



Original Article

Family caregivers' experiences of providing psychospiritual care to patients undergoing hemodialysis in Indonesia: A descriptive phenomenological study

La Rakhmat Wabula^{1,2*}, Krisna Yetti³, Masfuri Masfuri⁴, Widyatuti Widyatuti⁵, Ika Yuni Widyawati⁶, Cahyu Septiwi⁷, Muhammad Agung Akbar⁴

¹Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

²STIKes Maluku Husada, Maluku, Indonesia

³Department of Basic Science and Fundamental Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

⁴Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

⁵Department of Community Health Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

⁶Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia

⁷Department of Medical Surgical Nursing, Faculty of Health Sciences, Universitas Muhammadiyah Gombong, Gombong, Indonesia

ARTICLE INFO

Received 23 April 2026

Accepted 12 July 2026

Available online at:
<http://npt.tums.ac.ir>

Keywords:

family caregivers;
hemodialysis;
Indonesia;
phenomenology;
psychospiritual care

Corresponding Author:

La Rakhmat Wabula, Faculty of Nursing,
Universitas Indonesia, Depok, Indonesia;
STIKes Maluku Husada, Maluku, Indonesia.
E-mail: la.rakhmat.wabula.stikesmh@gmail.com

DOI: 10.18502/npt.v13i3.22135

ABSTRACT

Background & Aim: Patients undergoing long-term hemodialysis frequently experience emotional, existential, and spiritual distress that requires support beyond routine clinical care. Family caregivers are often the closest and most continuous companions throughout the treatment trajectory, yet limited evidence has examined how they experience and enact psychospiritual care in everyday hemodialysis contexts, particularly in Indonesia. This study aimed to explore family caregivers' experiences of providing psychospiritual care to patients undergoing long-term hemodialysis.

Methods & Materials: A descriptive phenomenological study was conducted in two hemodialysis units in Indonesia. Fifteen purposively selected family caregivers of patients undergoing long-term hemodialysis participated in semi-structured in-depth interviews. Data collection continued until informational redundancy was achieved. Interview data were transcribed verbatim and analyzed using Colaizzi's method.

Results: Three major themes were identified: (1) Enacting emotional presence as a therapeutic foundation in everyday care; (2) Facilitating spiritual meaning-making to foster inner peace and acceptance; and (3) Engaging in shared care navigation through practical support and collaborative decision-making. These findings indicate that family psychospiritual caregiving was experienced as a relational and meaning-centered process in sustaining patients' endurance during long-term hemodialysis.

Conclusion: Family psychospiritual care in long-term hemodialysis is a sustained relational practice that integrates emotional presence, spiritual meaning-making, and shared care navigation. Hemodialysis services should recognize family caregivers as important partners in supporting patients' emotional security, spiritual coping, treatment endurance, and gradual acceptance of illness.

Introduction

Chronic kidney disease (CKD) has become a major global challenge, with its burden rising steadily across regions and now extending beyond a purely nephrological concern into a broader public health and health systems problem (1). Recent global estimates show that CKD ranked as the ninth leading cause of death worldwide in 2023, accounting for approximately 1.49 million deaths, while also contributing substantially to disability-adjusted life years (2). This

trajectory signals that advanced kidney disease is no longer a marginal chronic condition, but a high-burden illness with profound implications for survival, functioning, and long-term care needs (3). As the burden of kidney failure grows, the adequacy of care can no longer be judged solely by biomedical indicators, because patients live the illness not only through laboratory values and treatment schedules,

Please cite this article as: Wabula L.R, Yetti K, Masfuri M, Widyatuti W, Widyawati I.Y, Septiwi C, et al. Family caregivers' experiences of providing psychospiritual care to patients undergoing hemodialysis in Indonesia: A descriptive phenomenological study. *Nursing Practice Today*. 2026; 13(3): 355-366.



but through fatigue, uncertainty, suffering, and altered life meaning (4).

For patients progressing to kidney failure, hemodialysis remains the dominant kidney replacement therapy in many countries, including Indonesia (5). Indonesian Renal Registry data for 2024 show that 136,793 patients (98%) were receiving hemodialysis, compared with only 3,085 patients (2%) on Continuous Ambulatory Peritoneal Dialysis (CAPD), confirming the overwhelming dependence on facility-based dialysis in the national care landscape (6). This pattern highlights that kidney failure care in Indonesia remains overwhelmingly oriented toward hospital-based hemodialysis, placing long-term demands on patients, families, and health services (5). Such dominance also underscores the urgency of strengthening the quality, continuity, and person-centeredness of hemodialysis care within the Indonesian healthcare system (7).

Long-term hemodialysis is a multidimensional experience involving symptom burden, impaired daily functioning, and psychological or psychosocial distress among patients receiving maintenance dialysis (8, 9). Within this context, psychospiritual care is clinically relevant because patients may face anxiety, uncertainty, spiritual distress, and challenges in sustaining well-being, treatment adherence, and quality of life (10, 11). Family members are frequently involved throughout the dialysis trajectory, but the meaning of their involvement as experienced by caregivers remains insufficiently understood (12, 13).

However, important gaps remain in the current literature. Existing studies have largely concentrated on caregiver burden, quality of life, stress, coping, fatigue, and general family support (14-17). Less is known about how family caregivers understand and give meaning to their caregiving role when supporting patients through the repeated, demanding, and uncertain experience of long-term hemodialysis (12, 18). This study therefore focused on caregivers' lived experiences to understand how psychospiritual caregiving is perceived,

interpreted, and enacted within family relationships during long-term hemodialysis (19).

The gap is especially consequential in Indonesia. Western studies framed caregiver support in chronic kidney disease as emotional, practical, and informational support obtained through healthcare professionals, family or friends, and wider support systems, while also highlighting caregivers' difficulties in navigating complex healthcare systems (4). In Indonesia, religion, prayer, family support, and community ties strongly shape health behavior and adaptation (10). In Indonesia, religious beliefs, family responsibility, and collective caregiving norms may shape how families accompany patients through chronic illness (20). A contextually grounded qualitative inquiry is therefore needed to illuminate the distinct ways Indonesian families provide psychospiritual care in the course of long-term hemodialysis.

In this descriptive phenomenological study, psychospiritual caregiving was approached as a phenomenon explored through caregivers' lived experiences rather than as a fixed a priori definition. This study aimed to explore family caregivers' experiences of providing psychospiritual care to patients undergoing hemodialysis in Indonesia.

Methods

Study design

This study employed a qualitative descriptive phenomenological design to explore family experiences of providing psychospiritual care to patients undergoing hemodialysis in Indonesia. A qualitative approach was considered appropriate because the study aimed to describe family caregivers' lived experiences and the meanings they attributed to psychospiritual caregiving within the everyday context of long-term hemodialysis. This design was appropriate because it enabled close attention to participants' subjective and relational experiences while allowing themes to emerge

from their descriptions rather than from predetermined analytic categories. The study was reported in accordance with the Standards for Reporting Qualitative Research (SRQR) to enhance transparency and rigor (21).

Setting and participants

This study was conducted in the hemodialysis units of two urban public teaching hospitals in Indonesia that provide maintenance hemodialysis for patients with chronic kidney disease. These settings were selected because family involvement is central to continuity of care and often includes emotional, spiritual, and practical support throughout repeated treatment encounters. Participants were family members who were actively involved in caring for patients undergoing maintenance hemodialysis, including spouses, children, siblings, or other relatives. They were recruited using purposive sampling to include information-rich caregivers with direct and sustained caregiving experience.

The inclusion criteria were: (1) aged 18 years or older; (2) identified as a primary or key family caregiver of a patient receiving maintenance hemodialysis; (3) had provided caregiving support for at least three months; (4) were able to communicate clearly in Indonesian; and (5) were willing to participate and provide written informed consent. The exclusion criteria were: (1) inability to participate fully in an in-depth interview; and (2) emotional distress or psychological condition at recruitment that could be worsened by participation. A total of 15 family caregivers participated. Recruitment was conducted iteratively and discontinued when concurrent data collection and preliminary analysis indicated sufficient depth, relevance, and repetition of experiential patterns, as confirmed through field notes, interview summaries, and team discussion.

Data collection

Data were collected between November and December 2025 through face-

to-face, semi-structured, in-depth interviews with 15 family caregivers in a private and quiet setting within or near the hemodialysis service area. Interviews were conducted in Indonesian after written informed consent had been obtained, lasted approximately 45–60 minutes, and were audio-recorded with participants' permission. The interview guide was developed based on the study aim, relevant literature on psychospiritual care, family caregiving, hemodialysis, and the Indonesian sociocultural context. Open-ended questions explored caregivers' experiences in accompanying patients, providing emotional or spiritual support, and participating in treatment-related decisions. Example questions included: "*Can you tell me about your experience in accompanying your family member during hemodialysis treatment?*"; "*How do you usually provide emotional or spiritual support when your family member feels distressed or tired?*"; and "*How do you and your family member make decisions related to treatment and care?*" Probing questions were used to obtain deeper clarification when needed.

All interviews were conducted by the principal researcher, a nursing researcher with experience in qualitative interviewing and familiarity with hemodialysis care, but who was not involved in the clinical care of participating patients or caregivers. To reduce potential bias, the interviewer used open-ended questions, avoided leading responses, wrote reflexive field notes after each interview, and discussed emerging interpretations with the research team. Field notes documented non-verbal expressions, contextual observations, interview atmosphere, and preliminary analytic reflections. Audio recordings were transcribed verbatim in Indonesian and checked against the recordings for accuracy. Selected quotations were translated into English by the principal researcher and reviewed by another bilingual team member to ensure conceptual and cultural equivalence. Data collection and preliminary analysis were conducted concurrently to support iterative inquiry.

Data analysis

Data were analyzed manually and iteratively using Colaizzi's phenomenological method, which was appropriate for identifying essential meanings within participants' lived experiences (22). Analysis began after the first interviews and continued alongside data collection. First, interview recordings were transcribed verbatim in Indonesian, and transcripts were read repeatedly to obtain an overall sense of participants' experiences. Second, significant statements related to family caregivers' experiences of psychospiritual caregiving were identified and extracted. Third, meanings were formulated from these statements while remaining grounded in participants' original accounts. Fourth, formulated meanings were grouped into theme clusters by comparing recurring experiential patterns across transcripts. Fifth, the thematic structure was integrated into an exhaustive description of the phenomenon. Finally, the findings were refined into a concise description of the essential structure of family psychospiritual caregiving in long-term hemodialysis.

Rigor and trustworthiness

Rigor and trustworthiness were established using the criteria of credibility, dependability, confirmability, and transferability. Credibility was enhanced through repeated immersion in the data, concurrent data collection and analysis, and member checking with selected participants to verify the accuracy of emerging interpretations. Dependability was supported by maintaining an audit trail documenting methodological and analytic decisions throughout the study. Confirmability was strengthened through reflexive discussions among the research team, use of field notes and analytic memos, and continual comparison between the developing themes and the original transcripts to ensure that interpretations remained grounded in participants' accounts. Transferability was

supported by providing rich descriptions of the study context, participant characteristics, and caregiving experiences.

Ethical considerations

This study obtained ethical approval from the Research Ethics Committee, Faculty of Nursing, Universitas Indonesia (Approval No. KET-324/UN2.F12.D1.2.1/PPM.00.02/2025). All participants received written and verbal information about the study purpose, procedures, potential risks and benefits, voluntary participation, confidentiality, and the absence of financial compensation. Written informed consent was obtained before data collection. Participants were informed that they could decline participation, skip questions, pause the interview, or withdraw at any time without consequences for themselves, their family members, or their relationship with healthcare providers. During interviews, the researcher monitored participants' emotional responses, offered breaks or debriefing when needed, and referred participants to relevant healthcare or psychosocial support if distress occurred, while maintaining confidentiality.

Results

A total of 15 family caregivers were included in this study, representing diverse familial roles, including wives, husbands, daughters, sons, a sister, a brother, and a mother. Participants also varied in educational background, ranging from senior high school to diploma and bachelor's degree levels. The duration of caregiving involvement ranged from 2 to 7 years, indicating ongoing experience in accompanying relatives through repeated hemodialysis treatment. This variation in family role, educational background, and caregiving duration provided a relevant contextual basis for understanding how psychospiritual care was enacted across the long-term hemodialysis trajectory. The demographic characteristics of participants are presented in Table 1.

Table 1. Characteristics of family caregiver participants

Participant code	Gender	Relationship to the patient	Educational background	Duration of caregiving involvement
P1	Female	Wife	Senior high school	3 years
P2	Male	Husband	Bachelor's degree	4 years
P3	Female	Daughter	Diploma	2 years
P4	Female	Wife	Bachelor's degree	5 years
P5	Male	Son	Senior high school	2 years
P6	Female	Sister	Diploma	3 years
P7	Female	Daughter	Bachelor's degree	4 years
P8	Male	Husband	Senior high school	6 years
P9	Female	Wife	Diploma	5 years
P10	Male	Brother	Bachelor's degree	3 years
P11	Female	Mother	Senior high school	7 years
P12	Female	Daughter	Bachelor's degree	2 years
P13	Male	Son	Diploma	4 years
P14	Female	Wife	Senior high school	6 years
P15	Male	Husband	Bachelor's degree	5 years

The development of themes followed Colaizzi's descriptive phenomenological process. Significant statements were extracted from participants' interview transcripts and then interpreted into formulated meanings. Similar formulated meanings were grouped into sub-themes, and the final themes were

developed by comparing recurring lived meanings across participants' descriptions. Table 2 presents examples of how the analysis progressed from significant statements to formulated meanings, sub-themes, and final themes.

Table 2. Development of themes and sub-themes based on Colaizzi's analytical process

Significant statements	Formulated meanings	Sub-themes	Themes
“When he starts saying that he is tired of everything, I do not answer immediately. I let him talk first, because usually after speaking for a while, he feels lighter.” (P3) “Sometimes she repeats the same complaints again and again, but I still listen. For her, being heard is more important than getting advice right away.” (P7)	The caregiver allowed the patient to express fatigue and distress before responding, which helped the patient feel emotionally relieved. Repeated listening was experienced as a way of validating the patient’s suffering and making the patient feel heard.	Attentive listening as a pathway to emotional validation Attentive listening as	Enacting emotional presence as a therapeutic foundation in everyday care
“Even when I feel worried inside, I try not to show it in front of him. If I look panicked, he becomes more anxious too.” (P5)	The caregiver concealed personal worry and maintained emotional control to prevent increasing the patient’s anxiety.	Sustaining a calming presence throughout the hemodialysis journey	
“I stay close to her and speak softly, especially before dialysis starts. She seems calmer when she sees that I am not afraid.” (P9)	The caregiver’s physical closeness and gentle communication helped create calmness and emotional security before dialysis.		
“When he becomes restless, I invite him to pray together. After that, he usually becomes quieter and more settled.” (P2) “I do not force her, but I gently remind her to keep remembering God. Sometimes we recite together, and that helps her feel stronger.” (P11)	Shared prayer helped the patient regain calmness and spiritual reassurance during distress. The caregiver provided spiritual support in a gentle and non-coercive way, helping the patient feel spiritually strengthened.	Guiding and participating in spiritual practices as shared coping strategies	Facilitating spiritual meaning-making to foster inner peace and acceptance
“At first he often asked, ‘Why did this happen to me?’ I kept encouraging him to be patient and to see this as part of God’s test.” (P6)	The caregiver helped the patient reinterpret illness through patience and religious meaning.		
“At first, she often cried and said that she was tired of dialysis because it felt endless. I could not force her to accept everything immediately, so I just stayed with her, reminded her slowly to be patient, and invited her to pray when she was ready. Over time, she became calmer and began to say that this was something she had to live through sincerely.” (P12)	Acceptance was experienced as a gradual and fragile process that required repeated emotional and spiritual accompaniment.	Cultivating acceptance, patience, and surrender as expressions of spiritual resilience	

Significant statements	Formulated meanings	Sub-themes	Themes
“I always try to accompany him to dialysis, because when there is family beside him, he feels stronger and less afraid.” (P11)	Accompaniment during dialysis helped the patient feel stronger, safer, and less alone.	Accompanying patients across treatment encounters and dialysis sessions	Engaging in shared care navigation through practical support and collaborative decision-making
“Sometimes it is exhausting for me too, but I still come with her because she is calmer when she knows she is not alone.” (P8)	The caregiver continued treatment accompaniment despite personal exhaustion because their presence reduced the patient’s loneliness and anxiety.		
“I prepare what he needs before treatment, from food to his personal things, so he does not have to think about too much.” (P4)	Practical preparation reduced the patient’s burden and communicated attentiveness and care.	Responding to patients’ practical and immediate care needs during treatment	
“Even small things matter. When I help her get comfortable or bring what she needs, she feels noticed and cared for.” (P10)	Small practical actions were experienced as meaningful expressions of concern that made the patient feel noticed and cared for.		
“We usually talk together before making decisions, because when he feels weak, he needs someone to help him think clearly.” (P13)	Treatment decisions were experienced as a shared process when the patient felt physically weak or uncertain.	Negotiating health conditions and treatment choices through shared decision-making	
“When she said she was tired and did not want to continue treatment, I felt confused because I wanted her to keep going, but I also knew that she was the one feeling the pain. We usually talked slowly, considered what the doctor said, and tried to decide together. For me, supporting her did not only mean telling her to continue dialysis, but also listening to her fear and helping her think when she felt too weak.” (P15)	The caregiver negotiated treatment continuation by balancing respect for the patient’s suffering with responsibility to support ongoing care.		

Theme 1: Enacting emotional presence as a therapeutic foundation in everyday care

This theme describes how family caregivers experienced emotional presence as the first and most immediate form of psychospiritual care. Participants emphasized remaining emotionally available when patients felt tired, discouraged, irritable, or overwhelmed by repeated hemodialysis. Emotional presence was not viewed as passive companionship, but as a relational foundation that helped patients feel safe, heard, and supported. However, this presence also required patience, restraint, and the ability to contain caregivers' own distress.

Sub-theme 1.1: Attentive listening as a pathway to emotional validation

Family caregivers described attentive listening as a way to acknowledge and contain patients' emotional distress. Patients often expressed fatigue, sadness, frustration, fear, and treatment exhaustion, especially after repeated dialysis sessions or during physical decline. Rather than giving immediate advice, caregivers allowed patients to speak openly,

which helped them feel understood and emotionally relieved.

"When he starts saying that he is tired of everything, I do not answer immediately. I let him talk first, because usually after speaking for a while, he feels lighter." (P3)

"Sometimes she repeats the same complaints again and again, but I still listen. For her, being heard is more important than getting advice right away." (P7)

Sub-theme 1.2: Sustaining a calming presence throughout the hemodialysis journey

Participants also described the importance of maintaining a calm and reassuring presence before, during, and after dialysis. They tried to stay physically close, speak gently, and avoid showing panic or despair so that patients would feel safer and less overwhelmed. This calmness was not always naturally felt, as caregivers often concealed their own anxiety or sadness to protect the patient emotionally.

“Even when I feel worried inside, I try not to show it in front of him. If I look panicked, he becomes more anxious too.” (P5)

“I stay close to her and speak softly, especially before dialysis starts. She seems calmer when she sees that I am not afraid.” (P9)

Theme 2: Facilitating spiritual meaning-making to foster inner peace and acceptance

This theme describes how family caregivers supported patients in interpreting illness through spiritual meaning-making. Spirituality was not experienced as an occasional part of care, but as something woven into everyday caregiving when patients felt anxious, tired of treatment, or uncertain about their condition. Caregivers helped patients reconnect with faith, reframe suffering, and gradually move toward peace and acceptance. In participants’ accounts, this process was often expressed through culturally familiar values such as sabar, or patience, and ikhlas, or sincere acceptance.

Sub-theme 2.1: Guiding and participating in spiritual practice as shared coping strategies

Family caregivers described prayer, recitation, remembrance, and worship as shared coping strategies during difficult moments. They prayed with patients, gently reminded them to worship, or engaged in spiritual reflection when patients appeared restless, discouraged, or emotionally unsettled. Spiritual support was offered carefully, as caregivers recognized that patients were more receptive when their emotional distress had first been acknowledged.

“When he becomes restless, I invite him to pray together. After that, he usually becomes quieter and more settled.” (P2)

“I do not force her, but I gently remind her to keep remembering God. Sometimes we recite together, and that helps her feel stronger.” (P11)

Sub-theme 2.2: Cultivating acceptance, patience, and surrender as expressions of spiritual resilience

Participants also described helping patients cultivate acceptance, patience, and surrender in response to chronic illness. Patients often questioned their condition, felt tired of treatment, or struggled emotionally. In response, caregivers encouraged them to view illness as part of God’s test or spiritual journey while continuing treatment with greater trust. Acceptance was described not as a fixed state, but as a gradual and sometimes fragile process that required ongoing emotional and spiritual support.

“At first he often asked, ‘Why did this happen to me?’ I kept encouraging him to be patient and to see this as part of God’s test.” (P6)

“At first, she often cried and said that she was tired of dialysis because it felt endless. I could not force her to accept everything immediately, so I just stayed with her, reminded her slowly to be patient, and invited her to pray when she was ready. Over time, she became calmer and began to say that this was something she had to live through sincerely.” (P12)

Theme 3: Engaging in shared care navigation through practical support and collaborative decision-making

This theme describes how family caregivers experienced practical support and shared care navigation as part of psychospiritual caregiving. Emotional support, spiritual encouragement, and practical assistance were not described as separate forms of care, but as interconnected ways of helping patients feel accompanied, valued, and not abandoned. Accompanying patients to dialysis, responding to immediate needs, and helping with treatment decisions became meaningful because these actions conveyed commitment, attentiveness, and shared responsibility.

Sub-theme 3.1: Accompanying patients across treatment encounters and dialysis sessions

Participants described accompaniment as one of the most consistent expressions of care. They accompanied patients to hemodialysis sessions, waited

during treatment, helped prepare for hospital visits, and remained available before and after procedures. This presence was not merely logistical but helped patients feel emotionally secure and less alone, although it could also be physically and emotionally tiring for caregivers.

"I always try to accompany him to dialysis, because when there is family beside him, he feels stronger and less afraid." (P11)

"Sometimes it is exhausting for me too, but I still come with her because she is calmer when she knows she is not alone." (P8)

Sub-theme 3.2: Responding to patients' practical and immediate care needs during treatment

Family caregivers also described practical support, such as preparing food, arranging transport, assisting mobility, improving comfort, and responding to symptoms, as emotionally meaningful. These actions helped patients feel noticed, cared for, and less burdened during treatment. Thus, practical assistance became a concrete expression of psychospiritual reassurance rather than merely routine support.

"I prepare what he needs before treatment, from food to his personal things, so he does not have to think about too much." (P4)

"Even small things matter. When I help her get comfortable or bring what she needs, she feels noticed and cared for." (P10)

Sub-theme 3.3: Negotiating health conditions and treatment choices through shared decision-making

Participants described treatment-related decisions as shared and negotiated rather than individual. When patients felt weak, overwhelmed, or uncertain, caregivers helped them understand information, consider options, and decide on ongoing care. This process was sometimes emotionally difficult, especially when caregivers tried to balance respect for patients' wishes with encouragement to continue treatment.

"We usually talk together before making decisions, because when he feels weak, he needs someone to help him think clearly." (P13)

"When she said she was tired and did not want to continue treatment, I felt confused because I wanted her to keep going, but I also knew that she was the one feeling the pain. We usually talked slowly, considered what the doctor said, and tried to decide together. For me, supporting her did not only mean telling her to continue dialysis, but also listening to her fear and helping her think when she felt too weak." (P15)

Discussion

The three themes in this study reflect participants' lived experiences of providing psychospiritual care within the repeated, uncertain, and emotionally demanding context of long-term hemodialysis. Caregivers described psychospiritual caregiving as an everyday relational process expressed through emotional presence, spiritual encouragement, practical responsiveness, and shared involvement in treatment-related decisions. These findings show how ordinary family caregiving practices were experienced as meaningful support in sustaining patients throughout the hemodialysis journey.

Emotional presence emerged as a therapeutic foundation of everyday family care. Family caregivers remained physically, relationally, and emotionally available during repeated cycles of exhaustion, uncertainty, symptom fluctuation, and psychological vulnerability. Previous studies have shown that caregivers of patients receiving hemodialysis often experience anxiety, emotional strain, and disruption in personal life while providing continuous practical and emotional support (13-15). Indonesian evidence also shows that caregiver burden is associated with hemodialysis compliance among patients with chronic kidney disease (23). The present findings extend this evidence by showing how emotional burden was lived relationally through restraint, calming presence, and efforts to protect patients from further distress. Thus, emotional

labor functioned as an informal psychospiritual care infrastructure that helped patients endure treatment and reduced relational gaps that formal services could not continuously address (13, 24).

Spiritual meaning-making was also central to caregiving, particularly in helping patients reinterpret suffering, sustain inner peace, and move toward acceptance (25). Studies from Tanzania, Palestine, and Ghana similarly show that families and caregivers in kidney care provide emotional support, practical assistance, coping support, and treatment accompaniment while experiencing considerable burden and unmet needs (13, 15, 26). In the Indonesian context, prayer, surrender, sabar, and ikhlas provided culturally meaningful language through which families interpreted suffering, encouraged endurance, and supported acceptance during long-term illness. Sabar was reflected in caregivers' efforts to remain calm and patient despite repeated treatment burdens, whereas ikhlas reflected sincere acceptance of illness and treatment as part of life's spiritual journey. These findings suggest that psychospiritual caregiving in Indonesia is shaped by religious practice, collectivist family responsibility, and repeated family interactions that co-construct acceptance over time (10, 27, 28). The contribution of this study lies not in claiming that emotional support, prayer, or family caregiving are unique to Indonesia, but in showing how these practices become psychospiritually meaningful through family obligation, collective decision-making, religious language, and values such as *sabar* and *ikhlas*.

Shared care navigation through practical support and collaborative decision-making was another important dimension of family psychospiritual caregiving. Previous studies have emphasized that family caregivers often organize treatment attendance, monitor symptoms, manage practical needs, and navigate fragmented health services (4, 18). Practical activities were not experienced merely as instrumental tasks, but as embodied expressions of commitment, attentiveness,

and shared responsibility. Accompaniment, preparation of treatment needs, communication with professionals, and shared decision-making reassured patients that they were not facing dialysis alone. This perspective challenges a strict separation between emotional, spiritual, and instrumental support and shows that family-based decision-making in dialysis care is relational, moral, and emotionally negotiated, not only informational or clinical. (3).

These findings suggest that family caregivers function as an informal care infrastructure that supports emotional safety, spiritual endurance, and practical continuity during repeated hemodialysis treatment. In practice, hemodialysis units should strengthen family-inclusive care by identifying the main caregiver, assessing caregiver burden and spiritual coping needs, and involving caregivers in brief care discussions. Family-inclusive psychospiritual care protocols may include caregiver education, culturally sensitive communication, referral to psychosocial or religious support, and documentation of family concerns in the care plan. Interprofessional collaboration is also required in family-inclusive psychospiritual care (29). This collaboration is particularly relevant in Indonesia, where religion, family support, sabar, ikhlas, and collectivist responsibility shape health behavior, coping, and treatment endurance (10, 23, 28, 30).

Limitations

This study should be interpreted within its contextual boundaries. The findings were derived from participants recruited in a specific setting and therefore reflect experiences situated within that particular context. The study also involved a limited number of participants. Although these participants provided rich and meaningful accounts, the sample was not intended to represent the full range of family caregivers of patients undergoing hemodialysis. For this reason, the findings cannot be generalized to all family caregivers in other hospitals, regions, or care contexts. Differences in sociocultural background, family roles, and

healthcare environments may shape caregiving experiences in ways not captured in this study.

Conclusion

This study shows that family psychospiritual caregiving in long-term hemodialysis is a relational practice that integrates emotional presence, spiritual meaning-making, and practical care navigation. Through listening, calming presence, shared prayer, encouragement of *sabar* and *ikhlas*, practical responsiveness, and shared decision-making, family caregivers helped patients manage distress, uncertainty, and treatment demands. In Indonesian hemodialysis services, nurses should recognize family caregivers as partners in care by identifying the main caregiver, assessing caregiver burden and spiritual coping needs, involving families in brief care discussions, and using culturally sensitive communication. Family-inclusive psychospiritual care protocols should include caregiver education, referral to psychosocial or religious support when needed, and documentation of family concerns in the care plan. Future research should develop and test culturally tailored family-based interventions across diverse Indonesian regions, religious backgrounds, and healthcare settings.

Acknowledgements

We gratefully acknowledge financial support from the Indonesian Endowment Fund for Education/Lembaga Pengelola Dana Pendidikan (LPDP).

Author contributions

Conceptualization: [LRW, KY, M, W]; Methodology: [LRW, KY, M, W]; Formal analysis and investigation: [LRW, KY, M, W, IYW, CS, MAA]; Writing - original draft preparation: [LRW, KY, M, W, IYW, CS, MAA]; Writing - review and editing: [LRW, KY, M, W, IYW, CS, MAA]; Funding acquisition: [LRW]; Resources: [LRW]; Supervision: [KY, M, W].

Conflict of interest

The authors declare that they have no competing interests.

Funding

This study was supported by the Lembaga Pengelola Dana Pendidikan (LPDP), or Indonesia Endowment Fund for Education Agency, Ministry of Finance, Republic of Indonesia.

References

1. Wang L, He Y, Han C, Zhu P, Zhou Y, Tang R, He W. Global burden of chronic kidney disease and risk factors, 1990-2021: An update from the global burden of disease study 2021. *Front Public Health*. 2025;13: 1542329. doi: 10.3389/fpubh.2025.1542329.
2. Li Z, He R, Wang Y, Qu Z, Liu J, Yu R, Yang S. Global trends of chronic kidney disease from 1990 to 2021: A systematic analysis for the global burden of disease study 2021. *BMC Nephrol*. 2025;26(1): 385. doi: 10.1186/s12882-025-04309-7.
3. Ho Y-F, Chen Y-C, Li IC. A qualitative study on shared decision-making of patients with chronic kidney disease. *Nursing Open*. 2021;8(6): 3430-3440. doi: 10.1002/nop2.891.
4. Coumoundouros C, Farrand P, Sanderman R, von Essen L, Woodford J. "Systems seem to get in the way": a qualitative study exploring experiences of accessing and receiving support among informal caregivers of people living with chronic kidney disease. *BMC Nephrology*. 2024;25(1): 7. doi: 10.1186/s12882-023-03444-3.
5. Toding D, Masfuri M, Waluyo A, Yona S, Mahmud R, Nining S, et al. Exploring the experiences of the hemodialysis patients during the COVID-19 pandemic: A qualitative study. *F1000Res*. 2024;13: 1404. doi: 10.12688/f1000research.158482.2.
6. Pernefri. Indonesian Renal Registry 2024. Available from: <https://www.indonesianrenalregistry.org/>.
7. Mailani F, Huriani E, Malini H, Setiawan S, Yuni AR. Barriers and Facilitators to Haemodialysis Care in Indonesia: Perspectives of Dialysis Nurses. *J Ren Care*. 2026;52(1): e70044. doi: 10.1111/jorc.70044.
8. Matulesy T. The vital role of nurses in alleviating anxiety in hemodialysis patients. *Indonesian Journal of Health Services*. 2025;2(2): 85-87. doi: 10.63202/ijhs.v2i2.105.

9. Kosmadakis G, Necoara A, Baudenon J, Deville C, Enache I, Chelaru E. The Multidimensional Impact of Expanded Hemodialysis: A Comprehensive Review. *Seminars in Dialysis*. 2025;38(3): 176-186. doi: 10.1111/sdi.13257.
10. Cipta DA, Andoko D, Theja A, Utama AV, Hendrik H, William DG, Reina N, Handoko MT, Lumbuun N. Culturally sensitive patient-centered healthcare: a focus on health behavior modification in low and middle-income nations—insights from Indonesia. *Frontiers in Medicine*. 2024 Apr 12;11:1353037. doi: 10.3389/fmed.2024.1353037.
11. Parizad N, Rahimpour M, Alinejad V, Khorami Markani A. Effect of a Spiritual Care Program on Treatment Adherence and Sleep Quality in Hemodialysis Patients: A Cluster-Randomized Clinical Trial. *Health Science Reports*. 2025 Dec;8(12):e71627. doi: 10.1002/hsr2.71627.
12. Solaimanimoghaddam R, Beydokhti TB, Firouzkohi MR. Family Caregivers' Experiences of Living with Hemodialysis Patients: A Descriptive Phenomenology. *Iranian Journal of Nursing and Midwifery Research*. 2024 Sep 1;29(5):535-41. doi: 10.4103/ijnmr.ijnmr_276_22.
13. Magenge AH, Ndile ML, Furia F. Family caregivers' experience of caring for patients undergoing hemodialysis: A qualitative study at Muhimbili National Hospital in Dar es Salaam, Tanzania. *PLoS One*. 2025;20(5): e0321732. doi: 10.1371/journal.pone.0321732.
14. Gurung S, Devkota N. Quality of life among hemodialysis patients in a referral center in Kathmandu: A mixed-method study. *PLoS One*. 2025;20(11): e0335990. doi: 10.1371/journal.pone.0335990.
15. Abu Bonsra E, Atsrim PY, Korankye A, Komesuor J. Experiences and coping strategies among patients with Chronic Renal Failure (CRF) in Ghana: A phenomenological study. *PLOS Mental Health*. 2025 Sep 19;2(9):e0000279. doi: 10.1371/journal.pmen.0000279.
16. Annisa TN, Muis N. The meaning of family medicinal plants for family health: A phenomenological study among rural housewives. *Journal of Community Nursing and Primary Care*. 2025;2(2): 56-64. doi: 10.63202/jcnpc.v2i2.115.
17. Aghamohammadi V, Ebadi J, Seyyedrasooli A, Aliasgarzadeh S, Ghaderi M, Khateri A, Nasiri K. Comparison of the effects of lavender oil inhalation and tea on sleep quality, fatigue, and pain in hemodialysis patients: A randomized clinical trial. *Nursing Practice Today*. 2025;12(2): 202-213. doi: 10.18502/npt.v12i2.18343.
18. Yu X, Nakayama M, Wu M-S, Kim Y-L, Mushahar L, Szeto CC, et al. Shared Decision-Making for a Dialysis Modality. *Kidney International Reports*. 2022;7(1): 15-27. doi: 10.1016/j.ekir.2021.10.019.
19. Hejazi SS, Hosseini M, Ebadi A, Alavi Majd H. Components of quality of life in hemodialysis patients from family caregivers' perspective: A qualitative study. *BMC Nephrology*. 2021;22(1): 379. doi: 10.1186/s12882-021-02584-8.
20. Musa AS, Elbqowm O, AlBashtawy M, Al Qadire MI, Suliman M, Tawalbeh LI, et al. Spiritual Wellbeing and Quality of Life among Hemodialysis Patients in Jordan: A Cross-Sectional Correlational Study. *Journal of Holistic Nursing*. 2023;41(3): 220-232. doi: 10.1177/08980101221083422.
21. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*. 2014 Sep;89(9):1245-51. doi: 10.1097/ACM.0000000000000388.
22. Vignato J, Inman M, Patsais M, Conley V. Computer-assisted qualitative data analysis software, phenomenology, and Colaizzi's method. *Western Journal of Nursing Research*. 2022 Dec;44(12):1117-23. doi: 10.1177/01939459211030335.
23. Al Muchtari TA, Syukri M, Yusni Y. Association between caregiver burden in family and hemodialysis compliance of chronic kidney disease patients in Aceh, Indonesia. *Narra J*. 2023;3(3): e255. doi: 10.52225/narra.v3i3.255.
24. Nimah L, Nursalam N, Wahyudi AS, Mariyanti H. Quality of Life of Family Caregivers of Patients Undergoing Dialysis: A Literature Review. *Sage Open Nursing*. 2024;10: 23779608241240124. doi: 10.1177/23779608241240124.
25. Boateng EA, Bisiw MB, Agyapomah R, Enyemadze I, Kyei-Dompim J, Kumi SP, Boakye DS. A qualitative study on the experiences of family caregivers of children with End-Stage Kidney Disease (ESKD). *BioPsychoSocial Medicine*. 2024;18(1): 17. doi: 10.1186/s13030-024-00314-8.
26. Shaabna Z, M SA, Zeilani R. Experiences and needs of family caregivers for patients with End Stage Renal Disease (ESRD) in Palestine. *BMC Palliative Care*. 2025;24(1): 81. doi: 10.1186/s12904-025-01722-5.

27. Bonilla Sierra P, Pérez-Jiménez JM, Espinoza Quezada DP, Lucchetti G, De-Diego-Cordero R. Association between religious/spiritual coping and quality of life among hemodialysis patients in Ecuador. *Frontiers in Public Health*. 2025 Apr 2;13:1510329. doi: 10.3389/fpubh.2025.1510329.
28. Wijayanti L, Septianingrum Y, Sultoni A, Fitriyani A, Wardani EM, Ramadhani L. Effectiveness of Combination Dhikr and Salawat on Anxiety and Sleep Quality in Hemodialysis Patients in Indonesia: A Randomized Controlled Trial. *Journal of Religion and Health*. 2025 Aug;64(4):2542-57. doi: 10.1007/s10943-025-02342-2.
29. Akbar MA, Sahar J, Rustina Y, Rekawati E. Interprofessional Collaboration in Primary Care: Concept Analysis. *Journal of Caring Sciences*. 2025 Oct 28;14(4):267-77. doi: 10.34172/jcs.025.33428.
30. Akbar MA, Sahar J, Rekawati E, Sartika RA, Gupta P. Analysis of Factors Related to Diabetes Self-Management in Patients with Type 2 Diabetes Mellitus in Rural Areas. *Nurse Media Journal of Nursing*. 2025 Apr 1;15(1):65-74. doi: 10.14710/nmjn.v15i1.62539.