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Health Literacy Challenges and Caregiving Burden among Family Caregivers of Hemodialysis Patients: A Qualitative Study from Nurses' Perspectives in Indonesia

Lailatun Nimah[1*], Herdina Mariyanti[1], Noor Hanita Zaini [2]

1- Medical-Surgical Nursing, Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia.
(Corresponding Author) lailatunnimah@fkp.unair.ac.id
2- Faculty of Nursing, Universiti Malaya, Kuala Lumpur, Malaysia.

Background and Objectives: Hemodialysis patients rely heavily on their family caregivers for daily care management. However, the complexity of care often presents challenges in health literacy and care burden, which can impact the quality of care. Nurses' perspectives are crucial for understanding the unmet needs of family caregivers. This study aims to explore the health literacy challenges, psychosocial burden, and support needs of family caregivers of hemodialysis patients from the perspectives of hemodialysis nurses.

Materials and Methods: This study used a conventional qualitative content analysis study with Graneheim and Lundman's methodology approach. It was conducted in the hemodialysis unit of a private hospital in Surabaya, East Java, Indonesia, in July 2025. Purposive sampling with fifteen hemodialysis nurses as participants. The Focus Group Discussions conducted for data collection lasted an averaged of 60-80 minutes and utilized open-ended, semi-structured questions.

Results: Content analysis of 26 codes resulted in three main categories that included 8 subcategories: 1) Barriers to health literacy in family caregiving for hemodialysis patients; 2) Managing emotional strain and psychosocial challenges in family caregiving; 3) The need for comprehensive support systems to strengthen caregiving capacity.

Conclusion: From the perspective of hemodialysis nurses, family caregivers of hemodialysis patients face various challenges, including non-compliance with diet and fluid restrictions, limited health literacy regarding symptoms, dietary knowledge, confusion about information, and barriers to education. Family caregivers experience fatigue, helplessness, and need emotional support and resilience. Family caregivers of hemodialysis patients also experience problems with social support from peers, family, and economic resources.

Keywords: Chronic Disease, Health Literacy, Hemodialysis, Non-Communicable Disease, Nurse Perspective

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Introduction

Family caregivers play a crucial role in supporting the success of hemodialysis therapy. Hemodialysis is the most frequently chosen renal replacement therapy for patients with chronic kidney disease, and it requires significant family support (1). Although hemodialysis can extend life expectancy, patients undergoing hemodialysis must face a variety of complex care demands, including adherence to schedules, fluid restrictions, dietary management, medication use, and ongoing health monitoring. This complexity causes most patients to rely heavily on family support for daily care activities (2). The crucial support provided by family caregivers during hemodialysis therapy requires good health literacy (3). The support provided by family caregivers during hemodialysis therapy extends over a long period, resulting in a chronic caregiving burden for them (4).

Indonesia is facing a rapid increase in the number of hemodialysis patients. Data from the Indonesian Renal Registry shows an increase in the number of hemodialysis patients from 22,140 in 2020 to 157,929 in 2022. Furthermore, the prevalence of kidney failure requiring renal replacement therapy in Indonesia reached 973 cases per million population, higher than the global median (5). Research in Indonesia indicates that the adequacy of hemodialysis treatment received by patients is significantly influenced by the level of caregiving burden perceived by family caregivers (4). Family caregivers in Indonesia experience an imbalance between their daily activities and the caregiving tasks for patients with chronic illnesses (6).

In addition to helping meet the patient's physical needs, family caregivers also play a role in health decision-making, managing diet, fluids, symptoms, medications, and providing emotional support throughout the treatment process (7). Various studies show that optimal family caregiver involvement influences treatment compliance, improves patient quality of life, and reduces complications (8). However, this responsibility often places family caregivers in situations that require adaptability, health knowledge, adequate and specific care skills for hemodialysis patients.

One of the factors that determines the success of family caregivers in carrying out their role in caring is health literacy (9). Health literacy includes not only the ability to read or understand health information, but also the ability to obtain, assess, interpret, and use information in making health-related decisions (10). In the context of hemodialysis care, family caregivers are required to understand various complex information, such as nutritional restrictions, fluid management, vascular access care, signs of complications, and the importance of adherence to therapy (11). Limited health literacy can lead to errors in decision-making, low home care management skills, and increased risk of complications in patients.

Despite its importance, various studies have shown that family caregivers of hemodialysis patients still face challenges in understanding and applying the health information they receive (4). Difficulties in understanding medical instructions, confusion due to inconsistent information, and limited access to educational resources are barriers frequently reported by family caregivers (12). In addition, the information needs of family caregivers continue to change as the patient's

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condition develops, making the education provided at the beginning of therapy often insufficient to meet long-term needs (13). This condition shows that family caregiver health literacy is a dynamic process that requires ongoing support from health workers.

On the other hand, the long-term role of family caregivers also has the potential to impose significant physical, psychological, social, and economic burdens (14). Family caregivers of hemodialysis patients often face exhaustion due to ongoing caregiving responsibilities, anxiety about the patient's condition, family conflict, limited social activities, and financial stress related to treatment needs (15). This prolonged burden not only impacts family caregivers but can also compromise the quality of care provided to patients (16).

As health workers who regularly interact with and accompany patients and their families, hemodialysis nurses are well positioned to observe the various challenges faced by family caregivers of hemodialysis patients. Through repeated interactions during the dialysis process, nurses can identify knowledge gaps, barriers to implementing health information, psychosocial issues, and unmet support needs(17). The nurses' perspective is a valuable source of information because it provides a more comprehensive understanding of family caregivers in experiences within hemodialysis services (18). Although several studies have explored the experiences of family caregivers of hemodialysis patients, most have focused on their own perspectives. Research specifically exploring the challenges of health literacy and the burden on family caregivers from the perspective of hemodialysis nurses remains limited, particularly in developing countries, including Indonesia. Yet, understanding nurses' perspectives can provide crucial information for developing educational interventions, family support programs, and health literacy improvement strategies that better address the needs of family caregivers.

Therefore, this study aims to explore the health literacy challenges and care burden experienced by family caregivers of hemodialysis patients, as perceived by hemodialysis nurses. The research findings are expected to inform the development of nursing interventions to improve family caregivers' capabilities, strengthen psychosocial support, and optimize the family's role in hemodialysis patient care.

Materials and Methods

Study Design

This research is a qualitative exploratory study that employed conventional content analysis, following Graneheim and Lundman's qualitative research methods (19).

Setting dan context

The study was conducted in July 2025 at a hemodialysis unit at a private hospital in Surabaya, East Java, Indonesia. This hospital was chosen because hemodialysis patients originate from Surabaya and surrounding cities, including Bangkalan, Gresik, Sidoarjo, Lamongan, and Bojonegoro. The diverse origins of hemodialysis patients beyond Surabaya create a representative sample of hemodialysis patients in Indonesia.

Participants and Sampling.

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Fifteen hemodialysis nurses were selected using purposive sampling. Data collection was conducted through in-depth interviews, with the characteristics of the hemodialysis nurses described in **Table 1.** Data saturation was achieved when no new codes emerged from the analysis of interview data across all participants, indicating that the phenomenon had been thoroughly explored. This participant-based approach recognizes that health literacy development occurs within a complex system and considers various aspects that influence it.

Table 1. Characteristics of Hemodialysis Nurses

Code	Age (years)	Gender	Educational Background	Years of nursing experience	Hemodialysis experience	Hemodialysis certificate	Clinical position
HN.01	40	Female	Bachelor's Degree in Nursing	17	10	Yes	Staff Nurse
HN.02	38	Female	Diploma in Nursing	14	10	Yes	Staff Nurse
HN.03	37	Female	Diploma in Nursing	11	7	Yes	Staff Nurse
HN.04	37	Female	Diploma in Nursing	13	7	Yes	Staff Nurse
HN.05	42	Female	Diploma in Nursing	18	10	Yes	Staff Nurse
HN.06	40	Female	Bachelor's Degree in Nursing	10	7	Yes	Staff Nurse
HN.07	41	Female	Bachelor's Degree in Nursing	11	7	Yes	Staff Nurse
HN.08	41	Female	Diploma in Nursing	12	5	Yes	Staff Nurse
HN.09	40	Female	Diploma in Nursing	15	5	Yes	Staff Nurse
HN.10	35	Female	Diploma in Nursing	9	6	Yes	Staff Nurse
HN.11	34	Female	Diploma in Nursing	8	6	Yes	Staff Nurse
HN.12	45	Female	Diploma in Nursing	12	8	Yes	Staff Nurse
HN.13	38	Female	Diploma in Nursing	12	7	Yes	Staff Nurse
HN.14	38	Female	Diploma in Nursing	13	6	Yes	Staff Nurse
HN.15	50	Female	Bachelor's Degree in Nursing	25	20	Yes	Head Nurse

Inclusion and Exclusion Criteria

Inclusion Criteria

Have experience as a hemodialysis nurse for at least 2 years, currently on duty at the time of data collection for the research.

Exclusion Criteria

Hemodialysis nurses who were on leave or absent from work at the time of data collection.

Data Collection

A focus group discussion (FGD) was conducted with a structured list of questions for all participants. The interviews and discussions lasted between 60 and 80 minutes. Two FGD sessions were conducted. One FGD group consisted of seven people, and the other consisted of eight people. Data collection in this study was conducted solely through FGD. The situation follows an agreement with the participants and researchers. This sample was selected to explore health literacy among family caregivers in caring for hemodialysis patients, based on the nurses' perspectives on caring for family members of hemodialysis patients. Audio recordings were made during the activity. Hemodialysis nurses viewed health literacy specifically in hemodialysis patient

care. The interview guide was developed to adapt to the conditions during the discussion and to the research questions. Data collection was conducted after nurses left duty and the next shift took over in the head of the hemodialysis unit.

Participatory Question Development Process

Prior to formal data collection, researchers contracted for a 3-day period before the Focus Group Discussion session with hemodialysis nurses. The ward head provided a list of nurses on duty on the day of data collection and recorded nurses on leave and holidays. The ward head then informed nurses who would participate in the FGD and those willing to participate in the research data collection activities. Data collection was guided by participant comfort, ease of understanding, preferred questioning style, and relevant topics, with hemodialysis nurses accompanying families in caring for hemodialysis patients to increase interview engagement. This process is consistent with recommendations to involve participants in co-designing research tools to enhance the relevance, accessibility, and ethical integrity of participant-centered qualitative research.

Interview Setting and Implementation

Participant comfort and autonomy were highly valued throughout the research process. Participants were given the opportunity to choose the interview location. All interviews were conducted in the office of the head of the hemodialysis unit, a comfortable setting equipped with adequate chairs and tables. Participants were allowed to engage in other activities during the interview, such as drinking or eating the refreshments provided. Interviews were conducted in Indonesian by trained qualitative researchers. Snacks and beverages were offered as a token of appreciation for participants' time and contribution. All interviews were audio-recorded with participants' informed consent and later transcribed verbatim.

Sample interview questions included

"Could you tell me about your experience caring for hemodialysis patients and supporting their families?"

"Could you tell me about the needs of family caregivers when caring for hemodialysis patients?"

"Could you tell me about the challenges family caregivers face when caring for hemodialysis patients?"

"Could you tell me about what supports family caregivers in caring for hemodialysis patients?"

Data Analysis

The data obtained were analyzed using inductive content analysis, in accordance with the qualitative research approach by Graneheim and Lundman (19). The researcher conducted data analysis manually. The analytical process began with repeated reading and in-depth reading of the transcripts to achieve familiarity with the data. The researcher then identified meanings and condensed sentences while retaining the core content. The condensed units were then open-coded using descriptive labels. Codes with similar features were grouped into subcategories,

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which were then abstracted into themes representing broader conceptual patterns. To enhance the credibility and rigor of the analysis, 30% of the transcripts were independently coded by a second coder. The coding results were compared with those of the primary researcher, and discrepancies in condensation, coding, or interpretation were discussed thoroughly until consensus was reached between the two coders.

The large number of initial codes reflects the detailed identification of relevant content across the interviews rather than the number of independent conceptual units. During analysis, codes with similar meanings were continuously compared and clustered, while conceptually distinct codes were retained. Through iterative condensation and abstraction, these codes were organized into eight subcategories, which were subsequently grouped into three broader categories reflecting shared underlying content.

Trustworthiness and Rigor

To ensure methodological rigor and increase the trustworthiness of the research, a series of strategies was implemented based on the four criteria put forward by Lincoln and Guba (20), namely credibility, transferability, dependability, and confirmability. Credibility: Trust in the research results was enhanced through in-depth engagement with the data through an iterative process of reading, coding, and analyzing. The interpretation of the findings was also reviewed through peer discussions with researchers experienced in qualitative methodology to minimize interpretation bias. Furthermore, source triangulation was applied by gathering information from hemodialysis nurse participants to obtain diverse perspectives and enrich the understanding of the phenomenon under study.

Transferability: The transferability of the research is strengthened by providing a rich description of the research setting, informant characteristics, and the interview process. The in-depth presentation of the findings, supported by representative quotes from participants, provides a basis for readers to determine the extent to which the research results can be applied or transferred to contexts with similar characteristics.

Dependability: The reliability of the research process was strengthened by implementing a comprehensive audit trail that documented all key decisions throughout the study. This documentation included the development of interview instruments, analysis and coding steps, and procedural changes that emerged during the study. Systematic documentation of the entire data collection and analysis process was conducted to ensure transparency, traceability, and reproducibility of the research process.

Confirmability: The confirmability of the findings was strengthened by using reflective journals, which enabled researchers to critically evaluate assumptions and subjective tendencies throughout the study. Validation of the analysis process was carried out by involving a second researcher to independently code portions of the transcripts, while differences in interpretation were resolved through in-depth discussions until consensus was reached. All changes and adjustments made during the study were also recorded transparently to support traceability of the research process.

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Ethical Considerations

Ethics approval for this study was obtained from the Hospital Ethics Committee at the research site (025/KEPK/RSPS-2024). All participants, namely hemodialysis nurses, signed a consent form after receiving clear and understandable information regarding the purpose, procedures, and their role in the study. The ethics committee also reviewed and approved the forms of appreciation given to participants to ensure that they were reasonable and did not constitute coercion or undue influence. Data confidentiality was ensured by anonymizing interview transcripts and managing data using a secure storage system.

Result

Conventional content analysis of 26 codes obtained from hemodialysis nurses revealed three main categories consisting of eight sub-categories **(Table 2).** The categories obtained represent comprehensive and varied health literacy challenges and caregiving burdens on family caregivers in caring for hemodialysis patients from the perspective of hemodialysis nurses.

Table 2. Comprehensive Health Literacy among Family Caregivers of Patients Undergoing Hemodialysis

Categories	Subcategories	Codes
Barriers to health literacy in family caregiving for hemodialysis patients	Challenges in managing patient compliance	Diet non-compliance
		Non-compliance with fluid restrictions
	Limitations in health literacy for hemodialysis care	Lack of symptom knowledge
		Limited dietary knowledge
		Confusion about health information
		Barriers to education
Managing emotional strain and psychosocial challenges in family caregiving	Burden on family caregivers in caring for hemodialysis patients	Family caregiver fatigue
		Family caregiver helplessness
		Need for emotional support
		Family caregiver resilience
	Social and economic barriers to care	Economic barriers to care
		Conflict between family caregivers and patients
		Family conflict
		Conflict between family caregivers
The need for comprehensive support systems to strengthen caregiving capacity	Professional support	Consultation to doctor
		Nurse as mediator
		Dietitian support
		Psychological support
		Pharmacist consultation
	Multidisciplinary support	Need for coordinated care among healthcare profesionals
		Communication among healthcare professionals
	Educational intervention	Structured family caregiver intervention
		Regular health education
		Practical caregiving training
	Service resources	Improved service resource
		Accessible follow-up services

Category 1: Barriers to health literacy in family caregiving for hemodialysis patients

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Hemodialysis nurses described family caregivers as facing various challenges in obtaining, understanding, evaluating, and applying hemodialysis-related health information. These challenges include limited understanding of diet, fluid restrictions, clinical signs and symptoms, confusion surrounding conflicting information, a lack of educational resources, and difficulty helping patients adhere to therapy regimens.

Challenges of managing patient compliance

Challenges in managing patient compliance experienced by family caregivers include dietary non-compliance and fluid restriction non-compliance.

"Patients sometimes eat prohibited foods, resulting in hyperkalemia" (HN.07, 7 years of experience)

"Patients have difficulty adhering to fluid restrictions" (HN.09, 5 years of experience) (HN.03, 7 years of experience)

Limitations of health literacy in hemodialysis care

Limitations in health literacy in the care of hemodialysis patients by family caregivers include a lack of knowledge of symptoms, limited dietary knowledge, confusion about health information, and family caregivers also experience barriers to receiving education about hemodialysis care.

"Families often fail to recognize early signs of a patient's deterioration" (HN.01, 10 years of experience).

"Families are confused about which foods to restrict and which to recommend" (HN.08, 5 years of experience).

"The information families receive is inconsistent, leading to confusion" (HN.07, 7 years of experience).

"Hemodialysis patients often forget or reject the information provided" (HN.04, 7 years of experience).

Category 2: Managing emotional strain and psychosocial challenges in family caregiving

This category describes the multidimensional burdens experienced by family caregivers while caring for hemodialysis patients. These burdens include physical exhaustion, emotional distress, anxiety, family conflict, financial difficulties, and the need for psychological support. Nurses believe that family caregivers require strong mental resilience because they must deal with patients with chronic illnesses over the long term.

Burden on family caregivers in caring for hemodialysis patients

The burdens experienced by family caregivers in long-term care for hemodialysis patients include fatigue, helplessness, the need for emotional support, and efforts to maintain resilience.

"Caregivers feel bored and exhausted while accompanying the patient" (HN.14, 6 years of experience).

"Patients get angry when told what to do, but ultimately have to comply" (HN.12, 8 years of experience).

"Caregivers need a place to vent because they don't know who to talk to" (HN.03, 7 years of experience) (HN.07, 7 years of experience).

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"Caregivers must be truly mentally strong" (HN.06, 7 years of experience).

Social and economic barriers to care

The needs of family caregivers increase while assisting patients in accessing hemodialysis. As a result, family caregivers experience financial constraints, resulting in conflicts between family caregivers and patients, as well as between family and inter-family caregivers.

"Some patients cannot undergo hemodialysis because they lack transportation costs" (HN.09, 5 years of experience).

"Patients become angry and argue with family caregivers because they are too controlling" (HN.11, 6 years of experience).

" The patient and their family are in conflict regarding assets and the rotation of caregiving duties" (HN.14, 6 years of experience).

"Conflicts occur between caregivers; when they meet while accompanying a patient on hemodialysis, they avoid each other" (HN.13, 7 years of experience).

Category 3: The need for comprehensive support systems to strengthen caregiving capacity

This category illustrates the importance of a comprehensive support system in enhancing family caregivers' capacity. This support includes professional support, multidisciplinary support, educational intervention and service resources.

Professional support

Family caregivers caring for hemodialysis patients require support from professionals specifically nurses, doctor, dietitian, psychological and pharmacist.

“ The family want consultation to doctor regularly about patient condition” (HN.05, 10 years of experience).

"The patient and their family agreed to meet privately with the nurse to resolve the issues between them” (HN.02, 10 years of experience).

“ They want to ask a dietitian about the types of food permitted and those restricted for hemodialysis patients” (HN.10, 6 years of experience).

“...this means they also need some kind of counselling.” (HN.07, 7 years of experience)

“Sometimes they are confused about the medications, so they need to consult the pharmacist about which medicines should be taken and how they should be used.” (HN.11, 6 years of experience)

Multidisciplinary support

“We need the doctors, nurses, and other healthcare professionals to communicate with each other. Sometimes we are confused because the information we receive is different.” (HN.09, 5 years of experience)

“The doctor has not yet informed the rest of the medical team that the patient needs to be hospitalized; they have to wait three hours.” (HN.14, 20 years of experience)

Educational intervention

The education required by family caregivers of hemodialysis patients consists of structured, regular educational interventions that include practical training.

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" The family would like to receive a book and training that include images of food examples suitable for hemodialysis" (HN.08, 5 years of experience)

"They want health education every week" (HN.04, 7 years of experience)

"Family caregivers want to practice methods for reducing potassium levels in vegetables and fruits." (HN.15, 20 years of experience)

Service resources

The service resources required by family caregivers are improved service resources and accessible follow-up services.

"Administrative staff should provide notification one day in advance if there is a change to the hemodialysis schedule " (HN.09, 5 years of experience).

"When the patient is at home, the family needs to have a contact person they can reach in the event of a problem or if they require further advice" (HN.14, 6 years of experience).

Discussion

This exploratory qualitative study provides comprehensive insights into the health literacy challenges and burdens experienced by family caregivers of hemodialysis patients, as perceived by hemodialysis nurses. This study reveals the complex and interconnected nature of the factors shaping health literacy acquisition in hemodialysis care. Findings across three main categories and eight subcategories illustrate perceived health literacy barriers, the emotional strain resulting from long term care, and the comprehensive support required.

Barriers to health literacy in family caregiving for hemodialysis patients

This study shows that family caregivers face various challenges in obtaining, understanding, and applying health information related to the care of hemodialysis patients. From the nurses' perspective, family caregivers still experience difficulties understanding dietary restrictions, fluid management, recognizing signs and symptoms of complications, and receiving inconsistent information from various sources. Furthermore, both patients and family caregivers sometimes resist the education provided, hindering the application of health information in daily life.

These findings align with the concept of health literacy as an individual's ability to access, understand, evaluate, and use health information to make informed health-related decisions (21). In the context of chronic kidney disease, this ability is crucial because patients and family caregivers must manage complex, lifelong treatment regimens. When health literacy is low, family caregivers are at risk of making poor decisions, failing to recognize signs of worsening patient conditions, and having difficulty supporting patient adherence to therapy.

The results of this study align with those of (7), who found that family caregivers of patients with end-stage renal disease often reported inadequate information regarding disease management, treatment, and home care. This limited information led to family caregivers feeling insecure in carrying out caregiving duties and facing uncertainty in decision-making. Similarly, a meta-synthesis showed that family caregivers of hemodialysis patients continually seek health information to understand their patients' conditions and maintain continuity of care (22).

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Another interesting finding was the influence of informal information obtained from fellow patients or other family members. Nurses reported that information circulating among patients often did not align with healthcare professionals' recommendations, yet patients and family caregivers still believed it and implemented it. This condition indicates that health literacy is influenced not only by access to information but also by the ability to evaluate the validity of information sources. The ability to assess the credibility of information is a crucial component of health literacy that determines an individual's success in managing chronic disease (23).

Although research in Indonesia specifically measuring the health literacy of family caregivers on hemodialysis is limited, several studies have shown that family caregivers require clear and ongoing information regarding patient care. Findings regarding family caregiver confusion about diet, fluid restrictions, and signs of complications align with reports that family caregivers often struggle to understand complex health information and require repeated education from healthcare professionals. These findings support the belief that the ability to acquire and apply health information is a critical component of successful care for hemodialysis patients. The quality of life of family caregivers of hemodialysis patients is influenced by their ability to adapt to the demands of care, which include access to and utilization of health information (24).

The findings of this study indicate that the challenges faced by family caregivers lie not only in a lack of information but also in their ability to interpret and apply health information in real-world situations. This situation highlights the importance of developing health literacy-based interventions that consider the specific needs of family caregivers of hemodialysis patients in Indonesia. Strengthening family caregiver health literacy needs to be a priority in hemodialysis services. Education is not sufficient just once at the start of therapy; it needs to be provided continuously, taking into account changing information needs as the patient's condition evolves. Providing easy-to-understand, affordable, and accessible educational media is also necessary to help family caregivers consistently apply health information at home.

Managing emotional strain and psychosocial challenges in family caregiving

Family caregivers face not only the demands of physical care but also significant psychological, emotional, social, and economic burdens. Nurses describe family caregivers often experiencing burnout due to the long-term caregiving process, difficulties dealing with patients who are non-compliant with therapy, family conflict, and economic pressures related to medication and transportation needs. These findings are consistent with the Caregiver Burden theory, which explains that family caregiver burden is a multidimensional consequence of the responsibility of caring for a family member with a chronic illness.

Family caregiver burden encompasses not only physical aspects but also emotional stress, changes in social relationships, limitations on personal activities, and financial issues. In hemodialysis patients, this burden tends to increase due to the routine and long-term nature of the therapy (25). Family caregivers also often experience anxiety, uncertainty, social isolation, and psychological stress due to unpredictable changes in the patient's condition (7).

Interestingly, the nurses in this study also highlighted interpersonal conflicts between patients and family caregivers, as well as among family members. These conflicts were often triggered by

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economic problems, changes in family roles, and the patient's inability to accept their condition. This situation demonstrates that caregiving for hemodialysis patients is not only a healthcare activity but also a complex social adaptation process. According to Family Systems Theory, changes in the health condition of one family member will affect the balance of the entire family system and potentially cause stress on interpersonal relationships (26).

Research in Indonesia on family caregivers of hemodialysis patients found that most family caregivers experience significant burden, particularly related to lack of family support, emotional distress, and changes in daily activities. Age, education, and family income are associated with the level of family caregiver burden (27). These findings are reinforced by other research in Indonesia, which showed that family caregivers of hemodialysis patients experience burden, anxiety, depression, and a reduced quality of life. The higher the family caregiver burden, the higher the levels of anxiety and depression experienced by family caregivers (28).

The findings of this study strengthen the evidence that caregiving for hemodialysis patients is an emotionally and psychosocially demanding process. In addition to facing the physical demands of accompanying patients through long-term therapy, family caregivers must also cope with psychological stress due to the uncertainty of the patient's condition, family conflict, and limited economic resources. Therefore, family caregiver burden should be viewed as a health issue that requires special attention in hemodialysis services. Despite facing various challenges, nurses believe that family caregivers with good psychological resilience tend to be better able to adapt to the demands of care. Therefore, nursing interventions should focus not only on improving family caregivers' knowledge but also on addressing mental health aspects, coping strategies, and strengthening resilience so that family caregivers can maintain the quality of care in the long term.

The need for comprehensive support systems to strengthen caregiving capacity

This study shows that family caregivers need a comprehensive support system to improve their ability to care for hemodialysis patients. Nurses have identified that family caregivers require support in caring for hemodialysis patients specifically professional support, with nurses acting as a support system and mediators for the issues they face. Additionally, family caregivers need multidisciplinary support, such as that provided by physicians and dietitians. Other requirements include well-structured educational interventions and access to service resources.

These findings align with Social Support Theory, which emphasizes the importance of informational, emotional, instrumental, and appraisal support in helping individuals cope with stressful situations. In the context of hemodialysis, this support can come from family, healthcare professionals, peer groups, and the healthcare system. Adequate support can enhance family caregivers' ability to manage patient care and mitigate the negative impact of caregiving burden (29). Previous research has shown that family caregivers of hemodialysis patients frequently report unmet needs related to education, psychosocial support, and access to healthcare. Family caregivers require structured support programs to help them understand their illness, manage stress, and improve caregiving skills (11). Furthermore, other research has found that family

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caregivers actively seek social and professional support as a strategy to reduce the burden of care (22).

In this study, nurses were seen as a primary source of support, often providing information and serving as a place for family caregivers to share their feelings. These findings reinforce the central role of nurses in the family-centered care model. Nurses serve not only as clinical service providers but also as learning facilitators, emotional support providers, and liaisons between families and available resources. Based on the research findings, the development of an integrated family caregiver support program needs to be part of hemodialysis services. This program could include ongoing education, accessible information, psychosocial counseling, family caregiver support groups, and increased family involvement in the care process.

Family caregivers also require multidisciplinary support, involving coordination among professionals and effective inter-professional communication. Structured, regular, and practical education is also essential; this includes the use of weekly modules and hands-on practice in reducing potassium levels in vegetables and fruits. Necessary service resources include improved service provision and accessible follow-up services.

This comprehensive approach is expected to increase the capacity of family caregivers and ultimately support the success of hemodialysis therapy for patients. Family caregivers also require consultation from a multidisciplinary team of experts, such as physicians, dietitians, and medical rehabilitation specialists. Dietary management for hemodialysis patients is unique, as it must be tailored to the specific characteristics of the individual patient. Scheduled and structured education is essential, adapted to blood test results, the patient's general condition, and their medical status. Adequate resource support within the hemodialysis unit also significantly impacts the caregiving burden faced by the family caregivers of hemodialysis patients.

Implications for Theory, Practice, and Policy

Theoretical Implications

This study contributes to the development of the concept of health literacy in the context of caregiving for hemodialysis patients. The findings indicate that health literacy is not only related to the ability of family caregivers to obtain and understand health information, but also includes the ability to evaluate, interpret, and apply that information in complex care situations. This study also expands understanding of the relationship between health literacy and caregiver burden. Limited health literacy can increase emotional distress, feeling of helplessness, and family caregivers' difficulties in supporting patients' adherence to therapy. Health literacy and caregiving burden are not two independent concepts, but rather influence each other in the care process for hemodialysis patients. These findings can form the basis for developing a conceptual model that integrates health literacy, caregiving capacity, and family caregiver well-being in chronic illness.

Practice and Policy Implications

The findings of this study demonstrate the need to strengthen nurses' role in supporting family caregivers of hemodialysis patients through a more comprehensive and sustainable approach.

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Health education should not only be provided at the beginning of therapy but should be conducted periodically, taking into account changes in the patient's condition and the information needs of family caregivers. Developing easy-to-understand educational media, such as booklets, educational videos, digital apps, or practical home care guides, can help improve family caregivers' ability to manage patient care independently.

In addition to their role as educators, nurses need to strengthen their role as counselors and facilitators of psychosocial support. Findings regarding emotional exhaustion, family conflict, and the need for family caregivers to share experiences demonstrate the importance of routinely assessing the psychological wellbeing of family caregivers throughout the care process. Integrating family caregiver burden and health literacy assessments into hemodialysis services can help healthcare providers identify family caregivers at risk of experiencing difficulties in fulfilling their roles, allowing for early intervention. This study also emphasizes the importance of implementing a family-centered care approach in hemodialysis services. Active family involvement in education, decision-making, and care planning can enhance family caregiver capacity and strengthen the success of disease management at home.

The results of this study demonstrate the need to develop family caregiver support programs as an integral part of hemodialysis services. To date, most services remain patient-focused, while the needs of family caregivers are often not prioritized within the healthcare system. Therefore, hospitals and hemodialysis units need to develop policies that support structured education, psychosocial counseling, and ongoing family caregiver support programs. The Ministry of Health and professional nursing organizations can consider developing service standards that incorporate assessments of family caregiver health literacy and caregiver burden as part of routine hemodialysis patient evaluations. Furthermore, policies are needed to encourage the provision of standardized, evidence-based educational resources so that the information family caregivers receive is more consistent and easier to understand.

The development of community-based support programs and peer support groups should also be considered to expand family caregivers' access to information and emotional support. Policies that support multidisciplinary collaboration among nurses, physicians, psychologists, social workers, and patient organizations have the potential to improve the quality of care that is oriented towards the needs of patients and families. Thus, increasing the capacity of family caregivers will not only improve quality of life but also enhance therapy adherence, patient quality of life, and the overall success of chronic kidney disease management.

Study Limitations and Strengths: The findings reflect nurses' experiences and observations of family caregivers, not the direct experiences of the family caregivers themselves. Although nurses interact intensively with patients and families, some family experiences may be subjective. The study was conducted in a hemodialysis unit with specific service characteristics and patient populations. Differences in organizational culture, healthcare systems, resource availability, and socioeconomic characteristics of patients and families in other healthcare facilities may influence

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family caregivers' experiences and nurses' perceptions. Therefore, the transferability of the findings to different contexts requires caution.

Despite its limitations, this study offers several strengths that make important contributions to the development of nephrology nursing and family-based care. This study explores the challenges of health literacy and the burden of caregiving from the perspective of hemodialysis nurses, a perspective that is still relatively rarely reported in the literature. While most previous research has focused on the experiences of family caregivers, this study provides insight into how healthcare professionals identify the needs, barriers, and challenges they face in daily clinical practice. This study provides a more comprehensive understanding of the relationship between limited health literacy, the psychosocial burden of family caregivers, and the need for an integrated support system. These findings broaden the understanding that successful care for hemodialysis patients is determined not only by the patient's clinical condition but also by the capacity and well-being of the family caregivers who accompany them.

Conclusion

Family caregivers of hemodialysis patients face various challenges in carrying out their home care roles, including limitations in obtaining and applying health information, prolonged psychosocial and emotional burdens, and the need for a more comprehensive support system. From the perspective of hemodialysis nurses, family caregivers often struggle to understand information related to dietary management, fluid restrictions, therapy adherence, and recognizing signs of complications. These limitations can impact the family caregiver's ability to support optimal disease management.

In addition to health literacy challenges, family caregivers face various psychological, social, and economic pressures arising from long-term care responsibilities. Emotional exhaustion, family conflict, difficulties dealing with patient non-compliance, and limited resources are contributing factors to the increased caregiving burden. These findings suggest that hemodialysis patient care should not only focus on patients' clinical needs but also address the well-being of family caregivers as an integral part of the care process.

This study also emphasizes the importance of ongoing educational, psychosocial, and social support to enhance the capacity of family caregivers. Nurses play a strategic role as educators, facilitators, and sources of support for caregivers in facing various care challenges. Therefore, developing family-oriented hemodialysis services through structured education, health literacy and caregiver burden assessments, and psychosocial support programs should be incorporated into routine care practices.

Improving family caregiver health literacy and strengthening family support systems are crucial components in supporting successful hemodialysis patient care. These efforts have the potential to enhance family caregivers' abilities to fulfill their roles, reduce the burden of care, and promote a better quality of life for both patients and their families. The findings of this study provide a basis for developing nursing interventions and health policies that are more responsive

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to the needs of family caregivers in the context of chronic kidney disease and hemodialysis therapy.

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