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Psychosocial Challenges and Care Burden Among Caregivers of Immobile Patients Receiving Home Care: A Phenomenological Study

Evde Bakım Alan İmmobil Hastaların Bakım Verenlerinin Yaşadığı Psikososyal Zorluklar ve Bakım Yükü: Fenomenolojik Bir Çalışma

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ABSTRACT

The aim of this study is to thoroughly investigate the disease burden and psychosocial difficulties experienced by caregivers of immobile home care patients. A qualitative phenomenological approach was adopted to explore the experiences of 16 caregivers providing home care for bedridden patients. Participants were recruited using snowball sampling, and data were collected through individual telephone interviews conducted at times convenient for the caregivers. The data were analyzed using Colaizzi's phenomenological method. The data analysis resulted in four themes (psychosocial attrition and burnout, physical and financial burden, caregiving responsibility and commitment, and need for and search for support) and nine sub-themes (mental difficulties, social isolation, spiritual distress and coping, physical difficulties, financial difficulties, conscientious approach, impact on family relationships, lack of professional support, spiritual and family foundation) were identified. This study provides preliminary evidence that the process of caring for immobile home care patients negatively affects individuals psychosocially. Relatives of immobile patients experience serious physical, psychological and social problems due to caregiving and their daily lives are negatively affected. It has been found that caring for an immobile patient has a negative psychosocial impact on individuals.

Keywords: Burden of disease, Immobile patient, Phenomenological study, Psychosocial problems

ÖZ

Bu çalışmanın amacı, hareketsiz evde bakım hastalarının bakım verenlerinin yaşadığı hastalık yükünü ve psikososyal zorlukları derinlemesine araştırmaktır. Hareketsiz hastalara evde bakım sağlayan 16 bakım verenin deneyimlerini araştırmak amacıyla nitel fenomenolojik bir yaklaşım benimsenmiştir. Katılımcılar kartopu örnekleme yöntemiyle seçilmiş, veriler bakım verenlerle uygunluk durumlarına göre gerçekleştirilen bire bir telefon görüşmeleri aracılığıyla toplanmış ve Colaizzi'nin yöntemi kullanılarak analiz edilmiştir. Veri analizi sonucunda dört tema (psikososyal aşınma ve yıpranma, fiziksel ve mali yük, bakım sorumluluğu ve bağlılığı, destek ihtiyacı ve arayışı) ve dokuz alt tema (zihinsel zorluklar, sosyal izolasyon, manevi sıkıntı ve başa çıkma, fiziksel zorluklar, mali zorluklar, vicdanlı yaklaşım, aile ilişkileri üzerindeki etki, profesyonel destek eksikliği, manevi ve ailevi temellendirme) elde edilmiştir. Bu çalışma, hareketsiz evde bakım hastalarına bakım verme sürecinin bireyleri psikososyal olarak olumsuz etkilediğine dair ön kanıtlar sunmaktadır. İmmobil hastaların yakınları bakım verme nedeniyle ciddi fiziksel, psikolojik ve sosyal sorunlar yaşamakta ve günlük yaşamları olumsuz etkilenmektedir. İmmobil bir hastaya bakmanın bireyleri psikososyal olarak olumsuz etkilediği bulunmuştur.

Anahtar Kelimeler: Hastalık yükü, Hareketsiz hasta, Fenomenolojik çalışma, Psikososyal sorunlar

Highlights

*The most commonly used keywords have been identified as "positive psychology," "depression," and "stress."
*China, the USA, the UK, Canada, and Australia are among the most actively collaborating countries.
*The most publications related to positive psychotherapy have appeared in the journal "Frontiers in Psychology." *Research on positive psychotherapy is increasing, but studies are not yet at the desired level.

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INTRODUCTION

Immobility, or bed dependency, refers to a condition marked by the loss of anatomical movement and physiological changes resulting from an inability to perform daily living activities for at least three consecutive days (1). This condition negatively affects many organs and systems, leading to deformities and loss of function in individuals (2). When patients are no longer able to manage basic daily functions like nutrition, hygiene, or mobility, these responsibilities are largely assumed by their family caregivers (3). Therefore, providing adequate support to home care patients and their family members is essential to facilitate their social integration, maintain their connection with everyday life, and alleviate the caregiving burden placed particularly on primary caregivers (1,4). Family members who provide home care for bedridden individuals encounter a range of challenges stemming from both financial strain and emotional burden. Long-term caregiving is a process that negatively affects the health, socioeconomic and mental status of individuals and reduces the quality of life. Studies conducted both internationally and nationally report that caregivers face multiple challenges, including physical, economic, and psychological strain, as well as difficulties in family relationships and in managing the care and treatment needs of the patient (1,5,6).

Hafez et al. reported that the duration of providing care significantly affected the total burden level, total practice level, coping mechanism, income, availability of health services and the presence of additional caregivers (7). Mamom and Daovisan stated that issues such as taking responsibility, daily workload, follow-up care, care tasks, caregiving difficulties, financial difficulties, patient support, external support and caregiving strategy are very important for caregivers of elderly immobile patients and that they should be supported in this regard (8). In a study conducted, it was found that family members giving care at home complained most about being isolated, therefore they needed to spend time outside the home and the most common emotion they felt was anxiety due to the responsibility of the individual they care for (9). Navaie-Waliser et al. found that 36% of caregivers of immobile individuals became more sensitive and had difficulty in providing care after they started to provide home care, and more than one third of them had deteriorated physical health (10). In another study, it was stated that 51.8% of the caregivers of stroke patients were negatively affected by their general health status and 57% of them experienced physical or mental problems (11). It is thought that this study, which was conducted to deeply examine the burden of illness and psychosocial difficulties experienced by caregivers of immobile home care patients, will contribute to the literature.

MATERIALS AND METHODS

Study Design

A phenomenological approach, situated within the qualitative research tradition, was employed to explore the illness burden and psychosocial challenges experienced by caregivers of immobile patients receiving home care. This approach was selected as it enables an in-depth exploration of a phenomenon through the lens of participants, allowing for detailed descriptions and the collection of rich, experience-based data (12). The goal of this approach is to capture and reflect the true essence of the lived experience, remaining faithful to the participants' narratives without modification or distortion (14,15).

Working Group

The study was conducted in a province in northern Turkey between January 15 and March 15, 2025. The study group was formed using snowball sampling, a non-probability sampling technique commonly employed to recruit participants through referrals from individuals who meet the study criteria (36). The sample consisted of family caregivers providing home care for immobile patients.

The inclusion criteria required participants to be relatives of immobile patients, to be actively involved in providing care, and to voluntarily agree to participate in the study. Individuals who declined participation or did not meet the criterion of being a family caregiver of an immobile patient were excluded from the study.

Participants were recruited through referrals from eligible caregivers, and data collection continued until data saturation was achieved. A total of 16 family caregivers participated in the study (12). Individual telephone interviews were conducted at times convenient for the participants. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (13).

Data Collection Tools

Family caregivers of 16 immobile patients receiving home care were interviewed. Data were collected through individual telephone interviews conducted at times convenient for the caregivers. Interviews were conducted using a semi-structured interview guide developed by the researchers in accordance with qualitative research principles. The interview guide was based on a review of the literature and refined following feedback from three subject-matter experts. With participants' permission, the interviews were audio-recorded to ensure the accuracy and completeness of the data.

Questions in the Semi-structured Interview Form:

1. What are the psychosocial problems you have experienced because your patient is immobile? What are your experiences in this regard?
2. What are your needs during the care process? What are your psychosocial needs?
3. What are the mental, social and physical effects of caring for an immobile patient at home?
4. What types of support have you relied on throughout the caregiving process? What are your experiences in this regard?

To assess the clarity and relevance of the interview questions, a pilot interview was conducted with one participant. This 20-minute session served to familiarise the researcher with the interview process and was excluded from the main data analysis. The length of the actual interviews varied depending on the participants' responses, typically ranging between 30 and 40 minutes.

Validity and Reliability of the Research

One of the most important indicators of the credibility of scientific studies is their validity. Validity refers to the impartial observation of the phenomena and events to be researched in their original form (14). Another important criterion for the credibility of scientific research is reliability. Reliability is the consistency of the measurement tool in reaching the same result for the characteristic it aims to measure in phenomena and events (15). In this context, the prerequisite for validity is the reliability of the tool used for measurement (16). To establish the validity and reliability of this research, importance was given to the research universe, the necessary number of participants was reached, the necessary attention was paid to the confidentiality of the data, and the research was presented in a completely unbiased manner by showing the interview areas where the research was conducted.

Data Analysis

The qualitative data obtained from the interviews were analysed using Colaizzi's (1978) seven-step descriptive phenomenological method (17). Initially, three researchers independently and repeatedly reviewed the interview transcripts to develop a comprehensive understanding of the content. Significant expressions were extracted, reformulated, and generalised to capture the essence of participants' experiences. These statements were then interpreted and categorised, with meanings being discussed collaboratively until consensus was achieved. Subsequently, overarching themes and corresponding sub-themes were identified and clearly structured. To enhance the credibility of the analysis, direct quotations from participants were

incorporated to support the interpretation and provide transparency.

Ethical Aspects of the Research

This research was approved by Gümüşhane University Scientific Research and Publication Ethics Committee (numbered E-95674917-108.99-239756 dated 2024/02). Participants provided informed consent before data collection commenced. All data were stored securely, and the research complied with the ethical guidelines of the 1964 Declaration of Helsinki and national ethical standards.

FINDINGS

Table 1. Demographic and Clinical Characteristics of the Patients and Their Family Caregivers

Patient No	Patient Age	Gender	Relationship	Caregiver Marital Status	Chronic Diseases	Cause of Immobility
1	82	Male	Daughter	Married	Tumor, stent, bypass, HT	Cancer treatment
2	85	Female	Son	Married	Gallbladder inflammation, kidney failure, HT	Advanced age
3	80	Male	Wife	Married	Heart disease, stent, CVA	Stroke
4	92	Male	Nephew	Married	Unknown	Advanced age, bedridden
5	78	Male	Son	Married	CVA	CVA
6	87	Female	Daughter	Married	HT, COPD, Alzheimer's	Alzheimer's, post-infection mobility loss
7	86	Male	Wife	Married	HT, Alzheimer's, history of angioplasty	Decline due to Alzheimer's
8	96	Female	Daughter	Married	Heart failure, kidney failure, Alzheimer's	Decline due to Alzheimer's
9	89	Female	Daughter-in-law	Married	Heart, HT, dyspnoea, multiple organ failure	Organ failure, system failure
10	90	Female	Daughter-in-law	Married	Alzheimer's	Multiple organ failure
11	87	Female	Daughter	Married	Alzheimer's, HT	CVA
12	72	Female	Daughter	Married	HT, psychiatric diagnosis, diabetes	CVA
13	81	Male	Son	Married	HT, paraplegia, history of heart attack	CVA
14	59	Male	Daughter	Married	HT, heart failure, renal failure, prostate disease	CVA
15	87	Male	Daughter-in-law	Married	HT, DM, CRF	Unknown
16	36	Male	Sister	Married	-	Traffic accident

As a result of the analysis of the data obtained from the semi-structured interviews, themes, sub-themes and codes were identified (Table 2).

Theme 1. Psychosocial Attrition

Subtheme 1. Spiritual Challenges

"I came from Antalya, I left my wife with the children, I am here one week and there the next, but my work is disrupted. I left my family, my order is broken. My social circle is there, I am here. We are staying in a shanty house. The patient's financial situation is not good, he has his own house but his means are very limited. That's why I take care of him in my own house. I am very psychologically affected. My soul is tired. At night he wheezes, sputum comes, he cannot swallow, he coughs. I am in fox sleep. I sleep in short bursts and in the morning guests come. I can't rest. I'm completely devoted to him. I live with him now. Those who have not experienced this job do not know" (P4).

Subtheme 2. Social Isolation

"There is no social life left. I cannot leave the house. For the last 2-3 months, I cannot leave my mother alone, she cannot stay alone. There are not many visitors anymore. I don't

accept guests much either, I don't have the time or the mood. I have also collapsed physically. My back, neck and head are always aching. I even had a hernia during this process. But I would take care of her again, because she is my mother. I am her only child. I take care of her for God's sake. I mean, no one tells me to take care of her, but I take care of her out of my heart. But fatigue is different, I can't describe it. I am sleepless, my nerves are very bad. I explode at the slightest thing. I was not like that before, but now my patience is very low. And this makes me very sad. I feel sad when I lose myself. Then I look back at my mother, she is sick... it breaks my heart" (P6).

Table 2. Psychosocial Challenges Experienced by Individuals Caring for Immobile Patients

Themes	Sub-Themes	Codes
1. Psychosocial Attrition	A. Emotional Challenges	A1.Crying spells A2.Hopelessness A3.Self-blame A4. Triggering of past traumas
	B. Social Isolation	B1.Inability to leave home B2.Inability to receive guests B3.Lack of social support B6.Anxiety B7.Decreased self-esteem B8.Hopelessness B9. Fear of the future
	C. Spiritual Distress and Coping	C1.Disruption of religious practices C2.Sustaining through prayers C3.Feeling of loneliness C4.Restriction of life C5. Decline in quality of life
2. Physical and Financial Burden	A. Physical Strain	A1.Lower back, back, and arm pain A2.Sleep disturbances A3. Worsening of own health conditions
	B. Financial Challenges	B1.Medical product expenses B2.Insufficient government support B3. Having to quit work
3.Responsibility and Commitment	A. Conscientious Approach	A1Conscience not allowing neglect A2.Caring for God's approval A3. Belief that no one else would provide care
	B. Impact on Family Relationships	B1.Distance from spouse and children B2.Domestic conflicts B3. Importance of supportive family members
4.Need and Search for Support	A. Lack of Professional Support	A1.Not receiving psychological counselling A2. Rejection of caregiver or nursing home options
	B. Spiritual and Familial Support	B1.Praying and seeking patience B2.Moral support from family members B3. Need for support groups

Subtheme 3. Spiritual Distress and Coping

"Now, hodja, the man is completely dependent on us. He cannot say anything. He can't say he's hungry, he can't say he's thirsty, he can't say he needs to go to the toilet. I take his diapers. He has bedsores, and that too. I take care of him all the time. He has been like this for five months, I have never left his bedside. He can't talk anymore, he can't tell me anything. He used to tell me everything, now he has no voice. I can't even understand what he's thinking. He used to be very active, I was very fond of him, now seeing him like this... it's very difficult. I'm crying all the time. I'm so depressed. Once, when I was feeding him, the food got into his lungs... he coughed

so hard that he stopped breathing and I was speechless. He was dying in front of me. He also had a headache, and sometimes I would say "your blood pressure must be high" and get angry. It turned out he had a brain tumor. We were late, we lost time. I also blame myself because of him. We have no hope, that's what the doctors say anyway, that his life is short" (P1).

Theme 2. Physical and Material Burden

Subtheme 1. Physical Strains

"I used to go out a lot, walk around, go to the neighborhood, go to the park to breathe. Now I can't step outside the house, I can't go anywhere. My social life has been zeroed out. Psychologically, I really have a lot of difficulty. My nerves are very bad. I can't tolerate even small things. I feel lonely. Insomnia has already turned my life upside down. I can't sleep, I wake up many times a night, I can't get up in the morning. My head hurts, my back hurts, my shoulder hurts. Sometimes I walk around the house bent double. But I still look at it. Physically, my body is signaling me now. I am running out of strength, but I don't feel comfortable leaving my husband. On the one hand, one ignores oneself, on the other hand, one tries to take care of one's loved ones" (P7).

Subtheme 2. Financial Difficulties

"My biggest problem is financial. Diapers are very expensive, we buy formula, we buy materials... Some of it is covered by the state, but most of it comes out of our pockets. Everything is expensive in this day and age. Sometimes I have guests I want to host at home, but I can't because I don't have the time or the energy. I mean, both financially and spiritually, it is very tight. I have my own health problems. I have a bad back, my sleep is very disturbed. I wake up several times a night, I can't sleep well, and I am not rested in the morning. I am very tired not only physically but also psychologically. I want to talk but I don't think I am understood most of the time. People talk but they don't understand. Only those who have experienced the same thing know" (P9).

Theme 3. Responsibility for Care and Commitment

Subtheme 1. Conscientious Approach

"It is very difficult to give care. I don't have to take care of him, but I can't do it. I couldn't do it in good conscience. They say to get a nursing home or a caregiver, but I heard that they behave badly there. I treat him like a baby with compassion. He can't give the food, he chews for a long time, he can't swallow. I'm afraid it might get in his throat. Bathing him has become a stress in itself. The other day the water stopped, he got cold and I was devastated. She diapers, I clean her, she vomits, I take care of her. My own wife is also sick, her heart squeezes, she faints, but I cannot be there. My mind is both here and there..." (P4).

Subtheme 2. Impact on Family Relationships

"Thanks to my family for their help. We are trying to run it together. We are already connected to each other as a family, otherwise this business would not work on its own. I also get help from my job and my sisters-in-law, so they support me to some extent. We have the salary given by the state, even if it is not enough, we are grateful that it is still something. We do the best we can. That's all I can tell you. I cannot say anything else, I am full of emotion but words are not enough" (P16).

Theme 4. Need and Seeking Support

Subtheme 1. Lack of Professional Support

"My son supports us but we don't get full support from anyone else. Sometimes the power goes out and we are scared to death. Because our patient's devices work with electricity. What if the electricity cuts off for a long time? What if he stops breathing? These are always on our minds. We bought a generator later on, but that's only up to a point. We don't know what we will do in case of a very long blackout. Even that has become a source of great stress" (P3).

Sub-theme 2. Spiritual and Family Basis

"My brothers are with me, they try to support me. But most of the work falls on me. We didn't receive any support from outside, we didn't even think about it. Such things are not tolerated in our traditions. We have the understanding that we will do whatever needs to be done as a family. That's why we neither applied to social services nor to any other institution. We have to fend for ourselves. But it is a very challenging process both financially and morally. Although I cannot explain it to anyone, I ask God for strength" (P2).

DISCUSSION

The aim of this study was to examine the burden of illness and psychosocial difficulties experienced by caregivers of immobile home care patients in depth. The burden of illness and psychosocial difficulties experienced by individuals who care for immobile home care patients were addressed in four categories.

Psychosocial Attrition

The study demonstrated that individuals providing care to immobile patients faced considerable emotional and psychological strain throughout the caregiving process. An effective psychosocial care service should be provided to patients and their relatives. For effective psychosocial care, it is necessary to know the difficulties experienced by patients, their reactions to the disease, personality traits and coping strategies. Effective psychosocial care must encompass the concerns of not only the patient but also those of their relatives, who often play a central role in the care process.[16] In an effective immobile patient care quality of life model for patients and their relatives; physical well-being (pain, appetite, sleep and rest, ability to function, constipation, fatigue), social well- being (family stress, caregiver burnout, roles and relationships, love, family ties, financial status), psychological well-being (anxiety, depression, pain, spiritual cognition) and spiritual well-being (hope, uncertainty, religiosity, acceptance) should be addressed in a holistic manner (20).

Psychosocial problems negatively affect the quality of life of both patients and their relatives. At this point, the aim of immobile patient care is to increase the quality of life during and after the immobile patient care process by being sensitive to the social and cultural beliefs and values of patients and their relatives and by intervening in the problems they experience due to the disease (19,21). In this context, it is thought that patient relatives should be supported psychosocially to improve their quality of life.

Physical and Material Burden

As a result of the study, it was found that individuals who care for immobile patients experience physical problems and care creates a financial burden for them. Various studies conducted in our country reveal that relatives of patients caring for immobile patients have concerns about care, experience fear of loss and uncertainty, have difficulty in maintaining their daily work, leave their work life due to caregiving, have financial difficulties and loss of income, experience problems in family relationships, and experience losses in their social environment and lives (22-24).

Health professionals who provide home care services to immobile patients state that patients and their relatives experience psychosocial problems in the home care process, including financial difficulties, difficulty in accepting the disease and death, fear of the disease and death process, adaptation problems, multiple losses, disruption of daily routine, mental symptoms, deterioration in family relationships, housing-related problems and caregiver burden.[22] In this respect, it is considered to be a very important necessity to utilize psychosocial support services for the solution of psychosocial problems experienced intensively by patients and their relatives.

Responsibility for Care and Commitment

As a result of the study, it was stated that the care responsibility of individuals caring for immobile patients is very important and

that they conscientiously feel obliged to care for their patients. Başdinç (2019), in his study with palliative care patient relatives, stated that the burden of caregiving generally negatively affects patient relatives (26). Özhan (2019) found that more than half of the patient relatives experienced depression (27). Karakartal (2017), in his study with the relatives of cancer patients in the treatment process, revealed that the relatives of the patients experienced problems such as restriction of their social lives and deterioration of the financial situation during the care process (28).

In immobile patient care, the integrated inclusion of caregivers in the care approach represents a key feature of immobile patient care (29). It is universally recognized that the basic needs of immobile patients are a sense of life, safety and integrity. Many of these basic needs are met by the caregiver who spends a lot of time and shares with the patient (30). These important duties and responsibilities of the caregiver affect caregivers physically, emotionally and socially. Emotionally, caregivers who experience fear or loss (31), as well as long-term caregiving, are often sleep deprived and feel tired and exhausted (32). In addition to determining the factors affecting caregiver burden, it is thought that intervention studies should be developed to reduce these factors.

Need and Seeking Support

The study revealed that caregivers of immobile patients expressed a clear need for psychosocial support as part of their caregiving experience. Life-threatening illness significantly affects the lives of not only patients but also their relatives. In particular, caregivers are negatively affected by this process as they assume many responsibilities for the patient, including personal hygiene, medical care, emotional support, financial and legal duties, housework, patient advocacy, and consultation with health personnel (33). Therefore, it is common for patient relatives to be overwhelmed by the extra responsibilities imposed on them with the immobile patient care process. Many have difficulty caring for a sick relative while trying to fulfill other responsibilities such as work, household chores and caring for other family members. Uncertainty about how to help their loved ones in medical situations, inadequate social support, high levels of anxiety and fear can also increase the stress of relatives (25,34).

Studies have reported that caring for individuals with life-threatening illnesses is associated with depression, anxiety, burnout, fatigue and sleep problems (35). Studies show that patient relatives experience loss of income, losses in their social circles and lives, fear of loss and anxiety during the immobile patient care process (24). Caregiving burden, which is caused by the imbalance between the caregiving role and the roles they fulfill regarding their personal time, social roles, physical, emotional and economic status, negatively affects the health of caregivers (25). In line with the literature, it is thought that the relatives of patients who care for immobile patients should be supported psychosocially in the study results. As a result of a study, those without social security, married individuals, those unable to cope with the challenges of caregiving, those with increased alcohol/tobacco use, those with an educational level of high school or below, parents, women, those in moderate to poor health, unemployed individuals, those taking medication and those with chronic illnesses were found to have higher levels of anxiety, caregiving burden, anxiety, and depression (37).

CONCLUSION AND RECOMMENDATIONS

Conclusion

In conclusion, this study provides preliminary evidence that the process of caring for immobile home care patients negatively affects individuals psychosocially. Relatives of patients experience serious physical, psychological and social problems due to caring for immobile patients and their

sexual lives are also negatively affected. Individuals experience significant financial problems due to caring for immobile patients. It has been determined that providing care to immobile patients negatively affects individuals. It is recommended that sustainable, multicenter studies in which immobile patients and caregivers are handled holistically should be expanded and psychosocial support of patient relatives should be provided by health professionals.

Limitations

One of the limitations of this study is that all participants were family caregivers of immobile individuals receiving home care services in a province in northern Turkey. As the study was conducted with a small, context-specific sample recruited through snowball sampling, the findings reflect the experiences of the participants and may not be generalizable to the broader population of family caregivers of immobile individuals.

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