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Experiences and needs of family caregivers for patients with End Stage Renal Disease (ESRD) in Palestine

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Abstract

Background Family caregivers of patients with End-Stage Renal Disease (ESRD) undergoing hemodialysis play a crucial yet demanding role in patient care. Understanding their experiences and needs is essential for improving support systems and caregiving outcomes. This study investigates the caregiving experiences and needs of caregivers for ESRD patients on hemodialysis in Palestine.

Methods A qualitative descriptive phenomenological approach was employed, utilizing purposive sampling to recruit participants from the Palestine Medical Complex from March 2023 to June 2023. Data collection proceeded until saturation was reached, resulting in a total of 22 interviews. Data were collected through in-depth interviews and analyzed using Colaizzi's phenomenological method to capture the essence of caregivers' lived experiences.

Results The analysis revealed four central themes that illustrate the diverse challenges caregivers encounter: Overwhelming Demands of Caregiving, Altruistic Commitment to Care, Balancing Roles and Responsibilities, and A Journey Marked by Fears and Anxieties. Additionally, six key categories of support needs were identified: Access to Healthcare, Transportation Coverage, Shared Responsibilities, Physical and Psychological Well-being, Information Dissemination, and Scheduling Flexibility. These themes highlight the multifaceted nature of caregiving, encompassing both the emotional and practical burdens faced by caregivers.

Conclusion Palestinian caregivers of ESRD patients experience significant physical, emotional, and financial hardships, compounded by the complexities of caregiving and the burdens of inflexible hemodialysis schedules. These challenges are exacerbated by systemic issues, such as shortages of hemodialysis machines and restrictions imposed by the Israeli occupation, which frequently impede access to essential treatments. To effectively support these caregivers, a multi-faceted approach is required. This should include financial assistance to alleviate economic stress, provision of necessary caregiving resources, and the creation of accommodating environments during dialysis sessions. Additionally, psychological support is crucial to help caregivers manage the emotional toll of their responsibilities. Clear and comprehensive information regarding treatment options and prognosis is essential to empower caregivers in navigating the complexities of ESRD care. Future implications of this study suggest the need for policy interventions aimed at improving healthcare infrastructure, enhancing caregiver support systems, and developing targeted programs to bolster resilience among caregivers. Implementing these strategies will be vital in mitigating caregiver burden and ensuring the sustainability of caregiving within the context of chronic illness management in Palestine.

Keywords Caregiving Experiences, Caregivers, End-Stage Renal Disease, Hemodialysis, Support Needs

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Background

Chronic kidney disease (CKD) has become one of the leading causes of mortality and morbidity in the twenty-first century [13]. CKD is a progressive condition in which kidney function gradually deteriorates, resulting in impaired filtration and accumulation of waste products, as well as fluid imbalances within the body [7]. End-Stage Renal Disease (ESRD) represents the most advanced phase of CKD, occurring when the glomerular filtration rate falls below 15 ml/min, necessitating dialysis or renal transplantation for survival [5].

Estimates suggest that CKD affects approximately 9.1% to 13.4% of the global population, equivalent to 700 million to 1 billion individuals, with around 4 million people worldwide depending on kidney replacement therapy (KRT) for renal support. In Palestine, particularly in the West Bank, the number of patients requiring hemodialysis increased significantly from 458 in 2008 to 1,651 in 2022, reflecting a rising trend in CKD cases similar to that seen in other developing regions [17]. Hemodialysis (HD) remains the most prevalent form of KRT, accounting for approximately 69% of all KRT modalities and 89% of all dialysis treatments globally [4, 6, 23].

The role of caregivers in supporting ESRD patients undergoing hemodialysis is often overlooked, despite the significant physical, emotional, and financial burdens they endure. Their caregiving responsibilities encompass a broad spectrum of tasks, both at home and in outpatient settings, aimed at enhancing or sustaining the quality of life, well-being, and longevity of older adults. These tasks include assistance with daily activities, such as personal care (e.g., bathing, eating, dressing, mobility), meal preparation, grocery shopping, and making necessary phone calls. Additionally, caregivers provide illness-specific support, which involves symptom management, helping patients cope with their condition, and administering prescribed treatments. Caregivers also play a critical role in care coordination, including accessing resources, communicating with healthcare providers, navigating healthcare and social services, and advocating for quality care and services. Financial support is often part of their role, involving direct financial aid and assistance with bill payments. Furthermore, caregivers deliver vital emotional support, offering companionship, reassurance, and a listening presence to those in their care [1, 10, 19].

Cultural expectations and family dynamics significantly shape caregiving practices, especially in collectivist societies such as Palestine, where caregiving is commonly viewed as a family obligation. In these contexts, caregiving is not only a responsibility but also an honor, reinforcing familial bonds and promoting social cohesion [3, 12].

Despite the critical importance of their role, caregivers of ESRD patients face numerous challenges, including physical exhaustion, emotional stress, and financial strain. The caregiving role is time-intensive, often requiring individuals to sacrifice their personal needs and well-being [9]. Caregivers also encounter additional stressors, such as the costs of medical treatments, caregiving equipment, and balancing work with caregiving duties [1]. These challenges are further compounded by the emotional toll of watching loved ones endure a life-threatening condition, which can lead to anxiety, depression, and social isolation [20].

In Palestine, the caregiving experience is uniquely shaped by the political context, as the Israeli occupation poses significant barriers to accessing healthcare services. Checkpoints, curfews, and the geographical separation of communities create logistical challenges for caregivers, making it difficult to accompany patients to dialysis appointments or seek emergency care [16]. The scarcity of healthcare resources, including dialysis machines and medications, adds to the burden on caregivers, who must navigate a complex healthcare system under politically imposed restrictions [11].

Existing research on caregiving in the context of hemodialysis has largely overlooked the unique experiences and needs of caregivers in Middle Eastern countries, particularly in Palestine. Given the rising prevalence of ESRD in the region and the increasing number of patients requiring dialysis, it is essential to explore the specific challenges faced by Palestinian caregivers. This study aims to address this gap by examining the caregiving experiences and needs of family caregivers for ESRD patients on hemodialysis in Palestine. The findings will contribute to a broader understanding of caregiving in a conflict-affected region and provide valuable insights for developing targeted interventions to support caregivers in this context.

Method

A qualitative descriptive phenomenological approach was employed to elucidate the subjective experiences of these caregivers. This approach was selected for its emphasis on understanding the essence of lived experiences through thorough exploration [8].

Study design and setting

To enable the exploration of varied caregiving experiences, the Palestine Medical Complex (Ramallah Governmental Hospital), the largest governmental hospital in the West Bank, was selected as the study's participant recruitment site. Established in 1963, the Palestine Medical Complex holds the distinction of being the region's primary dialysis center. With a capacity of 45 dialysis machines, the facility serves around 300 patients from different districts, enhancing the diversity of potential participants.

The dialysis unit spans two floors: the first-floor houses 16 dialysis machines, while the second floor accommodates 29 machines, all supported by a team of 22 nursing staff. This comprehensive setup offered an ideal environment for recruiting participants, allowing access to a range of caregiving experiences across the patient population.

Participants and sampling

Initially, the researcher, in collaboration with healthcare providers within the dialysis unit, identified patients who had been receiving hemodialysis for over six months. To achieve maximum diversity among participants, patients were selected across different genders, age groups, marital statuses, educational backgrounds, and dialysis schedules.

Subsequently, primary caregivers were identified with input from the patients themselves. Eligibility criteria for caregivers included the following: (a) they had to be recognized by the patient as a family member primarily responsible for providing unpaid home care, (b) they were at least 18 years of age, and (c) they were willing to participate and share their caregiving experiences. To further ensure variation, caregivers of both genders, with diverse marital statuses, educational levels, and familial relationships, were included. Data collection continued until saturation was achieved, with 22 interviews conducted, at which point no new themes or insights emerged.

During the data collection process, one male caregiver declined to participate in the study after being provided with the necessary information regarding its purpose, procedures, and confidentiality measures. His decision was respected in accordance with ethical guidelines, which emphasize the importance of voluntary participation and the right to withdraw at any stage.

Ethical consideration

The study adhered strictly to ethical considerations to ensure the rights, privacy, and well-being of all participants. Ethical approval was granted by the Institutional Review Board (IRB) of the University of Jordan (Decision 124–2022), as well as from the hospital administration. To uphold transparency and respect for participants, informed consent was obtained from each participant before data collection. Participants were provided with comprehensive information on the study's objectives, methods, potential benefits, and any associated risks. They were also informed about their right to withdraw from the study at any stage without facing any negative consequences, thereby reinforcing their autonomy and voluntary participation.

To safeguard participants' confidentiality, interviews were conducted in a private and comfortable setting, ensuring an environment where participants felt secure in sharing sensitive and personal information. Anonymity was strictly maintained throughout the study, with all identifiable information removed from transcripts and replaced with unique codes. Audio recordings and transcripts were stored securely, accessible only to the researchers involved, and were protected by encrypted files to prevent unauthorized access.

Moreover, to ensure participants' privacy, all personal identifiers were excluded from data presentations, publications, or reports. At the conclusion of the study, all raw data, including audio recordings, transcripts, and consent forms, were securely destroyed to further protect participant confidentiality. These measures not only adhered to ethical guidelines but also fostered a respectful and secure research environment, allowing participants to share their experiences openly and without fear of identification or breach of privacy.

Data collection process

Data collection for this study took place from March 2023 to June 2023, involving in-depth, face-to-face interviews guided by a semi-structured interview protocol. This approach was designed to encourage participants to express their thoughts and feelings freely. The researcher utilized a semi-structured interview guide developed by Oyegbile and Brysiewicz [19] to explore caregivers' experiences, as outlined in Appendix A. Additional questions were incorporated to investigate the needs of the caregivers. Permission to use the tool was obtained, as documented in Appendix B.

The semi-structured interview guide consisted of two sections. The first section gathered demographic information from participants, while the second section focused on exploring caregivers' experiences and needs related to patients with ESRD. To ensure accurate data collection, the researcher used an audiotape recorder to document the interviews.

Following ethical approval from the relevant authorities, the study proceeded with the following steps:

1. Registered nurses in the hemodialysis units assisted the primary researcher (ZS) in identifying patients diagnosed with ESRD.
2. The researcher introduced herself to the patients and explained the study's purpose.

3. The researcher identified the primary caregivers by consulting with the patients.
4. In collaboration with the nurse, the researcher met with the caregivers in a quiet and private room to explain the study's objectives and procedures.
5. The researcher ensured that the caregivers understood their participation was voluntary and that their decision would not affect the care provided to the patients. Participants were free to withdraw at any time without consequence.
6. For caregivers who were not present during their patients' dialysis sessions, the patients were asked to bring their caregivers to the next session, or the researcher contacted them by telephone to arrange a face-to-face interview.
7. Caregivers who agreed to participate completed an informed consent form with the understanding they could withdraw at any time.
8. Interviews were scheduled at times convenient for the participants. They were informed that the interviews would be conducted in a quiet and private room and recorded on an audiotape recorder, ensuring that no personal identifying information would be included in the recordings. The recorded data was securely stored and accessible only to the researcher.
9. During the interviews, which lasted between 25 and 50 min, the researcher posed probing and clarifying questions while documenting the discussions using an audiotape recorder.

Ensuring participant emotional safety

The researcher implemented a range of strategies to address and mitigate participant distress throughout the interview process. At the onset of each session, the researcher initiated a friendly introduction aimed at establishing rapport and fostering an atmosphere of trust, thereby promoting open communication. To further ensure participants' comfort, the interviews were conducted in a private and secure environment, which allowed participants to feel at ease and protected from external distractions. Additionally, the researcher demonstrated a sincere interest in participants' narratives by actively engaging with their stories through both verbal affirmations and nonverbal cues, such as nodding, which helped to convey empathy and attentiveness.

Recognizing the emotional intensity of the subject matter, the researcher consistently acknowledged and validated participants' emotions. For instance, expressions such as "That sounds really difficult" were used to affirm the participants' feelings and experiences, fostering an environment of emotional safety. The researcher also implemented periodic checks on participants' emotional states throughout the interviews, offering breaks when necessary and respecting participants' boundaries by permitting them to skip questions or topics that may have caused discomfort or emotional distress.

After the interview, the researcher allocated time for debriefing, ensuring that participants had the opportunity to reflect on their experiences during the interview. This post-interview discussion was aimed at addressing any emotions that may have arisen during the process, providing participants with reassurance and support, and allowing them to process any distressing feelings in a supportive and empathetic manner.

Data transcription, translation, and analysis

The process of data transcription and translation in this phenomenological research was conducted with meticulous attention to accuracy, cultural nuance, and linguistic integrity. All interviews were conducted in Arabic, the participants' native language, to ensure they could comfortably and fully express their thoughts and emotions.

Each day, following data collection, the interviews were promptly transcribed to uphold the integrity and accuracy of the data. This immediate transcription served multiple purposes. Primarily, it allowed the researcher to capture participants' responses while the context and subtleties of the interviews were still vivid, minimizing the risk of recall bias or misinterpretation. Transcribing on the same day also allowed the researcher to engage deeply with the data, fostering an initial level of immersion and familiarization with emerging themes or significant statements.

Additionally, this approach facilitated continuous reflection on the data, enabling the researcher to refine the interview process dynamically and identify areas warranting further exploration in subsequent sessions. By transcribing each interview verbatim at the end of each day, the researcher maintained a rigorous and organized approach to data management, preserving all verbal details and subtle conversational cues critical for later analysis.

Following transcription, the data analysis was conducted in Arabic to maintain the authenticity of participants' voices and experiences. This approach allowed the researcher to identify and interpret key themes, patterns, and nuanced expressions that might have been diluted through direct translation. By analyzing the data in its original language, the researcher maintained a holistic and intuitive understanding of the lived experiences of caregivers, benefiting from the cultural and contextual depth present in the original text.

Only after the thematic analysis was complete were the main themes and significant statements translated into English for reporting purposes. This sequential approach ensured that translation did not compromise the meaning or depth of participants' lived experiences. Consequently, this method preserved both linguistic and cultural integrity, allowing for an accurate and meaningful representation of the caregivers' experiences throughout the study.

The process of data analysis in this phenomenological study was guided by Colaizzi's method of phenomenological inquiry, which comprises seven distinct steps, as outlined by Speziale and Carpenter [22]. The first step involved familiarization with the data, where the researchers engaged deeply with the interview transcripts to immerse themselves in the participants' narratives. This initial immersion was crucial in developing an understanding of the context and content of the caregivers' experiences.

Next, the researchers identified significant statements within the transcripts, highlighting key phrases and expressions that captured the essence of the caregivers' experiences. This step involved careful reading and reflection, allowing the researchers to discern which aspects of the narratives were most relevant to the research questions and objectives. Following this, the researchers formulated meanings from the significant statements, interpreting the underlying themes and emotions expressed by the participants.

In the fourth step, the researchers clustered these meanings into themes, identifying patterns that emerged across different interviews. This thematic grouping facilitated a clearer understanding of the shared experiences and challenges faced by the caregivers. Subsequently, the researchers developed an exhaustive description of the phenomenon under study, articulating a comprehensive narrative that encompassed the key themes and insights gleaned from the data.

The sixth step involved the creation of a fundamental structure, which synthesized the themes into a coherent framework that represented the caregivers' lived experiences. This structure provided a foundation for understanding the complexities of their roles and the emotional landscapes they navigated while providing care to patients with ESRD. Finally, the verification of the fundamental structure was conducted to ensure the findings accurately reflected the participants' voices and experiences, allowing for feedback and refinement of the themes identified.

Throughout this analytical process, the data were analyzed in the original Arabic language, preserving the authenticity and nuance of the participants' voices. This choice enabled the researchers to uncover key themes, patterns, and subtleties that might have been lost in translation. The analysis was a collaborative effort among all researchers involved in the study, fostering a holistic and intuitive understanding of the data without relying on any software for analysis. Each researcher contributed their unique insights and perspectives, enriching the analysis and ensuring a comprehensive exploration of the caregivers' experiences.

Once the thematic analysis was finalized, the researchers translated the key themes and significant statements into English for reporting purposes. This careful translation process was undertaken to ensure that the meaning and depth of the participants' lived experiences remained intact, thereby allowing for an accurate representation of the caregivers' perspectives. By adhering to Colaizzi's method and engaging in a rigorous and systematic approach to data analysis, the researchers effectively illuminated the complexities of caregiving in a culturally relevant context, contributing valuable insights to the existing body of knowledge.

Results

Demographic characteristics of participants

In this qualitative study, 22 caregivers were interviewed, the majority of whom were female ($N=21$, 95.5%). Participants' ages ranged from 24 to 68 years, with caregiving experiences spanning from five months to eleven years. The sample included 9 wives (40.9%), 5 mothers (22.7%), 3 daughters (13.6%), 3 daughters-in-law (13.6%), 1 son (4.5%), and 1 sister (4.5%). Notably, 18 caregivers (81.8%) were unemployed, and 19 participants (86.4%) lived with the patients they cared for. These findings highlight the demographic diversity and caregiving dynamics among the participants. Table 1 provides a detailed overview of the participants' characteristics, and Table 2 presents themes of caregiver experiences for end-stage renal disease patients on hemodialysis.

Caregivers experiences

The analysis of participants' accounts revealed four primary themes along with their sub-themes: the overwhelming demands of caregiving, altruistic commitment to care, challenges in balancing roles and responsibilities, and a journey marked by fears and anxieties.

Theme 1. The overwhelming demands of caregiving

Subtheme 1.1. Living with physical and psychological pain The physical demands of caring for patients on maintenance hemodialysis were extremely challenging for caregivers, leading to significant exhaustion and pain. A 35-year-old daughter caring for her mother stated, *"I have developed pain in my hands, legs, and shoulders due to constantly pulling my mother on the wheelchair and transferring her to and from it."* Also, a 50-year-old male caring for his mother for 11 years shared, *"My caregiving*

Table 1 Characteristics of the participants

Caregiver ID	Gender	Age	Marital Status	Relationship to the Patient	Years/ Months of caregiving	Educational Level	Working Status	Living with the Patient
1	Female	47	Married	Wife	8 months	Secondary school	Self-employed	Yes
2	Female	56	Married	Wife	5 months	Elementary School	unemployed	Yes
3	Female	43	Married	Mother	5 Years	Secondary school	unemployed	Yes
4	Female	62	Married	Wife	5 Years	Secondary school	unemployed	Yes
5	Female	56	Married	Wife	7 Years	Elementary School	unemployed	Yes
6	Female	68	Married	Wife	5 Years	Elementary School	unemployed	Yes
7	Female	61	Married	Mother	2 Years	Secondary school	unemployed	Yes
8	Female	40	Married	Daughter in law	7 Years	Secondary school	unemployed	Yes
9	Female	41	Married	Wife	3 Years	Elementary School	unemployed	Yes
10	Female	58	Married	Wife	5 Years	Secondary school	unemployed	Yes
11	Female	40	Married	Daughter	one year and four months	Elementary School	unemployed	No
12	Female	47	Married	Mother	5 years	Secondary school	unemployed	Yes
13	Male	50	Married	Son	11 Years	Secondary school	unemployed	Yes
14	Female	43	Single	Sister	one and half year	Secondary school	unemployed	Yes
15	Female	25	Married	Daughter in law	Three years and six months	University	unemployed	No
16	Female	51	Married	Wife	Five years and a half	Secondary school	unemployed	Yes
17	Female	49	Married	Mother	1 year	Elementary School	unemployed	yes
18	Female	42	Married	Daughter in law	One and half year	Elementary School	unemployed	No
19	Female	49	Married	Wife	5 years	Elementary School	unemployed	Yes
20	Female	65	Widowed	Mother	7 years	Elementary School	unemployed	Yes
21	Female	24	Single	Daughter	3 years	University	Part-time Job	Yes
22	Female	35	Single	Daughter	10 Years	Bachelor	Full-time Job	Yes

Table 2 Themes of caregiver experiences for end-stage renal disease patients on hemodialysis

	Themes	Sub-Themes
Caring Experiences	The Overwhelming Demands of Caregiving	• Living with Physical and Psychological Pain • Experiencing Financial Stressors
	Altruistic Commitment to Care	• Limiting Personal and Social Life • Neglecting Self Needs and Personal Care • Decreased Emotional Intimacy
	Challenges in Balancing Roles and Responsibilities	• Compromising the Needs of the Family • Struggling with the Shifting in Roles and Expectations
	Journey Marked by Fears and Anxieties	• Fear of Inability to Access Dialysis Machine • Constant Worries of the Inconvenient Dialysis Scheduling • Worries of Patient Non-Compliance

for my mother has had an impact on my physical health, as I now experience back pain. I live on the second floor, while my mother lives on the third floor, and she cannot walk at all. There is no elevator in the building, and we do not have a wheelchair due to financial difficulties. On dialysis days, I have to carry my mother on my back from the third floor to the main entrance and back up to the third floor after her session."

Beyond physical fatigue, caregivers faced emotional and psychological distress. A 43-year-old mother caring for her young daughter expressed this as, *"Our hearts are heavy, and our minds are burdened with unspoken emotions. We are struggling with inner sorrow and pain. The situation confines us, leaving no room for personal outings, enjoyment, or comfort. Our lives oscillate between exhaustion and brief moments of relief from yesterday's weariness."*

Subtheme 1.2. Experiencing financial stressors Caregivers stated significant stress due to the financial responsibilities of caring for patients undergoing hemodialysis. They mentioned that caregiving involved not only physical care but also expenses for transportation, medications, and homecare supplies. A 50-year-old male caring for his mother stated, *"I buy my mother's medications every month with my own expenses, which costs around 500 shekels per month. Additionally, we use public transportation to attend her kidney dialysis sessions, which costs about 200 shekels weekly. It's very costly, but we have no other choice."*

Another 47-year-old mother caring for her son explained, *"We struggle a lot with transportation to get to the hospital. We have to take two different modes of transportation just to reach the hospital, and the same goes for returning home. This is not only financially burdensome but also physically exhausting. Sometimes when my husband has free time, he would drive us to the hospital, and at other times, he would let our son drive the car. Last week, my husband wasn't available to drive us, and since I don't know how to drive, I had to wait for my son to wake up and be well enough to drive us to the hospital. It's really a challenging situation."*

The financial burden was also exacerbated by challenges facing the Palestinian Ministry of Health due to the Israeli occupation, which impacts the healthcare system by limiting or delaying the importation of essential medications. This results in higher costs for patients, forcing them to purchase medications from pharmacies at elevated prices. A 56-year-old wife caring for her husband said, *"At times, the Palestinian Ministry of Health does not provide the medications that the patient needs, especially costly medications, which compels us to purchase them at exorbitant prices from pharmacies with our pocket money. For instance, one medication cost me 270 shekels and another 70 shekels, which is very expensive."*

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Theme 2. Altruistic commitment to care

Subtheme 2.1. Limiting personal and social life Caregivers often experienced increased isolation from their social lives due to the extensive time required to meet patients' needs. This demanding role limited their time and energy for social interactions and leisure activities, leading to a gradual withdrawal from their social circles. Ongoing caregiving responsibilities took precedence, prompting caregivers to prioritize their patients' well-being over personal commitments. A 47-year-old female caring for her husband expressed, *"My social life has been profoundly affected since my husband fell ill. I can no longer go out whenever I want, and even visiting my family has become infrequent, leaving me longing to see them. I can't take my husband with me or leave him alone, fearing the worst if something were to happen to him. Everything in my life has changed."*

A 35-year-old daughter caring for her mother said, *"I have rejected many suitors and sacrificed marriage because I am taking care of my mother, and there is no one else to take care of her except me."*

Subtheme 2.2. Neglecting self needs and personal care Participants frequently neglected their own needs, such as time for enjoyment, relaxation, and personal goals. The demands of caring for patients and accompanying them to dialysis sessions consumed much of their time, leaving little opportunity for self-care and personal aspirations. A 43-year-old mother caring for her daughter said, "*I don't attend social gatherings on the days when my daughter has her dialysis session, and even on days when I plan to go out, meet people, and change my environment, everyone asks me about my daughter, so I can't find joy. Sometimes, I think of going to Ramallah, walking in the streets, and enjoying new things, but in the end, I'm just sad inside, feeling exhausted and restricted. I can't relax, and I can't enjoy anything. Even if my neighbor comes to cheer me up and change the atmosphere, as soon as she asks about my daughter and her tests, there's no way to escape from the aura of illness."*

The following statement reflects the immense difficulty of kidney dialysis, especially when the patient is one's own child. The experience is both emotionally and physically taxing, affecting the caregiver's well-being. It underscores the constant attention required, regardless of the caregiver's health, and highlights the dedication and sacrifice involved. The caregiver emphasizes the need to prioritize the patient, even when time is limited, illustrating the relentless nature of caring for a loved one undergoing dialysis. A 47-year-old mother caring for her son expressed, *"The experience of kidney dialysis is extremely challenging and painful, especially when it's your child. It takes a toll on both your mental and physical well-being. Whether you're feeling sick or not, you have to constantly look after them. You have to make time for it, or even create time when there seems to be none. You're compelled to get up and attend to the patient under your care."*

Another 24-year-old daughter caring for her father said, "*I had to give up a lot in my life just to accompany my father to his morning dialysis sessions. For instance, I had to delay completing my college courses due to conflicts between some mandatory courses and my father's kidney dialysis schedule. These college courses were offered yearly rather than on a semester basis."*

Additionally, many caregivers reported a diminished focus on personal grooming due to the demands of caring for their loved ones and accompanying them to dialysis sessions. This shift in priorities resulted in a gradual neglect of their own grooming routines. A 51-year-old female caring for her husband stated, *"My personality has changed and shifted with my husband's illness, not just in my appearance and hair, but also in my behavior and emotions. I don't recognize myself anymore. I don't know what happened to me. Have I been struck by boredom, or have I lost the desire to take care of myself?".*

Another 25-year-old female caring for her mother-in-law expressed, *"I feel like I have neglected myself and my outward appearance. It's like imagining your face without cleaning it, and you stop taking care of yourself for your husband. He even tells me that I have let myself go and aged. But is that not because I worry about your mother? Additionally, I cannot bear the burden of another pregnancy. All of this affects my health, and I can't even go to the doctor to check on myself and address any potential issues."*

Subtheme 2.3. Decreased emotional intimacy Participants reported a "decline of Intimacy" in their relationships, noting a decline in their once vibrant sexual connections. The disease shifted their romantic intimacy to a sibling-like bond. A 47-year-old female caring for her husband expressed, *"After my husband started undergoing kidney dialysis, our lives changed. We sleep separately, each in our own room. However, I keep my bedroom door open in case my husband needs anything during the night."*

Another 56-year-old female caring for her husband said, *"Since my husband started kidney dialysis, our relationship has become like that of siblings, and he is no longer functional sexually."*

Theme 3. Difficulties in balancing roles and responsibilities

Subtheme 3.1. Compromising the needs of the family Balancing patient care with family obligations often required caregivers to sacrifice personal time and neglect household tasks. Their commitment to the patient's well-being sometimes hindered the maintenance of harmony between caregiving responsibilities and family needs. A 43-year-old mother caring for her daughter expressed this as, *"On days without kidney dialysis, I feel relieved compared to the days when it takes place. For example, on dialysis days, when I used to go with my daughter, I would make quick sandwiches instead of cooking. My husband didn't like the food I prepared; he wanted different food and cooking. I felt there was no cooperation, and sometimes, I had to leave my daughter during the dialysis session and go back home to cook, then return to the hospital just to check on her. I felt like no one understood my situation."*

Another 47-year-old mother caring for her son expressed, "*We have changed our eating system at home since my son started kidney dialysis. I only buy the permissible vegetables that he can eat. Even juices and cocktails, I no longer prepare them at home for his sake. If we buy bananas or dates, I feel an inner sadness for my son* *because he's not allowed to eat them. Even on the day of dialysis, when I tell him he can eat these fruits, he's not willing."*

Subtheme 3.2 Struggling with the shifting in roles and expectations Caregivers face the complex challenge of adapting to shifts in roles and expectations within the family. As the primary provider or another member assumed the caregiver's role due to illness, caregivers navigated altered family dynamics, managing new responsibilities often without significant support from others. A 49-year-old female caring for her husband stated, *"My husband used to be the main provider for the household, but with his illness and inability to work, my children were forced to leave their universities and search for jobs in order to support us. They have taken on their father's role, providing the necessary money for medications and household expenses. I have now become responsible for taking care of him, accompanying him to kidney dialysis sessions and other doctor appointments for regular check-ups."*

Moreover, caregivers adopted the new role of healthcare providers for their patients, requiring vigilance in monitoring medications and lab results. This transition made it challenging to balance previous responsibilities with caregiving demands, often resulting in constant alertness for the patient's well-being. As they navigated these role changes, caregivers struggled to maintain family equilibrium amid the pressures of patient care. A 43-year-old mother caring for her daughter said, *"The patient requires a companion who is awake and attentive at all times. Even though my daughter is very committed to her medications and remembers to take them on time, there are instances when she misinterprets the doctor's instructions or forgets what was said to her. That's why I remain vigilant and focused on everything the doctor says, especially when it concerns medications. For example, in a medication called alpha, there are two versions: one microgram and a quarter microgram. My daughter doesn't differentiate between them and thinks they are the same medication. That's why the patient needs someone to be with them and guide them."*

Another 47-year-old mother caring for her son expressed, *"I'm telling you, I'm a doctor without a degree. Thank God, my memory is sharp. I memorize medications, test results, everything. Even what the doctor tells me, I remember it. I actually wanted to study nursing, but circumstances changed, so now I've become a doctor for my children due to all that we've been through."*

Furthermore, caregivers face a significant challenge in navigating changing roles and expectations within the family. At times, they were responsible for the well-being of multiple patients, complicating their caregiving duties. Some caregivers also had to balance dual roles, such as being both nurturing mothers and dedicated caregivers for an ill child, requiring skillful management of these complex responsibilities while striving to maintain family cohesion. A 51-year-old female caring for her husband stated, *"I take care of both my sick husband and my elderly mother at the same time. In the morning, I accompany my husband to his dialysis sessions. Once he's done and back home with his needs taken care of, I then attend to my mother's needs as she is also a patient."*

Theme 4. A Journey marked by fears and anxieties

Subtheme 4.1. Fear of inability to access dialysis machine In caregiving for dialysis patients, participants commonly expressed fear regarding access to dialysis machines. Patients often worried about the unavailability of machines during scheduled sessions, compounded by the challenges posed by the Israeli occupation and political conflicts that could hinder access to hemodialysis. This uncertainty and vulnerability regarding machine availability and geopolitical factors heightened the distress felt by both patients and caregivers. A 43-year-old mother caring for her daughter expressed, *"My daughter always used to rush me and urge me to go with her early every time she had a kidney dialysis session, just to ensure that there would be a dialysis machine available for her. She would tell me, 'Let's go to the hospital before our appointment so that we make sure there's a dialysis machine available for her.' Sometimes we would arrive on time, and other times we would be a bit late. When we arrive, we do not find a dialysis machine available, it would be a major problem for her. Many times, we would have to wait for a machine to become available. It's like the patient already has the burden of the illness, and the additional worry of whether a machine will be available during her appointment adds even more stress."*

Another 24-year-old female caring for her father said, *"During the last events in the town of Anata, when the Israeli army closed the town, we couldn't go to the dialysis session on the first day because the army turned us back. The next day, we struggled a lot with them to allow us to leave for the hospital. Due to the total lockdown imposed on the area and the lack of transportation, we were forced to stay in the hospital for weeks to ensure that we could receive the dialysis sessions."*

Another 50-year-old male caring for his mother said, *"We often faced difficulties reaching the hospital due to the Israeli occupation. Sometimes they would take our IDs and check for any issues. Sometimes they even made us get out of the car. My mother, who is patient and unable to walk, falls under the category of people with special needs. Despite that, they would tell her to get out of the car, which was tiring and exhausting for her and for me. Even though she carries a special card for kidney dialysis patients, there were times when they wouldn't cooperate with her. At times, we were forced to delay her dialysis appointments because we had to take alternative routes due to road closures by the occupation forces."*

Subtheme 4.2. Constant worries of the inconvenient dialysis scheduling In the caregiving landscape for dialysis patients, a common concern was the challenges of inconvenient dialysis scheduling. Both caregivers and patients struggled to adhere to schedules that often disrupted their daily routines, adding stress to an already demanding situation. A 43-year-old mother caring for her daughter expressed, *"The challenge with kidney dialysis is that we need to adapt to its schedule, not the other way around. My daughter's dialysis sessions were scheduled at 8:00 PM, and they would end around 12:00 or 1:00 AM. Then, we had to request a taxi in the middle of the night to take us home. I used to tell the nurse to prioritize those who have their own cars at this late hour, and we would take a slot earlier. However, she didn't agree and said that everyone has their own schedule. It's truly a difficult and challenging situation."*

Subtheme 4.3. Worries of patient non-compliance Caregivers frequently experienced anxiety regarding their patients' reluctance to follow dietary restrictions, leading to increased stress about potential health impacts. This concern over ensuring patient compliance added to caregivers' responsibilities, making their caregiving experience emotionally taxing. A 47-year-old mother caring for her son expressed, *"As a mother, I find it very challenging to navigate my son's special dietary restrictions. Not all food or drinks are allowed, which is quite overwhelming for us. It's difficult to decide what to feed him. When his siblings buy snacks or treats, he can't resist and feels the need to eat with them. Even though I monitor his diet, and he knows that certain foods can be harmful and tiring for him, there are times when he gives in and says, 'Just let me eat whatever.' It's frustrating for me, and I can tell he's frustrated too."*

Another 51-year-old female caring for her husband said, *"God, everything was difficult. I mean, my mental state was exhausted. I even went to a psychologist because of this matter. It's tiring because he's negligent and doesn't care about his diet or medications. I keep getting upset and pressuring myself because of his actions and his lack of concern. I mean, one's mental state gets worn out."*

Caregivers' Needs'

This study highlights the challenges faced by caregivers of ESRD patients on hemodialysis and identifies their critical needs. Caregiving for ESRD patients is both demanding and emotionally taxing. Caregivers have expressed essential needs across various domains, including access to healthcare, transportation support, shared responsibilities, physical and psychological wellbeing, effective information dissemination, and scheduling flexibility.

Access to healthcare

Caregivers emphasized the need for convenient and accessible medications and resources to effectively fulfill their roles in caring for hemodialysis patients. Many noted the challenges of obtaining costly and often unavailable medications at the hospital. A 56-year-old female caring for her husband stated, *"There aren't medications available through the ministry of health. We have to buy them from outside. The cost is somewhat high, you know? Currently, we stopped using the one that is expensive. Now they've switched to different medications, which we have to get from the pharmacy on our own, and it's more expensive, of course."*

In addition to medications, caregivers highlighted the importance of resource availability, such as wheelchairs, bed sheets in dialysis units, and sufficient dialysis machines. A 24-year-old female caring for her father said, *"There are many aspects that the hospital should address to ensure the comfort of patients and their families. For example, they should provide an adequate number of wheelchairs here in the department to facilitate the movement and transportation of patients. It's quite exhausting for us to have to carry the patient to and from the car in the hospital."*

Transportation coverage

Transportation is a significant concern for both patients and their caregivers. Caregivers emphasized the importance of providing transportation services to and from the dialysis unit, viewing it as an essential entitlement for both the patient and their family. A 62-year-old female caring for her husband said, *"At the very least, transportation for the patient and their family should be provided; this is the least of their rights."*

Many caregivers also highlighted the need for financial support to cover transportation and other essential caregiving expenses. A 43-year-old mother caring for her daughter expressed, *"Not only do we need transportation support, but there also has to be financial assistance for the patient. This girl has the right to live with dignity. Many families of patients have children and families to support. Should they resort to begging? It's not just help, it's a rightful financial support throughout the year."*

Another 56-year-old female caring for her husband shared, *"Whenever my husband feels tired at night, we have to call a taxi to go to the hospital. Of course, transportation is costly. It costs us 16 and 16, a total of 32 shekels, not to mention food expenses, let's say 15 shekels. So, it amounts to around 50 shekels every day for kidney dialysis. If there's someone who could financially support us for transportation, I swear, ever since my husband started kidney dialysis, our financial situation has deteriorated. I even had a little gold, and I sold it to use for transportation. Now I don't have anything left, not even a single shekel."*

Shared responsibilities

The role of caregivers is time-consuming and demanding, requiring significant effort. As a result, caregivers need rest to focus on their well-being; however, such breaks are only possible if someone else can take over their caregiving responsibilities for family members undergoing hemodialysis. A 61-year-old female caring for both her daughter and elderly mother expressed, *"I used to take care of my mother before my daughter had kidney dialysis. My mother had a stroke, and I used to visit her. After my mother passed away, the responsibility fell on my daughter. I haven't even reached a year of rest yet. It feels like I've had such bad luck. If there was someone who could take this burden off me and give me some relief."*

Another 40-year-old female caring for her father said, *"May God help everyone who has a kidney patient undergoing dialysis. You don't truly understand the situation until you experience it firsthand. It's not just talk; it's not the same as reality. There are people who stand by and help. My sister, our children, and I take turns for kidney dialysis sessions with a substitute, but what I see here is that there's no substitute. It's nice to feel that members of the family want to ease the burden, even if just for a day. Still, each one of us has their own responsibilities, so it does alleviate the situation a bit."*

Physical and psychological well-being

Some caregivers were extremely stressed by the demands of caring for patients and requested professional psychological help. Although they feel that they offer support to their patients, they believe the demand for care is too high and may contribute to mental illness. A 51-year-old female caring for her husband stated: *"My experience with dialysis has been extremely hard, especially when accompanying my husband to his dialysis sessions. Seeing the blood being drawn out by the dialysis machine and going through this entire ordeal has been emotionally taxing for me. I found myself struggling mentally and eventually had to seek help from a mental health professional due to the psychological pressure I was under. My husband's disregard for his health and well-being added to my distress as I constantly worry about his behavior, causing me significant psychological strain."*

Another 47-year-old mother caring for her son expressed: *"Absolutely, providing psychological support is crucial for both the family and the patient, particularly when the patient experiences significant physical strain throughout the day. For instance, not long ago, my son was incredibly fatigued. His dialysis shunt was swollen, and he suspected it was malfunctioning and needed replacement. He became upset and cried, refusing to eat. At that moment, I was emotionally exhausted as well, and I couldn't help but cry."*

Caregivers also mentioned the importance of a tranquil setting and comfortable amenities, such as providing water and a heating system to help them unwind during their hemodialysis waiting periods. A 43-year-old mother caring for her daughter, who requires one and a half hours to travel to the hospital, said: *"Why isn't there accommodation near the hospital for patients and their families coming from distant places? It would be really helpful if there were places here where families of patients can find comfort."*

Information dissemination

Most caregivers stressed the need for clear and comprehensive information about their treatment and prognosis, particularly regarding the interpretation of lab results. A 25-year-old female caring for her mother-in-law said: *"It feels like the medical follow-up is neglected by the doctors. You have to chase after them for tests and such; it's like you have to constantly remind them. Sometimes there's a doctor, but they're not always available...... Yes, I feel they should show more care for the patients. It's not like you go there, and they tell you about the monthly tests or anything. You have to go and ask."*

Another 58-year-old female caring for her husband expressed, *"Some doctors here in the hospital do care about the patient. Every month, we have tests, and the doctor comes to quickly inform me about them, but I can't grasp what they're saying quickly. So, I go back to ask them to reassure myself, but I can't fully understand everything. My comprehension is slow, and the doctors explain everything quickly. Sometimes, the doctor is accompanied by* *trainee students who explain things to them in English so that they can understand, not us."*

Caregivers requested early healthcare education. They sought comprehensive information concerning patient care, including dietary requirements, anticipated changes in the patient's condition, and vascular access care. A 58-year-old female caring for her husband said, *"At the beginning of kidney dialysis, we struggled a lot to know what foods the patient should avoid. We used to search and inquire on our own, meaning if we didn't ask, no one would provide us with the information. Even the hospital's nutrition specialist didn't offer us the necessary information until a week later, after we requested to see her."*

Another 43-year-old mother caring for her daughter expressed, *"No one informs you about the extent of the challenges you will face due to kidney dialysis, and no one tells you about the medical procedures your sick daughter will undergo for the insertion of the kidney dialysis catheter. It truly is mentally and physically draining."*

Scheduling flexibility

Caregivers highlighted the need for convenient scheduling of hemodialysis sessions that accommodates both patients' needs and caregivers' availability. One statement pointed out that individuals undergoing dialysis must adhere to inconvenient schedules, such as midnight appointments, raising concerns about why more suitable times are not offered, especially for those traveling long distances. This issue is particularly challenging for women, who often return home around 1 a.m. using public transportation. The implication is that current scheduling practices fail to address the practical challenges and safety concerns for patients, especially women. A 43-year-old mother caring for her daughter expressed*: "Here, a person is obligated to adhere to the dialysis schedule rather than the opposite, even if the time, such as midnight at 12, doesn't suit them. Why don't they schedule appointments for those who come from distant places at a more suitable time, especially considering that we, as women, used to return home after dialysis at around 1 in the morning using public transportation?".*

Discussion

The findings of this study shed light on the profound challenges faced by caregivers of hemodialysis patients, illustrating both their personal experiences and critical support needs. Caregiving, particularly for patients undergoing hemodialysis, imposes significant physical and psychological burdens on caregivers, a theme that is consistent with findings from various international studies [1, 19, 24]. These challenges are multidimensional, encompassing emotional stress, financial strain, social isolation, and personal sacrifices that caregivers make to fulfill their roles. Understanding these challenges is crucial for informing healthcare policy and developing support systems that address the needs of caregivers, who often face obstacles that compromise their own health and well-being.

The emotional toll of caregiving is particularly pronounced, as caregivers are frequently confronted with the physical suffering of their loved ones. The emotional strain of witnessing this suffering, combined with the practical responsibilities of caregiving, often leads to feelings of isolation and distress. As noted in the literature, caregivers of hemodialysis patients are at risk for depression, anxiety, and burnout [19, 24]. In this study, caregivers reported high levels of stress, with many describing how the physical, emotional, and psychological demands of caregiving left them feeling overwhelmed. This is particularly evident in their accounts of juggling caregiving duties with other responsibilities, such as work, household chores, and caring for other family members.

A noteworthy observation in this study is that the majority of participants were female caregivers. This is reflective of cultural expectations in many societies, including Palestinian culture, where women traditionally bear the responsibility for family care, particularly in contexts of illness and caregiving. In Palestinian society, as in many others, caregiving is often viewed as a woman's duty, a role that extends beyond caring for children and elderly parents to include ill family members. Female caregivers, in particular, reported significant stress related to their caregiving roles, with many noting that these responsibilities left them with little time for personal activities, work, or social interactions. The cultural expectation that women take on caregiving duties, without adequate support systems, contributes to the physical and emotional strain these caregivers experience. This cultural dimension aligns with broader patterns identified in the literature, which highlight the disproportionate burden of caregiving placed on women in various cultural contexts [19, 21]. These findings underscore the need to consider gender roles and cultural norms when developing support programs for caregivers, as female caregivers may require targeted interventions to help them balance caregiving with other life responsibilities.

Financial stress emerged as another prominent theme in the study. Even in cases where patients were not directly responsible for dialysis costs, caregivers reported significant financial strain. This included the costs of transportation, medications, and other essential resources necessary for the patient's care. Caregivers often face the difficult decision of whether to continue incurring these costs or seek alternative, often less effective, solutions. Some caregivers even resorted to selling property to manage the financial burden, underscoring the severe economic impact caregiving can have. This finding aligns with previous research, which highlighted how caregivers, particularly in low- and middle-income countries, deplete savings and retirement funds to manage the costs associated with chronic illness care [14, 19, 24, 25]. In the Palestinian context, caregivers expressed frustration with the Ministry of Health's inability to provide necessary medications, forcing them to purchase medications at inflated prices from private sources. This further exacerbates their financial difficulties and creates additional stress, as caregivers already struggle with the time-consuming nature of caregiving, which limits their ability to work or generate income.

The need for financial support and more comprehensive healthcare coverage is evident. As the study findings suggest, caregivers in Palestine, as well as in other low- and middle-income countries, face systemic barriers to accessing necessary resources, making them vulnerable to financial hardship. This highlights the urgent need for governments and international organizations to provide financial assistance, transportation coverage, and access to essential healthcare services to alleviate the financial burden on caregivers and ensure that patients receive appropriate care.

Another critical issue that emerged from the study was the significant personal sacrifices made by caregivers. These sacrifices often affect their careers, education, social interactions, and relationships. Caregivers, especially female caregivers, often face the double burden of managing caregiving responsibilities while balancing household duties and professional obligations. This issue of social isolation, particularly among women, has been highlighted in other studies as well [18, 19]. The study also revealed that the intimate relationships of female caregivers are frequently strained, an area that has received limited attention in the existing literature, although some studies have pointed out related stressors [2, 21]. The emotional and psychological toll of caregiving, combined with the practical difficulties caregivers face in managing family and work responsibilities, underscores the need for targeted interventions to support caregivers, especially women, in maintaining their social and personal well-being.

Moreover, caregivers navigate shifting roles and competing responsibilities, which require them to constantly adjust their routines and priorities. This struggle to balance family needs with caregiving duties reflects broader trends observed in caregiving literature, particularly among female caregivers [15, 19]. As caregivers juggle multiple roles, they often face burnout and exhaustion, which can negatively impact their physical and mental health. These findings indicate that healthcare systems must recognize the complexities of caregiving and offer solutions that accommodate the needs of both patients and caregivers, particularly by offering respite care, flexible scheduling, and mental health support.

In the Palestinian context, caregivers voiced concerns about access to dialysis services, including fears related to the availability of dialysis machines and scheduling issues. The findings emphasize how systemic healthcare challenges, such as long wait times and machine shortages, add to the stress experienced by caregivers. Additionally, the geopolitical situation in Palestine complicates access to healthcare. Caregivers expressed not only concerns about delays in appointments but also fears of being unable to reach medical facilities due to Israeli-imposed barriers. These barriers to healthcare access further exacerbate the caregiving burden and highlight the need for greater advocacy for the right to healthcare, particularly in conflict-affected regions. International human rights laws affirm the right to healthcare, even in conflict zones, yet the experiences of Palestinian caregivers demonstrate the violation of these rights, as they face barriers that prevent them from accessing necessary medical treatment. This underscores the urgent need for international advocacy to ensure equitable access to healthcare for all individuals, particularly those in conflict zones.

Implication of the study

The findings of this study have significant implications for future research, policy development, and clinical practice. The study highlights the multifaceted challenges faced by caregivers of hemodialysis patients and underscores the need for comprehensive support systems to address their needs. Clinicians and healthcare providers must recognize the pivotal role that caregivers play in the care of patients with chronic conditions like ESRD and take steps to provide support through education, financial assistance, mental health services, and respite care. Future research should further explore the psychological, emotional, and social aspects of caregiving, particularly among female caregivers, to develop targeted interventions that mitigate the adverse effects of caregiving and promote the well-being of both patients and caregivers. Additionally, healthcare systems, particularly in conflict-affected regions, must be reformed to ensure access to essential services and resources for both patients and caregivers, ensuring that their rights are upheld, and their needs are met.

In conclusion, this study emphasizes the need for systemic changes to support caregivers, particularly in contexts like Palestine, where access to healthcare is further complicated by geopolitical factors. The findings suggest that comprehensive policies and interventions are necessary to address the emotional, financial, and logistical challenges faced by caregivers of hemodialysis patients, ultimately improving the quality of care and well-being for both patients and their caregivers. Additionally, attention must be given to the gendered nature of caregiving in cultural contexts, recognizing the disproportionate burden placed on women and developing gender-sensitive support systems that allow female caregivers to maintain their well-being while fulfilling their caregiving roles.

Limitations of the study

One primary limitation is the underrepresentation of male caregivers in the sample. The study contained only one male caregiver who agreed to participate, which significantly limits the ability to explore and comment comprehensively on the experiences of male caregivers in the context of hemodialysis. This skewed representation of caregivers, with the majority being female, restricts the generalizability of the findings to male caregivers.

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions

Zareefa Shaabna conducted this research, including data collection, transcription, and analysis. Dr. Maysoon Abdalrahim provided supervision throughout the research process and assisted in generating themes and subthemes. Dr. Ruqayya Zeilani reviewed the final version of the study and contributed valuable insights. All authors collaborated to ensure the integrity and quality of the research findings.

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Data availability

The data and materials generated and/or analyzed during the current study are available from the corresponding author upon request. Due to confidentiality agreements and the sensitive nature of the participant data, access may be granted only for legitimate academic or research purposes and in compliance with ethical guidelines.

Declarations

Competing interests

The authors declare no competing interests.

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