37.5
Living with children	3	18.8
Living alone	2	12.5
Primary sources of support during the illness*		
Family members	1	93.8
Healthcare professionals	1	68.8
Friends	9	56.3
Other patients	4	25.0

Note. Participants were allowed to select more than one response; therefore, percentages exceed 100%.

Themes

Thematic analysis identified three overarching themes and nine subthemes describing participants' psychosocial support experiences: (1) The Psychosocial Burden of Life Following Diagnosis, (2) Sources of Psychosocial Empowerment, and (3) Regaining Strength and Reconstructing Meaning in Life. The themes, subthemes, and representative participant quotations are presented in Table 2.

Table 2. Development of Themes, Subthemes, and Representative Participant Quotations

Main Themes	Subthemes	Representative Participant Quotations
The Psychosocial Burden of Life Following Diagnosis	The Shock and Uncertainty of Diagnosis	"I had no idea how long I was going to live. The uncertainty frightened me even more than the disease itself." (P1) "The moment the doctor said 'lymphoma,' everything became a blur. It felt as though my life had been divided into two parts—before and after." (P5) "At that moment, all I could think about was my children. I was terrified that I might not live long enough to see their future." (P9) "When I learned that I had cancer, the first thing that crossed my mind was whether I was going to die." (P11)
	Confronting a Changing Body	"When my hair started falling out, that was when I truly accepted that I was ill." (P3) "I used to be a very active person. Now, even a short walk leaves me exhausted." (P8) "It felt as though my body no longer belonged to me." (P14) "When I looked in the mirror, I could hardly recognize myself." (P15)

	Social Withdrawal and Loneliness	“Everyone called and checked on me at first, but as time passed, I was left alone.” (P2) “I stopped seeing my friends as often because I simply didn’t feel well.” (P7) “Even when I was surrounded by people, I still felt alone.” (P12) “I chose not to tell anyone what I was going through because I didn't want to be a burden.” (P14)
Sources of Psychosocial Empowerment	The Unconditional Presence of Family	“My father never showed it, but I knew he was more frightened than I was. Even so, he never left my side.” (P4) “My mother was with me during every chemotherapy session. Simply knowing she was there comforted me more than the treatment itself.” (P6) “I could not have gotten through this without my spouse. When I was no longer strong enough, my spouse became my strength.” (P9) “My sibling called me every night. Those conversations kept my spirits up.” (P15) “My family made me realize that I was not alone. We experienced this illness together.” (P16)
	Healthcare Professionals Who Fostered a Sense of Being Understood	“Sometimes, simply having someone listen to me was enough. The nurses were the people I could talk to about my fears.” (P1) “On the days when I felt my worst, even their smile made me feel better.” (P3) “Knowing what to expect at every stage of the treatment reduced my anxiety.” (P5) “The way they answered my questions patiently made me feel valued.” (P10) “I remember them not as the people who inserted the needle, but as the people who gave me hope.” (P12)
	Drawing Strength from Shared Experiences	“Seeing that they had made it through gave me confidence that I could make it too.” (P2) “My family supported me, but someone who had actually lived through the illness understood me in a completely different way.” (P11) “Talking to someone who had experienced what I was going through was different. I truly felt understood.” (P7) “Listening to the experiences of people who had gone through the same journey made me feel more at ease.” (P13) “Meeting people who had recovered gave me hope.” (P15)
Regaining Strength and Reconstructing Meaning in Life	Developing Coping Strategies	“I set small goals for myself every day. That was how I kept going.” (P4) “Praying gave me strength.” (P6) “I learned to live one day at a time.” (P8) “I learned to accept the things I could not control. That brought me peace.” (P10) “I tried to stay away from negative thoughts.” (P11)
	A Changed Perspective on Life	“I think I have become a calmer and more patient person.” (P5) “I realized that I had been putting life off all along.” (P9) “I came to understand that many of the things I once considered important were not really important after all.” (P13) “I learned that health is more important than anything else.” (P14) “Cancer taught me how precious life really is.” (P16)
	Hope for the Future and Personal Empowerment	“There are so many things I want to do once my treatment is over.” (P2) “I feel stronger than I was before.” (P3) “I believe a new life is waiting for me now.” (P5) “This journey broke me, but it also made me stronger.” (P8) “I am trying to look toward the future with hope rather than fear.” (P16)

Theme 1. The Psychosocial Burden of Life Following Diagnosis

Participants described the diagnosis of Hodgkin lymphoma as a life-changing event marked by uncertainty, fear of death, and disruption of body image and social life. This theme comprised three subthemes: “The Shock and Uncertainty of Diagnosis,” “Confronting a Changing Body,” and “Social Withdrawal and Loneliness.”

Subtheme 1.1. The Shock and Uncertainty of Diagnosis

Most participants described the diagnosis as an unexpected and overwhelming experience characterized by uncertainty, fear of death, and anxiety about the future.

“I had no idea how long I was going to live. The uncertainty frightened me even more than the disease itself.” (P1)

"The moment the doctor said 'lymphoma,' everything became a blur. It felt as though my life had been divided into two parts—before and after." (P5)
"At that moment, all I could think about was my children. I was terrified that I might not live long enough to see their future." (P9)
"When I learned that I had cancer, the first thing that crossed my mind was whether I was going to die." (P11)
These accounts portray the diagnosis as an existential event that disrupted participants' sense of security and future expectations.

Subtheme 1.2. Confronting a Changing Body
Participants described chemotherapy-related physical changes as profoundly affecting body image, self-perception, and self-confidence, with hair loss and reduced physical strength serving as visible reminders of the illness.
"When my hair started falling out, that was when I truly accepted that I was ill." (P3)
"I used to be a very active person. Now, even a short walk leaves me exhausted." (P8)
"It felt as though my body no longer belonged to me." (P14)
"When I looked in the mirror, I could hardly recognize myself." (P15)
These experiences reflected psychological as well as physical losses, challenging participants' identity and sense of self.

Subtheme 1.3. Social Withdrawal and Loneliness
Participants reported that the illness disrupted their social relationships, leading to reduced social participation and persistent loneliness during chemotherapy.
"Everyone called and checked on me at first, but as time passed, I was left alone." (P2)
"I stopped seeing my friends as often because I simply didn't feel well." (P7)
"Even when I was surrounded by people, I still felt alone." (P12)
"I chose not to tell anyone what I was going through because I didn't want to be a burden." (P14)
These narratives suggest that Hodgkin lymphoma contributed to both social isolation and emotional loneliness throughout treatment.

Theme 2. Sources of Psychosocial Empowerment
Participants highlighted social support as essential for coping with the physical and psychological challenges of chemotherapy. Family members, healthcare professionals, and peers were perceived as key sources of support throughout treatment. This theme comprised three subthemes: "The Unconditional Presence of Family," "Healthcare Professionals Who Fostered a Sense of Being Understood," and "Drawing Strength from Shared Experiences."

Subtheme 2.1. The Unconditional Presence of Family
Participants consistently identified family as their primary source of psychosocial support. The presence, emotional support, and caregiving provided by parents, spouses, and siblings fostered security and emotional stability during chemotherapy.
"My father never showed it, but I knew he was more frightened than I was. Even so, he never left my side." (P4)
"My mother was with me during every chemotherapy session. Simply knowing she was there comforted me more than the treatment itself." (P6)
"I could not have gotten through this without my spouse. When I was no longer strong enough, my spouse became my strength." (P9)
"My sibling called me every night. Those conversations kept my spirits up." (P15)
"My family made me realize that I was not alone. We experienced this illness together." (P16)
These accounts indicate that family support extended beyond practical care by fostering security, belonging, hope, and resilience.

Subtheme 2.2. Healthcare Professionals Who Fostered a Sense of Being Understood
Participants emphasized that healthcare professionals, particularly nurses, provided emotional support through empathetic communication, clear information, and compassionate care.
"Sometimes, simply having someone listen to me was enough. The nurses were the people I could talk to about my fears." (P1)
"On the days when I felt my worst, even their smile made me feel better." (P3)
"Knowing what to expect at every stage of the treatment reduced my anxiety." (P5)
"The way they answered my questions patiently made me feel valued." (P10)
"I remember them not as the people who inserted the needle, but as the people who gave me hope." (P12)
Participants viewed nurses as a source of trust, reassurance, and emotional security, with compassionate communication helping to reduce anxiety and facilitate treatment.

Subtheme 2.3. Drawing Strength from Shared Experiences
Several participants described peer support as an important source of emotional reassurance and hope. Meeting survivors or others who had successfully completed treatment strengthened their confidence in recovery.
"Seeing that they had made it through gave me confidence that I could make it too." (P2)
"My family supported me, but someone who had actually lived through the illness understood me in a completely different way." (P11)

"Talking to someone who had experienced what I was going through was different. I truly felt understood." (P7)
"Listening to the experiences of people who had gone through the same journey made me feel more at ease." (P13)
"Meeting people who had recovered gave me hope." (P15)
These accounts suggest that peer support reduced loneliness while fostering hope, emotional adjustment, and resilience.

Theme 3. Regaining Strength and Reconstructing Meaning in Life

Participants described the illness not only as a period of hardship but also as an opportunity for personal growth and meaning reconstruction. Over time, they developed adaptive coping strategies, reassessed their priorities, and regained hope for the future. This theme comprised three subthemes: "Developing Coping Strategies," "A Changed Perspective on Life," and "Hope for the Future and Personal Empowerment."

Subtheme 3.1. Developing Coping Strategies

Participants described using psychological and behavioral strategies to cope with treatment-related challenges, helping them manage emotional distress, maintain a sense of control, and adapt to chemotherapy.
"I set small goals for myself every day. That was how I kept going." (P4)
"Praying gave me strength." (P6)
"I learned to live one day at a time." (P8)
"I learned to accept the things I could not control. That brought me peace." (P10)
"I tried to stay away from negative thoughts." (P11)
These narratives suggest that adaptive coping strategies reduced emotional burden, supported psychological adjustment, and helped participants maintain hope throughout treatment.

Subtheme 3.2. A Changed Perspective on Life

Participants described the illness as a transformative experience that reshaped their priorities and values, leading to a greater appreciation of the present and of what truly mattered.
"I think I have become a calmer and more patient person." (P5)
"I realized that I had been putting life off all along." (P9)
"I came to understand that many of the things I once considered important were not really important after all." (P13)
"I learned that health is more important than anything else." (P14)
"Cancer taught me how precious life really is." (P16)
These accounts indicate that the illness became not only a source of suffering but also a catalyst for personal growth, self-awareness, and meaning reconstruction.

Subtheme 3.3. Hope for the Future and Personal Empowerment

Despite treatment challenges, participants described maintaining hope and gradually regaining strength as they began to envision life beyond cancer.
"There are so many things I want to do once my treatment is over." (P2)
"I feel stronger than I was before." (P3)
"I believe a new life is waiting for me now." (P5)
"This journey broke me, but it also made me stronger." (P8)
"I am trying to look toward the future with hope rather than fear." (P16)

For participants, hope represented not only recovery but also confidence in rebuilding their lives and pursuing future goals. Together with adaptive coping resources, psychosocial support strengthened resilience, personal empowerment, and psychological recovery throughout the cancer journey.

4. Discussion

This study explored the psychosocial support experiences of patients with Hodgkin lymphoma undergoing chemotherapy and identified three overarching themes: The Psychosocial Burden of Life Following Diagnosis, Sources of Psychosocial Empowerment, and Regaining Strength and Reconstructing Meaning in Life. The findings indicate that Hodgkin lymphoma is experienced not only as a biological disease but also as a life-changing event that profoundly affects psychological, social, and existential well-being. This is consistent with previous studies showing that hematological malignancies influence identity, social roles, and life meaning in addition to physical health (Goswami et al., 2020; Li et al., 2025).

The first theme, "The Psychosocial Burden of Life Following Diagnosis," highlighted uncertainty, fear of death, and loss of control following diagnosis. Mishel's Uncertainty in Illness Theory suggests that psychological adjustment is impaired when individuals cannot predict or understand the course of their illness (Mishel, 1988; Zhang, 2017). Likewise, psychological distress is greatest immediately after diagnosis and treatment initiation among patients with hematological malignancies (Muzzatti et al., 2020). Although Hodgkin lymphoma has high cure rates, patients commonly fear mortality, disease progression, and disruption of future life plans (McGrady et al., 2024), a pattern also reflected in the present findings.

Chemotherapy-related physical changes also emerged as a key psychosocial challenge. Hair loss, reduced physical strength, and altered appearance diminished self-confidence and negatively affected

body image. Body image is an important but often overlooked aspect of the cancer experience (Ivanova et al., 2023), particularly among young adults, for whom appearance-related changes can adversely affect self-esteem, intimate relationships, and social interactions (Mehnert-Theuerkauf et al., 2024). These findings highlight the need to address chemotherapy-related physical changes as psychosocial as well as medical concerns.

Social isolation and loneliness also emerged as prominent experiences during treatment. Participants reported disrupted social roles, weakened friendships, and persistent loneliness throughout chemotherapy. Previous studies have linked social isolation in patients with hematological malignancies to increased depression, anxiety, and poorer quality of life (Liang et al., 2022; Weis, 2015). Reduced social interaction due to immunosuppression, together with reluctance to burden others, may further intensify loneliness (Badger et al., 2023). Consistent with these findings, participants experienced loneliness as both physical isolation and emotional disconnection, highlighting the need to address both dimensions in psychosocial care.

The second theme, "Sources of Psychosocial Empowerment," highlighted the importance of social support for psychological adjustment. Family was consistently identified as the primary source of support. According to Social Support Theory, perceived social support is a key determinant of psychological well-being (Harris et al., 2017), and family support enhances resilience, reduces depressive symptoms, and improves treatment adherence among patients with cancer (Schnabel et al., 2023; Mehnert-Theuerkauf et al., 2024). Consistent with these findings, participants described family support as fostering security, belonging, and hope, emphasizing the importance of family-centered oncology care.

Healthcare professionals, particularly nurses, also emerged as key sources of psychosocial support. Empathetic communication, clear information, and emotional support facilitated psychological adjustment. Therapeutic communication has been shown to reduce psychological distress and improve patient satisfaction (Harris et al., 2020; Rosenzweig et al., 2024). Accordingly, nurses play a crucial role in building trust, reducing uncertainty, and promoting emotional well-being through compassionate, patient-centered care (Mackay et al., 2023).

Peer support also contributed to psychosocial empowerment. Participants reported that interactions with individuals with similar experiences fostered understanding, hope, and reassurance. Previous studies show that peer support reduces loneliness, strengthens coping (Kiemen et al., 2023), and improves psychological well-being and self-efficacy among patients with hematological malignancies (Milzer et al., 2023). Participants likewise viewed peer relationships as an important source of resilience.

The third theme, "Regaining Strength and Reconstructing Meaning in Life," reflected participants' psychological adjustment through redefining priorities, adopting adaptive coping strategies, and maintaining hope. These findings are consistent with posttraumatic growth theory, which describes positive psychological change following traumatic experiences (Zhang, 2017). Previous studies similarly report that cancer can increase appreciation of life, strengthen relationships, and enhance resilience (Burney et al., 2019; Casellas-Grau et al., 2017).

Hope emerged as a key resource for resilience. Higher hope is associated with more adaptive coping and lower psychological distress in oncology (Zingler et al., 2025; Rustøen et al., 2023; Gallagher et al., 2024). Participants likewise described hope as essential for rebuilding their lives.

Overall, these findings support systematic assessment of psychosocial needs from diagnosis. Early identification of psychological distress, family-centered interventions, nurse-led psychosocial care, and integration of peer support into routine oncology practice may improve psychological well-being, treatment adherence, adjustment, and quality of life in patients with Hodgkin lymphoma.

Strengths and Limitations

A major strength of this study is its in-depth exploration of the psychosocial support experiences of patients with Hodgkin lymphoma undergoing chemotherapy from their own perspectives. Using a phenomenological approach and in-depth interviews provided a rich understanding of patients' lived experiences, while examining family, healthcare professional, and peer support together offered a comprehensive view of psychosocial support throughout the cancer journey.

This study has several limitations. As it was conducted at a single center with a relatively small sample, the findings are not readily generalizable to other settings. In addition, only patients receiving active chemotherapy were included, limiting insights into the experiences of long-term survivors and individuals in the post-treatment survivorship phase. Despite these limitations, the findings provide valuable evidence to support the development of more comprehensive, patient-centered oncology care.

5. Conclusions

This study identified three overarching themes describing the psychosocial support experiences of patients with Hodgkin lymphoma undergoing

chemotherapy: “The Psychosocial Burden of Life Following Diagnosis,” “Sources of Psychosocial Empowerment,” and “Regaining Strength and Reconstructing Meaning in Life.” The findings demonstrate that Hodgkin lymphoma and its treatment affect psychological, social, and emotional well-being as profoundly as physical health. Support from family members, healthcare professionals, and peers promoted treatment adaptation, resilience, hope, and the development of adaptive coping strategies. These findings emphasize the importance of systematically assessing psychosocial needs from the time of diagnosis. Integrating family-centered care, nurse-led psychosocial interventions, peer support, and professional psychological counseling into routine oncology practice may enhance holistic, patient-centered care. Future multicenter qualitative and mixed-methods studies across diverse settings are needed to strengthen the transferability and applicability of these findings.

Conflict of Interest

The authors declare no conflicts of interest.

Author Contributions

Study concept: MGS; Study design: MGS; HB; Data collection: MGS; HB; Literature search: MGS; HB; Data analysis and interpretation: MGS; Manuscript preparation: MGS; Critical review: HB; OS.

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Perspectives in Palliative & Home Care

Research Article/Araştırma Makalesi

Investigation of the Associations Among Spirituality, Psychological Well-Being, and Caregiver Burden Among Family Caregivers of Hemodialysis Patients

Hemodiyaliz Hastalarına Evde Bakım Veren Aile Bireylerinde Maneviyat, Psikolojik İyi Oluş ve Bakım Yükü Arasındaki İlişkilerin İncelenmesi

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ABSTRACT

Background/ Objective: Family caregivers providing home care for hemodialysis patients experience significant physical and psychosocial challenges during the caregiving process. This study aimed to investigate the associations among spirituality, psychological well-being, and caregiver burden and to examine the factors associated with caregiver burden among family caregivers.

Materials and Methods: This cross-sectional analytical study was conducted with 223 family caregivers providing home care for patients receiving hemodialysis at a university hospital. Data were collected using the Personal Information Form, the Spiritual Orientation Scale, the Psychological Well-Being Scale, and the Primary Caregiver Burden Scale for Patients Receiving Hemodialysis. Data were analyzed using descriptive statistics, correlation analysis, and hierarchical multiple linear regression analysis.

Results: A significant positive correlation was found between caregiver burden and spirituality ($r=0.406$, $p< 0.001$), as well as between caregiver burden and psychological well-being ($r=0.407$, $p< 0.001$). Hierarchical regression analysis showed that spiritual orientation remained significantly associated with caregiver burden after adjustment for sociodemographic characteristics ($\beta = 0.150$, $p < 0.001$), whereas psychological well-being was not independently associated with caregiver burden ($p > 0.05$). In addition, age, employment status, relationship to the patient, and duration of caregiving were significantly associated with caregiver burden.

Conclusion: Spiritual orientation was independently associated with caregiver burden among family caregivers of hemodialysis patients. Considering spiritual, psychosocial, and sociodemographic characteristics together in the assessment of family caregivers may contribute to the early identification of individuals at risk and the planning of supportive interventions.

Keywords: Hemodialysis; family caregivers; caregiver burden; spirituality; psychological well-being.

ÖZ

Giriş/Amaç: Hemodiyaliz hastalarına evde bakım veren aile bireyleri bakım sürecinde önemli fiziksel ve psikososyal güçlüklerle karşılaşmaktadır. Bu araştırmada, aile bakım verenlerinde maneviyat, psikolojik iyi oluş ve bakım yükü arasındaki ilişkilerin incelenmesi ve bakım yükü ile ilişkili faktörlerin incelenmesi amaçlandı.

Gereç ve Yöntem: Kesitsel ve analitik tipteki araştırma, bir üniversite hastanesinde hemodiyaliz tedavisi gören hastalara evde bakım veren 223 aile bireyi ile gerçekleştirildi. Veriler Kişisel Bilgi Formu, Manevi Yönelim Ölçeği, Psikolojik İyi Oluş Ölçeği ve Hemodiyaliz Tedavisi Alan Hastada Birincil Bakım Veren Yükü Ölçeği kullanılarak toplandı. Veriler tanımlayıcı istatistikler, korelasyon analizi ve hiyerarşik çoklu doğrusal regresyon analizi ile değerlendirildi.

Bulgular: Bakım yükü ile manevi yönelim ($r=0.406$, $p< 0.001$) ve psikolojik iyi oluş ($r=0.407$, $p< 0.001$) arasında pozitif yönde anlamlı ilişki bulundu. Regresyon analizinde manevi yönelim, sosyodemografik özellikler kontrol edildikten sonra bakım yükü ile anlamlı düzeyde ilişkili kalırken ($\beta = 0.150$, $p < 0.001$), psikolojik iyi oluş bakım yükü ile bağımsız olarak ilişkili değildi ($p > 0.05$). Yaş, çalışma durumu, bakım verilen kişiyle yakınlık derecesi ve bakım verme süresi bakım yükü ile anlamlı ilişkili bulundu.

Sonuç: Manevi yönelim, hemodiyaliz hastalarına bakım veren aile bireylerinde bakım yükü ile bağımsız olarak ilişkili bulundu. Bakım verenlerin değerlendirilmesinde manevi, psikososyal ve sosyodemografik özelliklerin birlikte ele alınması, risk altındaki bireylerin belirlenmesine ve destekleyici girişimlerin planlanmasına katkı sağlayabilir.

Anahtar Kelimeler: Hemodiyaliz; aile bakım veren; bakım yükü; maneviyat; psikolojik iyi oluş.

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1. Introduction

Chronic kidney disease (CKD) is a major public health problem due to its increasing prevalence, the need for long-term treatment, and the burden it imposes on healthcare systems. Hemodialysis, one of the most commonly used renal replacement therapies for individuals with end-stage kidney disease, affects not only patients but also family members who actively participate in the caregiving process. Owing to regular dialysis sessions, medication use, dietary and fluid restrictions, and the need for daily living support, family members become an integral part of the caregiving process (Kovesdy, 2022; Francis et al., 2024).

Family caregivers of hemodialysis patients may experience various physical, psychological, social, and economic challenges due to the continuous nature of caregiving. This multidimensional strain is defined as caregiver burden. Caregiver burden among individuals caring for patients with end-stage kidney disease has been shown to be influenced by numerous sociodemographic and psychosocial factors (Alshammari et al., 2021). Furthermore, caregiver burden has been reported to negatively affect quality of life, increase depressive symptoms, and reduce overall well-being (Skoulatou et al., 2024; Askaryzadeh Mahani et al., 2023). In addition, caregiver burden has been reported to be common and to occur at moderate-to-high levels among family caregivers of hemodialysis patients (Azeez & Ambatipudi, 2024; Al Maqbali et al., 2024).

The caregiving process involves more than providing physical care alone. Caregivers also meet the emotional needs of patients and support their adherence to treatment. The caregiving experience has been reported to be perceived by family members as both a source of threat and an opportunity for adaptation (Ebadi et al., 2021). Moreover, informal caregivers have been shown to play a critical role in dialysis care; however, this role has substantial effects on caregiver burden, quality of life, and patient outcomes (Driehuis et al., 2024; Tong et al., 2013).

In recent years, interest in psychosocial factors associated with caregiver burden has increased. One of these factors is spirituality, a broad concept encompassing individuals' search for meaning, purpose, hope, and connection when coping with life challenges. Related constructs, including spiritual well-being and religious coping, have been examined in previous caregiver studies. For example, spiritual well-being has been reported to be significantly associated with caregiver burden, while spiritual well-being and religious coping have also been identified as relevant factors in caregivers' responses to demanding care situations (Rafati et al., 2020; Mirhosseini et al., 2024). Although these constructs are conceptually related, they are not interchangeable. In the present study, spirituality was specifically operationalized as spiritual orientation, as measured by the Spiritual Orientation Scale. Accordingly, the term "spiritual orientation" is used when referring to the variable examined in the present study, whereas "spiritual well-being" and "religious coping" are retained only when describing findings from studies that specifically assessed these constructs.

Another important factor thought to be associated with caregiver burden is psychological well-being. Psychological well-being encompasses positive psychological functioning, including finding meaning in life, establishing positive relationships, coping effectively with environmental challenges, and experiencing life satisfaction. Long-term caregiving responsibilities are known to challenge individuals' psychological resources. Caregivers' quality of life has been reported to be influenced by caregiving duration and socioeconomic factors, while family resilience has been shown to play an important role in caregiver burden (Zimbudzi et al., 2024; Zhang et al., 2024). These findings indicate that psychological well-being and family psychosocial resources are closely associated with caregiver burden.

Although previous studies have examined caregiver burden in relation to spiritual well-being, psychological well-being, and other psychosocial factors, these relationships have commonly been investigated in separate or more limited conceptual models (Rafati et al., 2020; Bakır et al., 2026; Prima et al., 2023). Evidence simultaneously examining spiritual orientation, psychological well-being, caregiver burden, and relevant sociodemographic characteristics within the same analytical framework among family caregivers of hemodialysis patients remains limited. Therefore, examining these psychosocial and sociodemographic factors together may provide a more comprehensive understanding of the characteristics associated with caregiver burden. Variables such as age, educational level, employment status, income level, relationship to the care recipient, and duration of caregiving may be associated with caregiver burden. Therefore, investigating psychosocial and sociodemographic factors associated with caregiver burden together may contribute to the identification of caregivers at risk and the development of more effective support programs.

This study aimed to investigate the relationships among spiritual orientation, psychological well-being, and caregiver burden among family caregivers

providing home care for hemodialysis patients and to examine the sociodemographic and psychosocial factors associated with caregiver burden.

Research Questions

1. What are the levels of caregiver burden, spirituality, and psychological well-being among family caregivers providing home care for hemodialysis patients?
2. Are spirituality, psychological well-being, and sociodemographic characteristics significantly associated with caregiver burden?
3. Are spiritual orientation and psychological well-being independently associated with caregiver burden after controlling for sociodemographic variables?

2. Methods

Study Design

This study was conducted using a cross-sectional analytical design to investigate the relationships among spirituality, psychological well-being, and caregiver burden among family caregivers providing home care for hemodialysis patients. The study also aimed to examine the associations between spirituality, psychological well-being, and caregiver burden while considering sociodemographic characteristics. The study was reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional studies (von Elm et al., 2007).

Study Setting and Participants

The study was conducted between April 2026 and June 2026 with family caregivers providing home care for patients receiving treatment at the hemodialysis unit of a tertiary university hospital. The study population consisted of family caregivers of patients receiving treatment at the unit during the data collection period. No sampling method was employed; instead, all eligible family caregivers who met the inclusion criteria during the study period were invited to participate. The study was completed with 223 family caregivers who voluntarily agreed to participate.

The minimum sample size was calculated using G*Power version 3.1. Based on multiple linear regression analysis with 14 predictors, a medium effect size ($f^2 = 0.15$), a statistical power of 95% ($1-\beta = 0.95$), and a significance level of 5% ($\alpha = 0.05$) were assumed. According to the power analysis, the minimum required sample size was 197 participants. The study was completed with 223 family caregivers, indicating that the achieved sample size was sufficient for the planned analyses. Individuals were eligible for inclusion if they were 18 years of age or older, had been providing home care for a patient receiving hemodialysis treatment for at least three months, were able to read and understand Turkish, and voluntarily agreed to participate in the study. Individuals with a diagnosed psychiatric disorder or cognitive or sensory impairments that could interfere with their ability to understand or complete the questionnaire were excluded.

Data Collection Instruments

Data were collected using the Personal Information Form, the Spiritual Orientation Scale, the Psychological Well-Being Scale, and the Primary Caregiver Burden Scale for Patients Receiving Hemodialysis.

Personal Information Form

The Personal Information Form was developed by the researchers based on the relevant literature. The form includes questions regarding the caregivers' age, sex, educational level, marital status, employment status, income level, relationship to the care recipient, duration of caregiving, and daily caregiving time.

Spiritual Orientation Scale

The Spiritual Orientation Scale was used to assess the participants' level of spirituality (Kasapoğlu, 2015). The scale consists of 16 items rated on a 7-point Likert scale. The items assess the fundamental dimensions of spirituality, including belief in a higher power, the search for meaning in life, and prayer/meditation. Higher scores indicate a higher level of spiritual orientation. In the original study, the Cronbach's alpha coefficient of the scale was reported as 0.87. In the present study, Cronbach's alpha coefficient was 0.994, indicating high internal consistency.

Psychological Well-Being Scale

The Psychological Well-Being Scale was used to assess the participants' level of psychological well-being (Diener et al., 2010). The scale was adapted into Turkish by Telef (2013). It consists of eight items rated on a 7-point Likert scale, ranging from 1 (Strongly Disagree) to 7 (Strongly Agree). All items are positively worded. Total scores range from 8 to 56, with higher scores indicating a higher level of psychological well-being. In the original study, the Cronbach's alpha coefficient was reported as 0.80. In the present study, Cronbach's alpha coefficient was 0.991, indicating high internal consistency.

Primary Caregiver Burden Scale for Patients Receiving Hemodialysis

The Primary Caregiver Burden Scale for Patients Receiving Hemodialysis was used to assess caregiver

burden among family caregivers of hemodialysis patients (Koşar Şahin et al., 2024). The scale consists of 34 items and four subscales: self-management support, psychological support, caregiver symptoms, and individual coping. Items are rated on a 4-point Likert scale. Higher scores indicate a higher level of caregiver burden. In the original study, the Cronbach's alpha coefficient of the total scale was reported as 0.95. In the present sample, internal consistency was high across the four subscales, with Cronbach's alpha coefficients of 0.988 for self-management support, 0.939 for psychological support, 0.981 for caregiver symptoms, and 0.983 for individual coping.

Data Collection Procedure

Data were collected between April 2026 and June 2026 using an online data collection method. Potential participants were identified among family caregivers of patients receiving treatment at the hemodialysis unit and were assessed for eligibility according to the predefined inclusion criteria. Eligible caregivers were informed about the study, and the Google Forms survey link was shared with those who agreed to participate via WhatsApp and e-mail. The first page of the online questionnaire provided information about the purpose and scope of the study, the voluntary nature of participation, and confidentiality. Participants were required to provide electronic informed consent before accessing the questionnaire. To prevent missing data, all questions were set as mandatory. No personally identifiable information was requested, and all data were analyzed anonymously. Completion of the questionnaire required approximately 10–15 minutes.

Ethical Considerations

Ethical approval for the study was obtained from the Institutional Scientific Research and Publication Ethics Committee (Approval No: 243241; Date: April 14, 2026). The study was conducted in accordance with the principles of the Declaration of Helsinki. Electronic informed consent was obtained from all participants through the online questionnaire prior to their participation in the study.

Statistical Analysis

Data were analyzed using IBM SPSS Statistics software. Descriptive statistics were presented as frequency, percentage, mean, and standard deviation. The internal consistency of the scales was assessed using Cronbach's alpha coefficient. The normality of the data was evaluated by examining skewness and kurtosis values.

An independent samples t-test was used for comparisons between two groups, whereas one-way analysis of variance (ANOVA) was used for comparisons involving more than two groups. Homogeneity of variances was assessed using Levene's test. When the homogeneity of variance assumption was violated, Games–Howell post-hoc comparisons were performed following statistically significant one-way ANOVA results. The relationships among spirituality, psychological well-being, and caregiver burden were evaluated using Pearson's correlation analysis.

Prior to the regression analyses, the assumptions of multiple linear regression were evaluated. Linearity and homoscedasticity were assessed by examining residual plots, normality was evaluated using skewness and kurtosis values and the distribution of residuals, and the independence of residuals was assessed using the Durbin–Watson statistic. Multicollinearity was evaluated using correlation coefficients, tolerance values, and variance inflation factors (VIFs). Robust standard errors were used to reduce sensitivity to potential heteroscedasticity.

To examine factors independently associated with caregiver burden, multiple linear regression analysis with robust standard errors was performed. The first model included sociodemographic variables. In the second model, spirituality was added to the sociodemographic variables. In the third model, psychological well-being was added to the sociodemographic variables. Multicollinearity was assessed using correlation coefficients, tolerance values, and variance inflation factors (VIFs). A very high correlation was observed between spirituality and psychological well-being ($r = 0.995$), with a tolerance value of 0.011 and a VIF of 93.51 when both variables were considered simultaneously. These findings indicated severe multicollinearity. Therefore, spirituality and psychological well-being were not entered simultaneously into the same regression model and were instead evaluated in separate hierarchical models.

3. Result

Table 1. Descriptive Statistics of the Study Variables

Variable	n	Mean	SD	Min	Max
Spiritual Orientation	223	4.779	1.435	2.375	7.000
Psychological Well-Being	223	4.512	1.750	1.500	7.000
Caregiver Burden	223	2.568	0.050	2.412	2.676

The relationships among caregiver burden, spirituality, psychological well-being, and sociodemographic

characteristics of family caregivers providing home care for hemodialysis patients were investigated in this study. The findings are presented below.

Table 2. Correlation Analysis Results Among the Study Variables

Variables	Caregiver Burden	Spiritual Orientation	Psychological Well-Being
Caregiver Burden	1.000		
Spiritual Orientation	0.406**	1.000	
Psychological Well-Being	0.407**	0.995**	1.000

*Note: ** $p < 0.01$.*

Table 1 presents the descriptive statistics of the main study variables. The mean Spiritual Orientation score was 4.779 ± 1.435, the mean Psychological Well-Being score was 4.512 ± 1.750, and the mean Caregiver Burden score was 2.568 ± 0.050. Sociodemographic characteristics are presented according to their respective categories in the subsequent tables.

Table 2 presents the correlations among the main study variables. Caregiver burden was significantly and positively correlated with spiritual orientation ($r = 0.406$, $p < 0.01$) and psychological well-being ($r = 0.407$, $p < 0.01$). A very strong positive correlation was also observed between spiritual orientation and psychological well-being ($r = 0.995$, $p < 0.01$).

Table 3. Results of Hierarchical Multiple Linear Regression Analysis

Variables	Model 1 β	Model 2 β	Model 3 β
Age	-0.085***	-0.219***	-0.090***
Gender	0.009	0.018	0.010
Education Level	0.012*	0.005*	0.011
Marital Status	0.003	0.017	0.005
Employment Status	-0.100***	-0.185***	-0.103***
Income Level	-0.012	-0.016	-0.010
Degree of Relationship	0.035**	0.063***	0.035**
Caregiving Duration	0.119***	0.082***	0.117***
Spiritual Orientation	—	0.150***	—
Psychological Well-Being	—	—	0.006
Constant	2.346***	2.072***	2.341***
R^2	0.425	0.474	0.425
F	35.28***	34.69***	33.46***

Note: Robust standard errors were used. Daily caregiving hours (CHRS) was excluded from the regression models because of severe multicollinearity, particularly its very high correlation with caregiving duration (CDUR; r = 0.984). * p < 0.05, ** p < 0.01, *** p < 0.001.

Abbreviations: β, standardized regression coefficient; R^2, coefficient of determination; CHRS, daily caregiving hours; CDUR, caregiving duration

Table 3 presents the results of the hierarchical multiple linear regression analysis. All three regression models were statistically significant ($p < 0.001$).

In Model 1, age (β = -0.085; $p < 0.001$), educational level (β = 0.012; $p < 0.05$), employment status (β = -0.100; $p < 0.001$), degree of relationship to the patient (β = 0.035; $p < 0.01$), and caregiving duration (β = 0.119; $p < 0.001$) were significantly associated with caregiver burden.

In Model 2, after adding spirituality to the model, SPIRIT was found to be positively and significantly associated with caregiver burden (β = 0.150; $p < 0.001$). The explanatory power of this model was $R^2 = 0.474$.

In Model 3, psychological well-being was not significantly associated with caregiver burden (β = 0.006; $p > 0.05$). Age, employment status, degree of relationship to the patient, and caregiving duration remained significant across all models. Daily caregiving hours (CHRS) was excluded from the regression models because of severe multicollinearity, particularly its very high correlation with caregiving duration (CDUR; r = 0.984).

Table 4. Comparison of Caregiver Burden Scores According to Binary Sociodemographic Variables

Variable	n	Mean ± SD	t	p
Gender				
Female	112	2.572 ± 0.037	1.019	0.310
Male	111	2.565 ± 0.060		
Marital Status				
Married	138	2.580 ± 0.044	4.555	< 0.001
Single	85	2.550 ± 0.054		
Employment Status				

Working	107	2.564 ± 0.061	-1.156	0.249
Not Working	116	2.572 ± 0.036		

Table 4 presents the results of the independent samples *t*-test. Caregiver burden scores did not differ significantly according to gender (p = 0.310) or employment status (p = 0.249). In contrast, caregiver burden scores differed significantly according to marital status (t = 4.555; p < 0.001). Married participants had higher mean caregiver burden scores than single participants.

Table 5 presents the results of the one-way ANOVA. Caregiver burden scores differed significantly according to age group (F = 18.62; p < 0.001), educational level (F = 13.79; p < 0.001), degree of relationship to the patient (F = 57.14; p < 0.001), caregiving duration (F = 69.56; p < 0.001), and daily caregiving hours (F = 75.33; p < 0.001). However, no significant difference in caregiver burden scores was found according to income level (F = 1.17; p = 0.314).

Games–Howell post-hoc analyses indicated significant pairwise differences among several categories of age, educational level, relationship to the patient, caregiving duration, and daily caregiving hours. In particular, the lowest age category differed significantly from the other age categories, while for relationship to the patient, category 4 differed significantly from categories 2 and 3. Multiple significant pairwise differences were also observed across educational level, caregiving duration, and daily caregiving-hour categories.

Table 5. Comparison of Caregiver Burden Scores According to Multicategory Sociodemographic Variables

Variable	Number of Groups	Mean ± SD Range	F	p
Age Group	4	2.537 – 2.590	18.62	< 0.001
Education Level	5	2.545 – 2.587	13.79	< 0.001
Income Level	3	2.565 – 2.582	1.17	0.314
Degree of Relationship	3	2.476 – 2.580	57.14	< 0.001
Caregiving Duration	6	2.476 – 2.608	69.56	< 0.001
Daily Caregiving Hours	5	2.499 – 2.609	75.33	< 0.001

Note: *Results are based on one-way ANOVA analyses. Games–Howell post-hoc tests were performed for variables with statistically significant overall differences because the homogeneity of variance assumption was not met.*

4. Discussion

This study investigated the relationships among spirituality, psychological well-being, and caregiver burden among family caregivers providing home care for hemodialysis patients. The findings demonstrated significant positive relationships between spirituality, psychological well-being, and caregiver burden. Hierarchical regression analysis further showed that spiritual orientation remained significantly associated with caregiver burden after adjustment for sociodemographic variables, whereas psychological well-being was not independently associated with caregiver burden. In addition, age, employment status, degree of relationship to the patient, and caregiving duration were identified as factors associated with caregiver burden.

The positive association observed between spirituality and caregiver burden in the present study is noteworthy. Previous studies have reported significant relationships between spiritual well-being and caregiver burden among family caregivers of hemodialysis patients; however, the direction of this relationship has varied across studies. A study conducted among caregivers of hemodialysis patients demonstrated a significant association between spiritual well-being and caregiver burden (Rafati et al., 2020). In contrast, a recent study conducted in Türkiye among family caregivers of hemodialysis patients reported a significant negative association between spiritual well-being and caregiver burden (Bakır et al., 2026). Similarly, studies involving caregivers of individuals with other chronic diseases have shown that spiritual well-being may reduce caregiver burden and strengthen coping abilities (Türkben Polat & Kıyak, 2023; Çevik Özdemir et al., 2025). However, the positive relationship identified in the present study should not be interpreted as indicating that spirituality increases caregiver burden. Rather, it may suggest that individuals experiencing greater caregiving responsibilities are more likely to seek spiritual resources. The fact that this study was conducted in eastern Türkiye, where family ties are generally strong and caregiving is often perceived as a cultural, moral, and religious responsibility, may represent an important contextual factor influencing these findings. Furthermore, the relatively common presence of extended family structures and the tendency for caregiving responsibilities to be undertaken primarily by close family members rather than shared among

relatives may also help explain this result. In this context, spirituality may also function as a coping resource through which caregivers seek meaning, hope, and emotional support in response to increasing caregiving demands. Religious and spiritual coping may become particularly salient when caregiving is perceived as a familial, moral, or religious responsibility. Therefore, the positive association observed in this study may reflect greater reliance on spiritual resources among caregivers experiencing higher levels of burden rather than a burden-enhancing effect of spirituality.

Although psychological well-being was significantly correlated with caregiver burden, it was not independently associated with caregiver burden in the multivariable analysis. This finding suggests that psychological well-being is associated with caregiver burden; however, this relationship may weaken when considered together with variables such as sociodemographic characteristics, caregiving duration, degree of relationship to the patient, and spirituality. Previous studies have demonstrated that caring for patients undergoing hemodialysis imposes substantial physical and psychological challenges on caregivers, reduces their quality of life, and increases the need for psychosocial support (Ebadi et al., 2021; Driehuis et al., 2024; Azeez & Ambatipudi, 2024; Pio et al., 2022). In addition, family resilience has been reported to mediate caregiver burden, while caregivers' quality of life has been shown to be associated with socioeconomic conditions and caregiving-related factors (Zhang et al., 2024; Zimbudzi et al., 2024; Gray et al., 2019). Similarly, self-care behaviors have been identified as strong predictors of psychological well-being among patients receiving chemotherapy, emphasizing that psychological well-being is a multidimensional construct influenced by numerous individual and environmental factors (Yiğit et al., 2025). Therefore, the relationship between psychological well-being and caregiver burden should not be regarded as unidirectional and direct but rather as a multidimensional phenomenon shaped by caregivers' personal, familial, and social resources. The very high correlation observed between spiritual orientation and psychological well-being ($r = 0.995$) indicates substantial empirical overlap between these constructs in the present sample. Although spiritual orientation and psychological well-being are theoretically distinct constructs, responses to these measures may have been closely aligned in this caregiver population, potentially reflecting shared dimensions related to meaning, purpose, positive functioning, and coping. Given the unusually strong magnitude of this association, the item-level data, scoring procedures, and calculation of the scale scores were rechecked, and the reported correlation was confirmed. Nevertheless, this finding should be interpreted cautiously and may reflect substantial construct overlap or sample-specific response patterns. Consistent with this finding, multicollinearity diagnostics indicated a tolerance value of 0.011 and a VIF of 93.51 when both variables were considered simultaneously. Therefore, to avoid unstable coefficient estimates resulting from severe multicollinearity, spiritual orientation and psychological well-being were evaluated in separate regression models.

In the present study, caregiving duration, degree of relationship to the patient, age, and employment status were significantly associated with caregiver burden. These findings indicate that caregiver burden is associated not only with individual psychological characteristics but also with the duration and intensity of caregiving and the caregiver's social role. Systematic reviews have reported caregiving duration, caregiving intensity, patients' symptom burden, caregivers' sociodemographic characteristics, and social support as major factors associated with caregiver burden (Alshammari et al., 2021; Skoulatou et al., 2024). Similarly, informal caregivers involved in dialysis care have been shown to experience moderate-to-high levels of caregiver burden, which is closely related to patients' symptom burden, treatment dependency, and quality of life (Driehuis et al., 2024; Al Maqbali et al., 2024). Likewise, a study conducted among family caregivers of patients with cancer reported that caregiver burden was closely associated with quality of life and that the caregiving process negatively affected caregivers' physical and psychosocial well-being (Yiğit & Erci, 2023). Furthermore, caregiver burden has also been reported to be influenced by age, caregiving duration, caregiving intensity, and financial difficulties (Azeez & Ambatipudi, 2024; Pio et al., 2022). These findings support the notion that caregiver burden is influenced not only by caregivers' internal resources but also by the objective conditions of caregiving.

The findings of the present study also highlight the importance of supportive interventions for family caregivers. Educational interventions promoting health-related behaviors have been shown to reduce caregiver burden among family caregivers of hemodialysis patients (Hayati et al., 2023). Likewise, stress management training programs have been reported to be effective in reducing perceived stress and caregiver burden among family caregivers (Khouban-Shargh et al., 2024). In addition, psychoeducational interventions, coping skills training, and family-centered support programs have been shown to improve caregivers' quality of life, psychological adjustment, and adaptation to the

caregiving process (Shukri et al., 2020; Hoang et al., 2019; Tong et al., 2013). Therefore, approaches focusing solely on the patient may be insufficient in hemodialysis care; family caregivers should also be regularly assessed and supported.

Our findings indicate that the assessment of family caregivers should encompass not only caregiver burden but also their spiritual and psychosocial needs. Such an approach may contribute to the early identification of caregivers at risk and facilitate the development of individualized supportive interventions.

Strengths and Limitations

This study has several strengths. One of its main strengths is the simultaneous evaluation of spiritual orientation, psychological well-being, caregiver burden, and relevant sociodemographic characteristics among family caregivers providing home care for hemodialysis patients. The use of validated measurement instruments and an adequate sample size further supports the methodological rigor of the study. In addition, robust standard errors were used in the regression analyses to reduce sensitivity to potential heteroscedasticity.

Nevertheless, this study has several limitations. Owing to its cross-sectional design, causal inferences cannot be made regarding the relationships among the study variables. The data were collected online using self-report questionnaires; therefore, response bias and the influence of social desirability cannot be completely ruled out. Furthermore, the online data collection method may have introduced selection bias, as caregivers with limited internet access or lower digital literacy may have been underrepresented in the study sample. In addition, because the study was conducted at a single hemodialysis center in eastern Türkiye, the generalizability of the findings to caregiver populations with different cultural and sociodemographic characteristics may be limited. Future multicenter, longitudinal, and interventional studies conducted in different regions are recommended to confirm these findings.

5. Conclusions

This study demonstrated that caregiver burden among family caregivers providing home care for hemodialysis patients was significantly associated with spiritual orientation, psychological well-being, and various sociodemographic characteristics. Spiritual orientation remained significantly associated with caregiver burden after adjustment for sociodemographic characteristics, whereas psychological well-being was not independently associated with caregiver burden in the multivariable analysis. In addition, age, employment status, degree of relationship to the patient, and caregiving duration were significantly associated with caregiver burden. These findings suggest that caregiver burden may be better understood by considering the social, cultural, spiritual, and psychosocial dimensions of the caregiving process together. In clinical practice, family physicians, nurses, nephrology teams, and dialysis professionals may consider incorporating assessments of caregiver burden and psychosocial and spiritual needs into the routine follow-up of families of patients receiving hemodialysis. Caregivers with greater support needs may subsequently be referred to appropriate psychosocial, social, or spiritual support services within a multidisciplinary care approach. Given the cross-sectional and single-center design of this study, these clinical implications should be interpreted cautiously and confirmed in future multicenter and longitudinal studies.

Conflict of Interest

The authors declare no conflict of interest.

Author Contributions

Conceptualization/Design: MU, MFY; Data Collection: MFY; Data Analysis and Interpretation: MU, MFY, TA; Drafting of the Manuscript: MU, TA; Critical Revision of the Content: MU, MFY, TA; Final Approval and Accountability: MU, MFY, TA; Technical and Material Support-Supervision: MU, MFY, TA.

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Perspectives in Palliative & Home Care

Research Article/Araştırma Makalesi

Care Dependency and Quality of Life of Patients Receiving Outpatient Chemotherapy and the Burden of Caregivers

Ayaktan Kemoterapi Alan Hastaların Bakım Bağımlılığı ve Yaşam Kalitesi ile Bakım Verenlerin Yükü

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ABSTRACT

Background/ Objective: Cancer is a disease that impacts quality of life, and over time, people with cancer can become dependent on care. Aim to examine the relationship between care dependency and quality of life of outpatient chemotherapy patients and the burden of their caregivers.

Material and Methods: The sample of the study was treated at State Hospital Outpatient Chemotherapy Unit; the study group consisted of 116 patients and 116 caregivers. The research is conducted as a cross-sectional and descriptive type of relationship-seeking study. Data were collected by the researcher; Using the Patient Information Form, Patient Caregiver Information Form, European Cancer Treatment and Organization Committee Quality of Life Scale (EORTC QLQ-C30), Care Dependency Scale (CDS) and Zarit Caregiving Burden Scale (ZCBS). It was collected through face-to-face interviews with written permission.

Results: It was determined that there was a statistically significant relationship between the CDS score and the general quality of life score from the EORTC QLQ-C30 subscale (r= 0.531; p<0.001), ZCBS score (r=-0.411; p<0.001). A statistically significant relationship was found between the general quality of life score from the EORTC QLQ-C30 QLS subscale and the ZBVYS score (r=-0.453; p<0.001).

Conclusion: Increasing patients' dependency on care and decreasing quality of life also increased the burden of care.

Keywords: Care dependency; quality of life; chemotherapy; caregiver burden.

ÖZ

Giriş/Amaç: Kanser, yaşam kalitesini etkileyen bir hastalıktır ve zamanla kanser hastaları bakıma bağımlı hale gelebilir. Bu çalışmanın amacı, ayakta tedavi gören kemoterapi hastalarının bakıma bağımlılığı ile yaşam kalitesi ve bakım verenlerin yükü arasındaki ilişkiyi incelemektir.

Gereç ve Yöntem: Çalışmanın örneklemi, Devlet Hastanesi Poliklinik Kemoterapi Ünitesinde tedavi gören hastalardan oluşmuştur; çalışma grubu 116 hasta ve 116 bakım verenden oluşmuştur. Araştırma, kesitsel ve tanımlayıcı bir ilişki arama çalışması olarak yürütülmüştür. Veriler araştırmacı tarafından toplanmıştır; Hasta Bilgi Formu, Hasta Bakıcı Bilgi Formu, Avrupa Kanser Tedavi ve Organizasyon Komitesi Yaşam Kalitesi Ölçeği (EORTC QLQ-C30), Bakım Bağımlılığı Ölçeği (CDS) ve Zarit Bakım Yükü Ölçeği (ZCBS) kullanılarak, yazılı izin alınarak yüz yüze görüşmeler yoluyla toplanmıştır.

Bulgular: CDS puanı ile EORTC QLQ-C30 alt ölçeğinden elde edilen genel yaşam kalitesi puanı (r= 0,531; p<0,001) ve ZCBS puanı (r=-0,411; p<0,001) arasında istatistiksel olarak anlamlı bir ilişki olduğu belirlenmiştir. EORTC QLQ-C30 QLS alt ölçeğinden elde edilen genel yaşam kalitesi puanı ile ZBVYS puanı arasında istatistiksel olarak anlamlı bir ilişki bulunmuştur (r=-0.453; p<0.001).

Sonuç: Hastaların bakıma bağımlılığının artması ve yaşam kalitesinin düşmesi, bakım yükünü de artırmıştır.

Anahtar Kelimeler: Bakım bağımlılığı; yaşam kalitesi; kemoterapi; bakım yükü.

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1. Introduction

The World Health Organization reports that approximately one in five people worldwide will experience cancer in their lifetime and that there will be approximately twenty million new cancer cases and 9.7 million deaths by 2022 (The International Agency for Research on Cancer [IARC], 2024; The World Health Organization [WHO], 2024). In Türkiye, the most common types of cancer are larynx and trachea/bronchi/lung, colon, lymphoid and hematopoietic cancers (Türkiye İstatistik Kurumu [TÜİK], 2025; Türkiye Cumhuriyeti Sağlık Bakanlığı Halk Sağlığı Genel Müdürlüğü [HSGM], 2020).

People with cancer can become care-dependent and have low quality of life. Patients and their families are aware of the symptoms that may develop during the cancer disease process and how to manage them, and the patient is involved in the treatment process. Communication, positive attitudes, and caregiver support are important in improving the quality of life of patients (Tamayo et al., 2020; Wittenberg et al., 2017). Thus, it is expected that patients who become care-dependent during the disease process will improve their quality of life with this cognitive and secure state (Bilgiç & Pehlivan, 2023; Alaca et al., 2024).

Care dependency, a concept affected by both the individual and their environment, is defined as a decrease in the ability to meet individual care needs and their need for expert support (Durgun et al., 2022; Nursiswati et al., 2022). Caregivers may be affected by this process in various ways depending on the patient's care dependency. While the caregiving situation brings many difficulties to the caregiver in terms of economic, physical, mental, freedom, and social relations, the patient also experiences benefits such as developing close relationships, increased emotional bonds, personal development, and personal satisfaction (Bilgehan & İnkaya, 2021; Thomas Hebdon et al., 2023; Malki et al., 2025).

In Türkiye, those who care for cancer patients and meet their material and spiritual needs are generally the closest family members. Having a low level of education, being female, living with the patient, spending more time on care are risk factors for caregiver burden. Caregivers of cancer patients experience problems such as quitting work, inability to plan their own activities, spending less time with their family, interrupted education, headaches, fatigue, anger, decreased life satisfaction, and communication issues due to the care burden (Rezaei et al., 2024). Some studies have shown that the care burden increases as the patient's functional status worsens (Semere et al., 2021) and caregivers whose basic needs are not met perceive care as more burdensome (Kol & Karabulutlu, 2021).

This study examined the relationship between care dependency, quality of life, and caregiver burden in patients receiving outpatient chemotherapy treatment in the oncology clinic. This is thought to be important in terms of obtaining data that will improve the quality of life of patients, support caregivers in identifying and reducing their burden, and develop oncology nursing.

2. Methods

Patients and Settings

This research was conducted as a descriptive study with a relationship-seeking nature. The study population consisted of adult patients diagnosed with cancer who received outpatient chemotherapy treatment in a state hospital outpatient chemotherapy unit and their caregivers. The study was conducted between August 2022 and January 2024. It included patients diagnosed with cancer for at least six months, without any comorbidities that would affect their quality of life. Caregivers who had been providing care for at least six months, without any comorbidities that would affect their care burden, were also included. Participants who gave informed consent were included in the study. To determine the minimum sample size for this study, a power analysis was performed using the G*Power 3.1 program, considering appropriate tests and a 95% confidence interval, yielding 116 patients and 116 caregivers (Faul et al., 2007).

Instruments

Demographic and Clinical Characteristics

Patient Information Form

The eight items on the information form, created by the researchers through a literature review, consisted of patient characteristics such as education level, gender, age, income level, marital status, individuals living together, employment status, and occupation. The next eight items included disease characteristics such as primary cancer diagnosis, cancer stage, presence of metastasis, time of first cancer diagnosis, time of first chemotherapy, presence of another chronic disease, presence of a family member with cancer, and chemotherapy side effects (Menekli et al., 2020).

Caregiver Information Form

The form, created by the researchers through a literature review, contained a total of 14 multiple-choice questions about the caregivers' gender, age, marital status, individuals they live with, educational

status, profession, employment status, presence of another person they care for, degree of closeness to the patient, duration of care, presence of another caregiver, previous patient care experience and duration (if any), physical health status, and psychological status (Lafcı et al., 2020).

EORTC-QLQ-C30 Quality of Life Scale

It is a cancer-specific scale created by the European Organization for Research and Treatment of Cancer [EORTC] (Aaronson et al., 1993). Its validity and reliability in Turkish cancer patients was evaluated by Cankurtaran et al. (2008). The scale's sub-dimensions include functional scale (physical, role, cognitive, emotional, and social), symptom scale (fatigue, pain, and nausea/vomiting), and global health/quality of life (QoL) scale. The first 28 of the 30 items are four-point Likert type questions and are scored as follows: not at all: 1–-a lot: 4. A high score on global health status questions indicated a high quality of life, a high score on functional scales indicated a healthy functional level, and a high score on symptom scales indicated intense symptoms and a high level of problems (Cankurtaran et al., 2008; Giesinger et al., 2020). The 29th question asked the patient to evaluate their health, and the 30th question asked the patient to evaluate their overall quality of life on a scale of 1 to 7 (1: very poor and 7: excellent). The scale does not have a total score, so all the sub-dimension scores were converted to a 0–100 score, to be analyzed with the same system (Cankurtaran et al., 2008). The Cronbach's alpha coefficient value of the scale, which typically ranges from 0.56 to 0.85, was between 0.80 and 0.90 in this study.

Care Dependency Scale (CDS)

The scale was developed by Dijkstra in 1998 based on Virginia Henderson's human needs (Dijkstra et al., 1998). The validity and reliability study in Türkiye was conducted by Hakverdioğlu Yönt et al. (2010). The scale, which has no sub-dimensions and consists of 17 items to determine individuals' addiction levels, is rated as follows: 1: I am completely dependent–5: I am not dependent. The lowest score that can be obtained from the scale is 17 and the highest score is 85. A high score indicated that the patient was independent in meeting their care needs, while a low score indicated that the patient was dependent on others in meeting their care needs. The Cronbach's alpha coefficient value is 0.91 (Yönt et al., 2010). The Cronbach's alpha value found in this study was 0.94.

Zarit Caregiving Burden Scale (ZCBS)

It is a scale developed by Zarit, Reever, and Bach-Peterson in 1980 (Zarit & Bach-Peterson, 1980). The Turkish validity and reliability study of the scale was conducted by İnci and Erdem (2008). It consists of 22 items that determine the impact of caregiving on the caregiver's life. The scale is Likert-type, ranging from 0 to 4. The minimum score on the scale is 0, and the maximum score is 88. Higher scores indicated a higher care burden experienced by caregivers. Cronbach's alpha coefficient value is 0.95 (İnci & Erdem, 2008). The Cronbach's alpha value found in this study was 0.90.

Study Procedures

Before starting the research, ethical approval was obtained from the Non-Interventional Clinical Research Ethics Committee of a University (decision no: 18, decision date: June 16, 2022), and permission was obtained from the relevant institution where the study was conducted, with a board decision dated July 21, 2022. This study was conducted in accordance with the principles of the Declaration of Helsinki.

To collect data, the researcher asked the questions in the scales via face-to-face interviews, and after voluntary consent was obtained from the patients and caregivers, approximately 15-20 minutes were allocated to each individual to complete each form.

Data Analysis

Statistical Package for Social Sciences (SPSS) v26 statistical software was used to analyze the data. Numbers and percentages were used for descriptive questions about patients and caregivers. The reliability of the data was checked using Cronbach's alpha value, and their suitability for normal distribution was checked by examining skewness and kurtosis values. During the analysis process, Pearson's correlation analysis was used to investigate a possible linear relationship between two or more quantitative variables. In statistical analyses, results with $p < 0.05$ were considered significant.

3. Result

Findings of patients

The mean age of the patients included in the study was 60.01 ± 13.10, with a minimum age of 26 and a maximum age of 92. Other socio-demographic data are shown in Table 1.

When the patients' primary diagnoses were examined, the three diagnoses with the highest rates were breast cancer (31.9%), lung cancer (19%), and colon cancer (17.2%), respectively. Other variables are shown in Table 1.

Table 1. Sample Scores for Patients Receiving Chemotherapy and Disease Characteristics (n=116)

Variable	Group	n	%
Age	26-44 years	19	16.4
	45-59 years	30	25.8
	More than 60 years	67	57.8
	Mean ± SD (Range)	60,01 ± 13,10 (26-92)	
Gender	Female	67	57.8
	Male	49	42.2
Marital status	Single	10	8.6
	Married	106	91.4
Individuals living together	Single	18	15.5
	Family	98	84.5
Education	Literate	22	19
	Elementary/Junior high	57	60.3
	Senior high/ University and above	24	20.6
Working status	Working	8	6.9
	Not working	88	75.9
	Leaving due to illness	20	17.2
Occupation/Sector	Public	5	4.3
	Private sector	23	20.7
	Retired	43	37.1
	Housewife	45	37.9
Income	Income less than expenses	63	54.3
	Income equals expenses	53	45.7
Primer diagnosis	Breast cancer	37	31.9
	Lung cancer	22	19.0
	Pancreatic cancer	8	6.9
	Colon cancer	20	17.2
	Rectum kanseri	2	1.7
	Liver cancer	1	0.9
	Stomach cancer	2	1.7
	Endometrial cancer	1	0.9
	Kidney cancer	2	1.7
	Skin/Soft tissue cancer	3	2.6
	Leukemia	1	0.9
	Lymphoma	2	1.7
	Prostate cancer	7	6.0
	Testicular cancer	2	1.7
	Ovarian cancer	2	1.7
	Small intestine cancer	1	0.9
	Thyroid cancer	3	2.6
Diagnosis period	6-12 months	50	43.1
	13-24 months	18	15.5
	25 months and above	48	41.4
Cancer stage	1. stage	11	9.5
	2. stage	19	16.4
	3. stage	24	20.7
	4. stage	62	53.4

	No	55	47.4
	Breast	3	2.6
	Respiratory system	15	12.9
	Digestive system	24	20.7
Metastasis area (n=138)	Neurological system	4	3.4
*(*multiple answers)*	Blood and Circulatory system	4	3.4
	Lymphatic system	13	11.2
	Musculoskeletal system	15	12.9
	Head and Neck system	4	3.4
	Excretory system	1	0.9
Chemotherapy period	6-12 months	66	56.9
	13-24 months	19	16.4
	25 months and above	31	26.7
	No	29	25.0
Chemotherapy side effects (n=160)	GIS** symptoms-weakness	70	60.3
(*multiple answers**)**	Anemia-tiredness	31	26.7
	Alopecia	16	13.8
	Pain-PPE***	14	12.1
Cancer in the family	Yes	56	48.3
	No	60	51.7
	No	65	56.0
	Diabetes Mellitus	25	21.6
	Hypertension	34	29.3
Chronic disease (n=140)	Circulatory System Disorder	6	5.2
(multiple answers***)***	Sickle Cell Anemia (Portör)	1	0.9
	Respiratory System Disease (Asthma /Bronchitis /COPD ****)	4	3.4
	Neurological disease	3	2.6
	Hypothyroidism	2	1.7
	Total	116	100.0

**GIS: Gastrointestinal; ***PPE: Palmar-Plantar Erthrodysesthezia (hand and foot syndrome); ****COPD: Chronic Obstructive Pulmonary Disease

Findings of Caregivers

The average age of the patient caregivers was 45.87 ± 13.21, with a minimum age of 18 and a maximum age of 70. Other socio-demographic variables are shown in Table 2.

36.2% of the caregivers were patients' relatives , 45.7% had been providing care for 1–12 months, 67.2% did not receive anyone's help in caregiving, 70.7% were inexperienced in caregiving, 29.3% did not experience any physical problems during caregiving, while fatigue with 64.7% was the most common physical problem. Other findings are shown in Table 2.

Table 2. Sample Scores for Patient Caregivers and the Care Process (n=116)

Variable	Group	n	%
	18-29 years	13	11.2
	30-39 years	24	20.7
	40-49 years	30	25.9
Age	50-59 years	25	21.6
	60-70 years	24	20.7
	Mean ± SD (Range)	45.87 ± 13.1 (18-70)	
Gender	Female	78	67.2
	Male	38	32.8
Marital status	Single	23	19.8
	Married	93	80.2

Having someone to depend on	Yes	78	67.2
	No	38	32.8
Education	Literate	6	5.2
	Elementary	44	37.9
	Junior high	12	10.3
	Senior high	19	16.4
	University and above	35	30.2
Working status	Working	41	35.3
	Not working	75	64.7
Occupation/Sector	Student	7	6.0
	Public	18	15.5
	Private sector	27	23.3
	Retired	16	13.8
	Housewife	48	41.4
Income	Income less than expenses	50	43.1
	Income equals expenses	66	56.9
Relationship to the patient	Children	36	31.0
	Partner	38	32.8
	Relative	42	36.2
Patient care duration	6-12 months	53	45.7
	13-24 months	16	13.8
	25 months and above	47	40.5
Presence of someone helping with care	Yes	38	32.8
	No	78	67.2
Experiencing physical problems while providing care *(* multiple answers)*	No	34	29.3
	Tiredness	75	64.7
	Change in appetite	22	19.0
	Sleep / Attention shift	54	46.6
	Change in self-care	17	14.7
Experiencing psychological problems while providing care *(* multiple answers)*	No	38	32.8
	Laugh /Cry state	40	34.5
	Not wanting to talk /	17	14.7
	Excessive desire to talk/	58	50.0
	Distress / Weakness / Hopelessness/ Fear	49	42.2
Changes in social life during caregiving (n=134) *(* multiple answers)*	No	55	47.4
	Change in current events tracking	19	16.4
	Decrease in Relationships with People Around and Neighborhood	60	51.7
Experiencing financial problems while providing Care	Yes	69	59.5
	No	47	40.5
Changes in family relationships due to caregiving	No	89	76.7
	Positive change	5	4.3
	Negative change	22	19.0
	Total	116	100.0

EORTC QLQ-C30 Quality of Life Scale, Care Dependency Scale, and Zarit Caregiver Burden Scale Scores and Their Relationship Findings

Findings regarding the sub-dimensions and total scores of the CDS, ZCBS, and EORTC QLQ-C30 are presented in Table 3.

Table 3. Care Dependency Scale (CDS), Zarit Caregiving Burden Scale (ZCBS) ve EORTC-QLQ-C30 Quality of Life Scale's (EORTC-QLQ-C30 QoL) Sub-dimensions and Findings Regarding Total Scores (n=116)

Scale	Sub-dimension	Mean	SD	Range	Number of scale questions
EORTC QLQ-C30 QoL	**Functional scales**	51.398	24,551	4.44-97.78	
	Physical functioning	49.912	23,938	0-89.74	1, 2, 3, 4, 5
	Role functioning	46.983	24,973	0-100	6, 7
	Social functioning	42.069	26,875	0-100	26, 27
	Emotional functioning	46.480	35,613	0-100	21, 22, 23, 24
	Social functioning	67.098	33,003	0-100	20, 25
	Symptom scales	46.696	35,659	0-100	8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 28
	Global health status	71.839	28,353	0-100	29, 30
CDS	**-**	73.379	15,930	21	1-17
ZCBS	**-**	41.595	19,001	6	1-22

n: Sample

The relationship between the scales was analyzed using Pearson correlation analysis.

A statistically significant, positive correlation was found between the CDS total score and the functional status score from the EORTC QLQ-C30 subscale ($r = 0.545$; $p < 0.001$). A statistically significant, negative correlation was found between the symptom subscale scores ($r = -485$; $p < 0.001$). A statistically significant, positive correlation was found between the general quality of life subscale ($r = 0.531$; $p < 0.001$) (Table 4).

A statistically significant, negative correlation was found between the CDS total score and the ZCBS total score ($r = -0.411$; $p < 0.001$) (Table 4).

A statistically significant, negative correlation was found between the ZCBS total score and the EORTC QLQ-C30 functional status subscale score ($r = -0.588$; $p < 0.001$); a statistically significant, positive correlation was found between the symptoms subscale ($r = 0.540$; $p < 0.001$); and a statistically significant, negative correlation was found between the general quality of life subscale ($r = -0.453$; $p < 0.001$) (Table 4).

Table 4. Correlations between EORTC-QLQ-C30 Quality of Life Scale, Care Dependency Scale and Zarit Caregiving Burden Scale Scores

Pearson Correlation		**EORTC QLQ-C30 QoL**			**CDS**
		Functional scales	Symptom scales	Global health statü	
CDS	r	0.545	-0.485	0.531	1.000
	p	**<0.001**	**<0.001**	**<0.001**	
ZCBS	r	-0.588	0.540	-0.453	-0.411
	p	**<0.001**	**<0.001**	**<0.001**	**<0.001**

r: Pearson Correlation coefficient, p: Significance level

4. Discussion

In this study examining care dependency, quality of life, and caregiver burden in cancer patients, patients' functional health status was found to be moderate. They exhibited moderate symptoms, and their general quality of life was good.

Patients experience various side effects, most notably fatigue and GI symptoms. This is thought to be related to the disease, pain, and fatigue experienced during treatment. In their study, Yıldırım et al. (2025) mentioned practices to reduce symptoms, increase independence, and improve the quality of life in cancer patients (Yıldırım et al., 2025).

The low dependency level seen in patients indicated less reliance on others for care and vital needs. The fact that their caregivers also experienced moderate levels of difficulty may be considered a parallel finding. As the functional status of patients undergoing outpatient chemotherapy improved, their care dependency decreased. This finding demonstrates that they can independently perform activities of daily living and maintain good functional status without needing assistance.

As patients experienced more symptoms, their care dependency increased. Patients who can independently perform activities of daily living may be considered to have fewer symptoms. While reviewing the literature on symptoms and quality of life reported by patients, Berry (2011) mentioned that evaluating disease-related symptoms and treatment-related side effects in cancer patients and controlling symptoms effectively is crucial for improving quality of life in these patients (Berry, 2011). The increase in care dependency may be attributed to the increase in symptoms experienced by the patient.

It has been found that patients' quality of life increases as their care dependency decreases. One study found that care dependency and overall quality of life are interrelated factors. Support from nurses or caregivers who interact with patients receiving treatment can help patients focus on their daily activities (dressing, eating, bathing, etc.), while improving their overall quality of life (Hakverdioğlu Yönt, 2023).

As study participants' care dependency increased, their caregiver burden also increased. Studies have also determined that care dependency affects both patients and caregivers (Burucu et al., 2023). In their study, Morgan et al. (2022) stated that advanced cancer patients face increasing challenges in their daily living as disease progresses, and their caregivers may lose self-worth and personal values and also postpone their physical, emotional, and social needs (Morgan et al., 2022).

Cancer disease can lead to increased psychosocial distress and decreased health-related quality of life in caregivers (Kusi et al., 2023). In their study with patients registered in a home health unit and their primary caregivers, Taşdelen and Ateş (2012) found that as patients became more care dependent, the time caregivers spend on them increased, resulting in a time burden on caregivers (Taşdelen & Ateş, 2012). As a patient's functional status worsened, a caregiver's burden increased in terms of daily caregiving hours and intensity (Unsar et al., 2021). It is expected that patients will depend on others for vital issues such as nutrition, body hygiene, mobility, sleep, dressing, avoiding dangers, and communication, resulting in a material and moral burden on the caregiver. In Liou and Huang's (2023) study of colorectal cancer patients and their caregivers, family caregivers of patients with higher resourcefulness experienced less impact on their health than those with lower resourcefulness (Liou & Huang, 2023). It is recommended that caregivers choose appropriate coping methods when facing caregiving difficulties based on their own characteristics and the difficulty of the situation (Yan et al., 2024).

As patients improve their functional status and quality of life, their caregiver burden decreases. As patients' symptoms increase, the care burden increases. It can be argued that the symptoms associated with chronic illness lead to prolonged caregiving and increase caregiver burden. Effective management of symptoms improves patients' quality of life and enables them to live more active, safe and comfortable daily lives (Şahin & Özhanlı, 2025). Along with perceived burden, caregivers may experience depression and anxiety symptoms that may affect their capacity to provide care (Thana et al., 2021). Fellia et al. (2023) found that increased burden was associated with caregivers' stress (Fellia et al., 2023). It is possible that increased patient burden creates stress in caregivers and causes the burden to increase.

Limitations

The study was limited by the fact that it was conducted using a single research method, with outpatient chemotherapy patients and their caregivers participating at a state hospital in the district.

5. Conclusions

It was found that patients receiving outpatient chemotherapy had a moderate functional health status, experienced moderate symptoms, and had a good quality of life.

Patients' care dependency was low, and caregivers' care burden was moderate.

It was found that care dependency increased as symptoms increased and decreased as functional status and quality of life improved.

Nurses, as health professionals, are recommended to determine patients' quality of life, care dependency, and caregiver burden in cancer management and plan nursing interventions based on the results.

For caregivers to cope with the physical, psychological, social, and economic difficulties they experience, counseling services should be provided and public policies supporting caregivers should be developed.

The burden on caregivers should also be taken into consideration in the education of patients and oncology nurses.

It is recommended that caregivers of patients with high care dependency and low quality of life be given more support.

Conflict of Interest

The authors have no competing interests to declare that are relevant to the content of this article.

Author Contributions

All authors contributed to the conceptualization, design, literature review, analysis, writing, and editing of this study. Material preparation and data collection were performed by [ED]. Critical review and editing were performed by [SS]. All authors have read and approved the final text.

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Perspectives in Palliative & Home Care

Derleme Makalesi/ Review Article

Palyatif Bakımda Sarkopeni ve Hemşirelik Bakımı

Sarcopenia and Nursing Care in Palliative Care

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ÖZ

Giriş/Amaç: Palyatif bakım, yaşamı tehdit eden hastalıklara sahip bireyler ve ailelerinin yaşam kalitesini artırmayı amaçlayan bütüncül bir sağlık hizmetidir. Ağrı ve diğer semptomların erken tanılanması ve yönetimini hedefleyen bu yaklaşım; fiziksel, psikolojik, sosyal ve spiritüel boyutları kapsamaktadır. Başlangıçta yalnızca kanser tanılı hastalara yönelik olarak geliştirilen palyatif bakım, günümüzde tüm kronik hastalıkları kapsayacak şekilde genişletilmiştir. Sarkopeni, yaşlanma ile birlikte kas kütlesi, kas gücü ve fiziksel performansta ilerleyici azalma ile karakterize edilen, yaşam kalitesini olumsuz etkileyen bir geriatrik sendromdur. Primer ve sekonder olarak sınıflandırılan sarkopenide, erken tanı ve multidisipliner yaklaşımlar düşme, fraktür ve mortalite riskinin azaltılmasına katkı sağlamaktadır. Direnç ve denge egzersizleri ile protein ve D vitamini desteği temel korunma ve tedavi stratejileri arasında yer almaktadır. Bu geleneksel derleme ile palyatif bakım hastalarında sarkopeni farkındalığını artırmayı ve hemşirelik girişimlerinin fonksiyonel kapasiteyi destekleyerek yaşam kalitesini geliştirmedeki rolünü vurgulamak amaçlanmaktadır.

Sonuç: Palyatif bakım, semptom kontrolünün yanı sıra hastanın fiziksel bütünlüğünü ve bağımsızlığını korumayı da hedeflemektedir. Sarkopeni, palyatif hastalarda fonksiyonel kaybı hızlandıran ve mortaliteyi artıran önemli bir risk faktörü olarak değerlendirilmektedir. Bu derleme, sarkopeni yönetiminin palyatif bakımın temel bileşenlerinden biri olması gerektiğini ortaya koymaktadır. Hemşireler, tarama araçları ve bireyselleştirilmiş egzersiz ile beslenme girişimleriyle bu sürecin merkezinde yer alabilir. Bu bağlamda, palyatif bakımda sarkopeni farkındalığının artırılması ve kanıta dayalı hemşirelik protokollerinin geliştirilmesi öncelikli bir gereklilik olarak görülmektedir.

Anahtar Kelime: Palyatif bakım; sarkopeni; hemşirelik; hemşirelik bakımı.

ABSTRACT

Background/Objective: Palliative care is a holistic healthcare service aimed at improving the quality of life for individuals with life-threatening illnesses and their families. This approach, which focuses on the early identification and management of pain and other symptoms, encompasses physical, psychological, social, and spiritual dimensions. Originally developed exclusively for patients diagnosed with cancer, palliative care has since been expanded to include all chronic illnesses. Sarcopenia is a geriatric syndrome characterized by a progressive decline in muscle mass, muscle strength, and physical performance associated with aging, which negatively affects quality of life. In sarcopenia, which is classified as primary and secondary, early diagnosis and multidisciplinary approaches contribute to reducing the risks of falls, fractures, and mortality. Resistance and balance exercises, along with protein and vitamin D supplementation, are among the fundamental prevention and treatment strategies. The aim of this traditional review is to raise awareness of sarcopenia among palliative care patients and to highlight the role of nursing interventions in improving quality of life by supporting functional capacity.

Conclusion: Palliative care should aim to preserve the patient's physical integrity and independence in addition to symptom control. Sarcopenia is considered an important risk factor that accelerates functional decline and increases mortality in palliative care patients. This review demonstrates that sarcopenia management should be regarded as one of the fundamental components of palliative care. Nurses can play a central role in this process through the use of screening tools and individualized exercise and nutritional interventions. In this context, increasing awareness of sarcopenia in palliative care and developing evidence-based nursing protocols are considered priority requirements.

Keywords: Palliative care; sarcopenia; nursing; nursing care.

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1. Giriş

Sarkopeni, özellikle terminal dönem kanser hastalarında sistemik yıkım ve kas kütlesi kaybı ile karakterize olup, yaşam kalitesini ciddi oranda kısıtlayan kritik bir geriatrik sendromdur (Utku et al., 2025). Bu durum, hastaların kemoterapiye bağlı toksisite geliştirme riskini artırarak tedaviye verilen yanıtı ve genel sağ kalım oranlarını doğrudan olumsuz etkilemektedir (Toruk & Akbulut, 2023). Ayrıca, bu klinik durumun beraberinde getirdiği ağır semptom yükü, hastaların fonksiyonel kapasitelerini daha da düşürerek palyatif bakım sürecindeki yaşam standartlarını önemli ölçüde zayıflatmaktadır (Araújo et al., 2020). Hemşirelerin bu süreçte multidisipliner bir yaklaşımla sarkopeniyi erken evrede taraması, hastaların fonksiyonel bağımsızlıklarını korumak ve bakım kalitesini iyileştirmek için hayati bir öneme sahiptir (Sağlam & Küçükgüçlü, 2021). Klinik uygulamalarda palyatif ve onkoloji hemşireleri, kas kütlesi kaybını düzenli olarak izlemeli ve hastaların prognozunu iyileştirebilecek uygulanabilir erken müdahaleleri izlem süreçlerine dahil etmelidirler (Jang et al., 2021). Bu doğrultuda bu derleme, güncel ulusal ve uluslararası literatür doğrultusunda palyatif bakım hastalarında sarkopeni farkındalığını artırmayı; hemşirelik girişimlerinin fonksiyonel kapasiteyi destekleyerek, yaşam kalitesini geliştirmedeki kritik rolünü vurgulamayı amaçlamaktadır.

Palyatif Bakım

Palyatif bakım, yaşamı tehdit eden hastalıkları bulunan bireyler ve ailelerinin yaşam kalitesini yükseltmeyi amaçlayan bütüncül bir sağlık hizmetidir. Dünya Sağlık Örgütü (DSÖ), palyatif bakımı; ağrı ve diğer semptomların erken tanılanması, değerlendirilmesi ve giderilmesine odaklanan; fiziksel, psikolojik, sosyal ve ruhsal boyutları kapsayan bir yaklaşım olarak tanımlamaktadır. Bu yaklaşım, yaşamı onaylarken ölümü doğal bir süreç olarak kabul etmekte ve bireylerin yaşamlarının sonuna dek mümkün olan en yüksek yaşam kalitesine ulaşmalarını hedeflemektedir. Başlangıçta yalnızca kanser hastalarına yönelik geliştirilen palyatif bakım, günümüzde tüm kronik ve ilerleyici hastalıkları kapsayacak biçimde genişlemektedir. Multidisipliner bir ekip tarafından yürütülen bu hizmetler, yalnızca hastayı değil, aynı zamanda ailesini de kapsamakta; psikososyal destek, danışmanlık ve yas sürecinde rehberlik sunarak ölüm öncesi, ölüm anı ve yas dönemini içine alan kapsamlı bir bakım modeli oluşturmaktadır (Cook et al., 2020; World Health Organization (WHO), 2023).

Palyatif Bakım

Palyatif bakım, yaşamı tehdit eden hastalıkları bulunan bireyler ve ailelerinin yaşam kalitesini yükseltmeyi amaçlayan bütüncül bir sağlık hizmetidir. Dünya Sağlık Örgütü (DSÖ), palyatif bakımı; ağrı ve diğer semptomların erken tanılanması, değerlendirilmesi ve giderilmesine odaklanan; fiziksel, psikolojik, sosyal ve ruhsal boyutları kapsayan bir yaklaşım olarak tanımlamaktadır (WHO, 2023). Bu yaklaşım, yaşamı onaylarken ölümü doğal bir süreç olarak kabul etmekte ve bireylerin yaşamlarının sonuna dek mümkün olan en yüksek yaşam kalitesine ulaşmalarını hedeflemektedir. Başlangıçta yalnızca kanser hastalarına yönelik geliştirilen palyatif bakım, günümüzde tüm kronik ve ilerleyici hastalıkları kapsayacak biçimde genişlemektedir. Multidisipliner bir ekip tarafından yürütülen bu hizmetler, yalnızca hastayı değil, aynı zamanda ailesini de kapsamakta; psikososyal destek, danışmanlık ve yas sürecinde rehberlik sunarak ölüm öncesi, ölüm anı ve yas dönemini içine alan kapsamlı bir bakım modeli oluşturmaktadır (Cook et al., 2020; WHO, 2023). Bu süreçte temel odak noktası, hastalıkla ilişkili semptomların kontrol altına alınması yoluyla bireyin acı çekme deneyiminin önlenmesi veya hafifletilmesidir (Kavşur & Sevimli, 2020). Ayrıca bu model, hastaların tedavi süreçlerinde karşılaştıkları karmaşık tıbbi ve etik sorunları yönetirken, hasta yakınlarının bilgilendirilmesi ve eğitilmesi noktasında da kritik bir rol üstlenmektedir (Akalın & Modanlıoğlu, 2019). Bu kapsamda yürütülen çalışmalar, hastanın primer hastalığının kontrolünün ötesine geçerek, hasta ve yakınlarına yönelik duygusal destek ve sosyal hizmet süreçlerini içeren bütüncül bir yapı sunmaktadır (Aslan, 2020). Bununla birlikte palyatif bakımda hastalarda sıklıkla görülen ağrı, yorgunluk, iştahsızlık, bulantı, dispne, sarkopeni ve depresyon gibi semptomların düzenli olarak değerlendirilmesi ve bireyin gereksinimlerine uygun biçimde yönetilmesi temel hedefler arasında yer almaktadır (Tsai et al., 2006). Palyatif bakım sürecinde sıklıkla gözden kaçan bir semptom olan sarkopeni, iskelet kası kütlesi ve gücünün ilerleyici kaybı ile karakterize; özellikle kanser hastalarında yaygın fakat yetersiz tanınan bir durumdur (Go et al., 2025). Geniş çaplı bir meta-analizde solid tümörlü hastalarda sarkopeni prevalansı %35.3 olarak bildirilmiş; palyatif bakım alan hastalarda bu oranın (%49.2) küratif tedavi gören hastalara (%39.6) kıyasla anlamlı düzeyde daha yüksek olduğu bildirilmiştir (Surov & Wienke, 2022). Bu nedenle palyatif bakım sürecinde sarkopeni açısından hastaların kas gücü, fiziksel işlevselliği ve beslenme durumu değerlendirilmeli; uygulanacak beslenme ve fiziksel aktivite destekleri hastanın genel durumu, prognozu ve konforu doğrultusunda

bireyselleştirilmelidir. (Araújo et al., 2020; Go et al., 2025). Sarkopeni, hastaların yaşam kalitesini birçok yoldan etkilemektedir. Sarkopenisi olan ileri evre kanser hastalarının yaşam kalitesinin daha düşük olduğu ve depresyon semptomlarını daha fazla deneyimlediği vurgulanmıştır (Nipp et al., 2018). Ayrıca sarkopeni; palyatif kemoterapinin toksisite riskini artırmakta, sağkalımı olumsuz etkilemekte ve semptom yükünü artırarak yaşam kalitesini daha da bozmaktadır (Araújo et al., 2020). Kötü beslenme durumu ile ilişkilendirilen ve fonksiyonel bozulmayı hızlandıran sarkopeni, ileri evre kanser hastalarında yaşam kalitesinin düşmesine katkıda bulunmaktadır. Bu noktada palyatif bakımın bütüncül yaklaşımı, sarkopeninin yönetiminde belirleyici bir rol üstlenir. Palyatif bakımda sarkopeniye yaklaşım, kas kütlesini geri kazanmaktan çok semptomların hafifletilmesi, fonksiyonel kapasitenin korunması ve hastanın konforunun sağlanması temeline dayanmalı; beslenme desteği prognostik duruma göre bireyselleştirilmeli ve yaşam sonu dönemde agresif müdahalelerden kaçınılmalıdır (Go et al., 2025). Multidisipliner ekip içinde hemşire; tarama, yönlendirme, koordinasyon, beslenme ve egzersiz danışmanlığı, psikososyal destek, semptom kontrolü ve bakımın sürdürülmesi görevleriyle sarkopeni ve kaşeksi yönetiminde kilit bir konuma sahiptir (Zhao et al., 2021). Ülkemizde yapılan bir çalışmada kemoterapi alan kanser hastalarının %392unda yüksek malnütrisyon riski saptanmış; geriatrik hastalarda bu oranın (%46.6) geriatrik olmayanlara (%32.3) göre anlamlı derecede yüksek olduğu gösterilmiştir (Aytulu ve ark., 2022). Bu bulgular, sarkopeninin erken dönemde tanınarak palyatif bakım sürecine entegre edilmesinin, hastaların yaşam kalitesini korumada kritik önem taşıdığını ortaya koymaktadır.

Sarkopeni

Sarkopeni, yaşlanma süreci ile birlikte iskelet kası kütlesi, kas gücü ve fiziksel performansta ilerleyici ve istemsiz azalma ile karakterize edilen, bireyin fonksiyonel kapasitesini ve yaşam kalitesini doğrudan etkileyen çok boyutlu bir geriatrik sendromdur (Rogeri et al., 2021). İlk olarak Rosenberg tarafından "yaşa bağlı kas kaybı" olarak tanımlanan sarkopeni, günümüzde kas kütlesi, kas gücü ve fiziksel performans kaybını içeren ilerleyici bir kas hastalığı olarak kabul edilmektedir (Schaap et al., 2018). Global Leadership Initiative in Sarcopenia (GLIS) uzlaşı raporu da bu tanımı desteklemekte ve hastalığın ilerleyici seyrinin düşme, fonksiyonel bağımsızlık kaybı, hastaneye yatış, yaşam kalitesinde azalma ve mortalite gibi olumsuz klinik sonuçlarla doğrudan ilişkili olduğunu vurgulamaktadır (Beaudart et al., 2025).

Avrupa Yaşlılarda Sarkopeni Çalışma Grubu (EWGSOP) kriterlerine göre düşük kas gücü temel belirleyici olup, kas kütlesi azalması tanıyı doğrularken fiziksel performanstaki bozulma şiddetli sarkopeniyi göstermektedir (Cruz-Jentoft et al., 2019; Cruz-Jentoft & Sayer, 2019). Sarkopeni yalnızca yaşlanmaya bağlı olmayıp, birçok faktör gelişimine katkıda bulunmakta; bu nedenle primer ve sekonder sarkopeni sınıflandırmaları tanı ve tedavi stratejilerinde yol göstermektedir. Bu doğrultuda standart değerlendirme yöntemlerinin kullanılmasıyla sağlanan erken tanı ve müdahale, düşme, fraktür, yeti yitimi ve mortalite riskini azaltmaktadır (Liu et al., 2023). Patofizyolojik olarak, sarkopeni anabolik ve katabolik dengesizlik, mitokondriyal disfonksiyon ve nöromüsküler kavşak bozulmaları ile ilişkili olduğu görülmektedir (Edwards et al., 2023).

Dünya genelinde yaklaşık 1.71 milyar kişi kas-iskelet sistemi hastalıklarından etkilenmekte olup, bu durum engelliliğe, düşük yaşam kalitesine ve toplumsal katılımın azalmasına neden olmaktadır. Nüfus artışı ve yaşlanma ile birlikte, kas-iskelet hastalıkları ve buna bağlı fonksiyonel sınırlamalar hızla artmakta, rehabilitasyon ihtiyacı önemli bir sağlık sorunu olarak öne çıkmaktadır. Sarkopeni ise yaşlanmaya bağlı kas kütlesi ve fonksiyon kaybı ile karakterize olup, DSÖ tarafından kas-iskelet sistemi hastalıkları arasında yer almakta ve yaşlı bireylerde yaygın görülmektedir (World Health Organization, (WHO), 2022).

Sarkopeni, etiyolojisine göre *primer* ve *sekonder* olmak üzere sınıflandırılmaktadır. *Primer sarkopeni*, yaşlanma dışında belirgin bir neden olmaksızın gelişen kas kaybını ifade ederken; *sekonder sarkopeni* kronik hastalıklar, inflamatuar süreçler, organ yetmezlikleri, maligniteler, malnütrisyon ve fiziksel inaktivite gibi çeşitli faktörlere bağlı olarak ortaya çıkmaktadır (Supriya et al., 2021).

Sekonder sarkopeni üç alt kategoriye ayrılmaktadır:

- *Aktiviteye bağlı:* Sedanter yaşam tarzı, uzun süreli yatak istirahati veya fiziksel kondisyonsuzluk.
- *Hastalığa bağlı:* İleri organ yetmezliği, inflamatuar hastalıklar, maligniteler veya endokrin bozukluklar.
- *Beslenmeye bağlı:* Yetersiz enerji/protein alımı, malabsorbsiyon ya da ilaç kaynaklı anoreksi (Uchitomi et al., 2020).

Sekonder sarkopeni çoğunlukla birden fazla faktörün etkileşimi ile geliştiğinden, klinik pratikte sınırlarının kesin olarak belirlenmesi zordur. Bu sınıflandırma, yalnızca tanısal açıdan değil, aynı zamanda

bireyselleştirilmiş tedavi stratejilerinin planlanmasında da önemli bir yol gösterici rol üstlenmektedir (Cruz-Jentoft et al., 2019).

Sarkopeni başlangıç süresine göre de sınıflandırılmaktadır. Son altı ay içinde ortaya çıkan ani kas kaybı *akut sarkopeni* olarak adlandırılmakta ve genellikle hastalık, yaralanma, ameliyat veya uzun süreli immobilizasyona bağlı gelişmektedir. Altı aydan uzun süren, ilerleyici ve kalıcı hastalık süreçleriyle ilişkili kas kaybı ise *kronik sarkopeni* olarak kabul edilmekte ve mortalite riskini artırmaktadır (Cruz-Jentoft & Sayer, 2019).

Fonksiyonel açıdan sarkopeni, Avrupa Yaşlılarda Sarkopeni Çalışma Grubu (EWGSOP) tarafından *presarkopeni, sarkopeni ve şiddetli sarkopeni* olmak üzere üç evrede değerlendirilmiştir. Presarkopeni evresinde yalnızca kas kütlesi azalmış olup kas gücü ve fiziksel performans korunmaktadır. Sarkopeni evresinde düşük kas kütlesine ek olarak kas gücü veya fiziksel performans da azalmaktadır. Şiddetli sarkopenide ise kas kütlesi, kas gücü ve fiziksel performansın tümü düşmektedir (Bayram & Güneş, 2020).

Sarkopeni gelişiminde hormonal değişiklikler, yaşam tarzı, beslenme durumu, kronik hastalıklar ve genetik yatkınlık temel etmenlerdir (Cannataro et al., 2021). Yaşlanma ile büyüme hormonu (GH), insülin benzeri büyüme faktörü-1 (IGF-1), testosteron ve östrojen düzeylerinde azalma, kas protein sentezini ve anabolik sinyalleri azaltarak sarkopeni riskini artırmaktadır (Basualto-Alarcón et al., 2014). Kronik inflamasyon ve proinflamatuar sitokinler (TNF-α, IL-6), malnütrisyon, D vitamini eksikliği ile fiziksel aktivite azalması kas katabolizmini desteklemekte ve yaşla birlikte kas kaybını hızlandırmaktadır (Tessier & Chevalier, 2018). Diyabet, kalp yetmezliği, kronik böbrek ve karaciğer hastalıkları, KOAH ve nörolojik hastalıklar ile bazı ilaç kullanımları kas kaybını artıran diğer faktörler olarak kabul edilmektedir (Shafiee et al., 2017). Nöromusküler mekanizmalar açısından, alfa motor nöron apoptozu, akson retraksiyonu ve kas liflerinin innervasyon kaybı ile mitokondriyal disfonksiyon ve oksidatif stres, özellikle 60 yaş sonrası kas kütlesi ve fonksiyon kaybını hızlandırmaktadır (Liguori et al., 2018).

Avrupa Yaşlılarda Sarkopeni Çalışma Grubu-2 (EWGSOP2) kriterlerine göre, sarkopeni tanı süreci öncelikle kas gücü değerlendirmesi ile başlamaktadır. Düşük kas gücüne sahip bireylerde olası sarkopeni değerlendirilmekte; kas kütlesi veya kas kalitesinde azalma doğrulandığında kesin sarkopeni tanısı konmaktadır. Kas gücü ve kas kütlesindeki azalmaya ek olarak fiziksel performans kaybının bulunması ise "ciddi sarkopeni" olarak sınıflandırılmaktadır. Bu doğrultuda, sarkopeni riskinin belirlenmesinde Sarkopeni Teşhisi İçin Basit Hızlı (SARC-F) anketi kullanılmakta; 4 ve üzeri puan alan bireyler ileri değerlendirmeye alınmaktadır (Dent et al., 2018; Okazaki et al., 2020). Değerlendirme sürecinde kas kuvveti, kas kütlesi ve fiziksel performans ölçümleri temel parametreler olarak kullanılmaktadır (Buckinx et al., 2018). Bu sistematik yaklaşım, sarkopeninin erken tanılanması ve yönetiminde standart bir yöntem sağlayarak klinik karar verme süreçlerine katkı sağlamaktadır (Voelker et al., 2021).

Sarkopeni tedavisinde önleyici ve yönetici yaklaşımlar, fiziksel fonksiyonun korunması ve sağlık sonuçlarının iyileştirilmesi açısından kritik öneme sahiptir. Bu doğrultuda egzersiz, beslenme desteği ve gerektiğinde farmakolojik yaklaşımlar birlikte değerlendirilmekte; uygulanan müdahaleler hastanın klinik durumu, prognozu ve bakım hedeflerine göre bireyselleştirilmektedir.

Yapılan çalışmalar, yapılandırılmış ve bireyselleştirilmiş egzersiz programlarının hastalarda fiziksel fonksiyon, egzersiz kapasitesi ve yaşam kalitesini iyileştirdiğini; aynı zamanda yorgunluk ve ağrı düzeylerini azaltabildiğini göstermektedir (Schwonke et al., 2024). Sarkopeni yönetiminde özellikle direnç egzersizleri önemli bir yere sahip olup, kas liflerinin büyümesini ve güçlenmesini destekleyerek miyosit hacmini ve hücresel metabolik yolların etkinliğini artırmaktadır. Bununla birlikte, aerobik, denge ve germe egzersizleri de yaşlı bireylerde fiziksel performansın ve günlük yaşam aktivitelerinin sürdürülmesine katkı sağlamaktadır (Seo & Hwang, 2020). Egzersiz programları genellikle haftada üç gün, yaklaşık 30 dakika süreyle orta yoğunlukta uygulanmaktadır (Nascimento et al., 2019).

Egzersiz uygulamalarına ek olarak, beslenme desteği de sarkopeni yönetiminin temel bileşenlerinden biri olarak değerlendirilmektedir. Beslenme desteğinin hastanın klinik durumu, prognozu ve beklenen yaşam süresine göre bireyselleştirilmesini; semptom kontrolü ve yaşam kalitesinin korunmasının ön planda tutulmasını önermektedir (Muscaritoli ve ark., 2021). Bu kapsamda, özellikle protein ve dallı zincirli aminoasitler (lösin, izolösin, valin) açısından zengin beslenme yaklaşımlarının kas kütlesi ve fonksiyonunun korunmasına katkı sağladığı bildirilmektedir. Günlük protein alımının kilogram başına en az 1,2 g olması önerilmekte olup, protein desteğinin direnç egzersizleriyle birlikte uygulanmasının kas kütlesi ve fonksiyonunun artırılmasında sinerjik etki oluşturduğu belirtilmektedir. D vitamini eksikliği kas kuvveti kaybı ile ilişkili

olduğundan, yeterli D vitamini desteği de sarkopeni yönetiminde destekleyici bir yaklaşım olarak önerilmektedir (Calvani et al., 2023).

Literatürde farmakolojik müdahalelerin etkinliği sınırlı olup, günümüzde doğrudan sarkopeni tedavisine yönelik onaylanmış bir farmakolojik ajan bulunmamaktadır. Bu nedenle, sarkopeni yönetiminde egzersiz ve beslenme desteği gibi farmakolojik olmayan yaklaşımlar temel tedavi stratejileri arasında yer almaktadır (Chen et al., 2021).

Günümüzde Amerika Birleşik Devletleri Gıda ve İlaç Dairesi (FDA) onaylı doğrudan sarkopeni tedavi edici farmakolojik ajan bulunmamaktadır. Anabolik steroidler ve testosteron kas kütlesini artırabilse de ciddi yan etkiler nedeniyle rutin kullanımda önerilmemektedir; büyüme hormonunun etkisi ise yalnızca kas kütlesi ile sınırlıdır. Güncel araştırmalar, miyojenik kök hücreler ve miyostatin yolağı gibi moleküler hedefler ile sarkopeni tedavisini geliştirmeye odaklanmakta ve antioksidanların terapötik potansiyeli incelenmektedir (Perna et al., 2020).

Sarkopeni ve Hemşirelik Bakımı

Hemşirelik bakımı, sarkopeninin önlenmesi, erken tanısı ve yönetiminde merkezi bir rol oynamaktadır. Hemşireler, yalnızca klinik bulgulara değil, bireyin fiziksel, psikolojik, sosyal ve çevresel durumunu dikkate alan kapsamlı bir değerlendirme süreci yürütmelidir. Birincil korumada risk faktörlerinin belirlenmesi, sağlıklı yaşam davranışlarının teşvik edilmesi, dengeli beslenme ve düzenli egzersiz ön planda yer almakta, ikincil koruma sarkopeni riski taşıyan bireylerde multidisipliner iş birliğiyle egzersiz programları, beslenme düzenlemeleri ve destekleyici müdahaleleri içermektedir. Üçüncül koruma, tanı konmuş bireylerde komplikasyonların önlenmesi, yaşam kalitesinin yükseltilmesi ve bağımlılığın azaltılmasına yönelmekte; dördüncül koruma ise kanıta dayalı olmayan ve potansiyel olarak zararlı uygulamalardan korunmayı kapsamaktadır (Garrard et al., 2020).

Palyatif Bakım ve Sarkopeni

Palyatif bakım ve sarkopeni, yaşam kalitesinin korunması ve fonksiyonel kapasitenin artırılması açısından birbirini tamamlayan alanlar olarak değerlendirilmektedir. Palyatif bakım sürecinde hemşireler, sarkopeni riskini değerlendirerek uygun egzersiz ve beslenme müdahalelerini planlayabilmekte, multidisipliner ekip içinde koordinasyonu sağlayabilmekte ve hastaların yaşam kalitesini yükseltebilir. Bu yaklaşım, hem hastalık sürecinde hem de yaşamın son dönemlerinde fiziksel ve psikososyal sağlığın korunmasına katkı sağlamaktadır (Park et al., 2023).

Son yıllarda yapılan çalışmalar, palyatif bakım alan kanser hastalarında sarkopeninin prognoz ile yakından ilişkili olduğunu göstermektedir. Yüksek SARC-F skorunun daha kısa genel sağkalım ile ilişkili olduğu ve prognostik değere sahip olduğu bildirilmiştir (Mori et al., 2022).

Özellikle yaşamı tehdit eden hastalığı olan yaşlı bireylerde sarkopeni yaygın görülmekte olup fonksiyonel bağımsızlığı olumsuz etkilemektedir. Bu nedenle palyatif bakım, yalnızca semptom yönetimi ve yaşam kalitesinin sürdürülmesini değil; aynı zamanda sarkopeni riskinin değerlendirilmesi, kas kaybının önlenmesi ve fiziksel fonksiyonun desteklenmesini de kapsayan bütüncül bir çerçeve sunmaktadır.

Tüm bu yaklaşımlar birlikte değerlendirildiğinde, palyatif bakımda sarkopeni yönetiminin multidisipliner ve bireyselleştirilmiş bir anlayışla yürütülmesi önem taşımaktadır. Etkili hemşirelik müdahaleleri ile palyatif bakım stratejilerinin entegrasyonu, sarkopeninin ilerlemesini yavaşlatabilmekte, komplikasyonları azaltabilmekte ve hastaların fiziksel ile psikososyal sağlığının korunmasına katkı sağlayabilmektedir (Dent et al., 2018; Cook et al., 2020; Garrard et al., 2020; Park et al., 2023).

2. Sonuç ve Öneriler

Palyatif bakım ile sarkopeni önleme ve yönetim stratejilerinin birlikte uygulanması, yalnızca hastalık sürecinde semptom yönetimini sağlamakla kalmaz; aynı zamanda yaşlı ve kronik hastalığı olan bireylerde kas kaybını önleyerek fiziksel fonksiyonun korunmasına, komplikasyonların azaltılmasına ve genel yaşam kalitesinin artırılmasına önemli katkı sağlar. Hemşireler ve multidisipliner ekipler, bireyin fiziksel, psikolojik ve sosyal gereksinimlerini dikkate alarak uyguladıkları müdahalelerle, palyatif bakım sürecinde sarkopeni riskinin değerlendirilmesi ve uygun önleyici tedbirlerin planlanmasını sağlayabilir, böylece hastaların bağımsızlık ve yaşam doyumunu sürdürmesine destek olur.

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