

Original Research

Palliative Care Needs among Patients with End-Stage Kidney Disease: A Descriptive Observational Study

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Abstract

Background: End-stage kidney disease (ESKD) represents an increasing health burden in Indonesia, with affected individuals experiencing complex needs that substantially diminish quality of life.

Objective: aimed to identify palliative care needs among end-stage kidney disease patients undergoing hemodialysis.

Methods: This cross-sectional study was conducted at a hemodialysis center in North Sulawesi in 2024. Respondents were selected using purposive sampling. The Sociodemographic Questionnaire and the Supportive and Palliative Care Indicators Tool (SPICT) were employed to collect sociodemographic data and identify potential palliative care needs. Univariate analysis was performed to examine palliative care needs among ESKD patients.

Results: A total of 150 participants were included. Almost all respondents were identified as needing palliative care, with the majority presenting two general indicators and two clinical indicators.

Conclusion: Nearly all patients with end-stage kidney disease undergoing haemodialysis are identified as having palliative care needs. This finding suggests the need to integrate routine palliative care assessment and services into patients with end-stage kidney disease, especially those in haemodialysis care to ensure comprehensive and patient-centered management of physical, psychosocial, and spiritual needs.

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Keywords

Palliative Care; End-Stage Kidney Disease; Hemodialysis

Background

Chronic kidney disease (CKD) represents a significant public health concern, with a global prevalence of 13.4% in stages 1-5 and 10.6% in stages 3-5 (1). Projections indicate that CKD prevalence will increase by 16.7% by 2030 (2). Global epidemiological data indicate that 1.2 million individuals died from CKD in 2017, reflecting a 41.5% increase in mortality from 1990 to 2017 (3). In Indonesia, CKD prevalence rose from 0.2% in 2013 to 0.3% in 2018, with North Sulawesi ranking third nationally in terms of CKD prevalence (4).

Progression to End-Stage Kidney Disease (ESKD) requiring maintenance hemodialysis is associated with physiological decline, a range of cardiovascular complications, comorbidities, and significant psychological, social, and financial challenges (5, 6). Consequently, recent guidelines recommend palliative care for patients with CKD (7, 8).

This multidimensional burden requires a transition from exclusively curative or life-sustaining approaches to integrated palliative care models (9, 10). Palliative care plays a critical role in supporting patients with non-curative conditions by emphasizing restoration of functional capacity, symptom management, and respect for patients' beliefs, culture, and spirituality (11). Evidence indicates that early palliative intervention can improve quality of life, enhance symptom management (12), and reduce healthcare utilization costs (13). A study in China found that unmet palliative care needs among CKD patients undergoing hemodialysis were influenced by education level, financial status, functional capacity, symptom burden, and social factors (14). Despite these advantages, integration of palliative services into renal care remains limited, often due to inadequate early identification of patient needs.

Delayed identification of palliative care needs has been shown to adversely affect patient outcomes (15). Accordingly, screening constitutes a critical initial step in palliative care (16, 17). This study employs the Supportive and Palliative Care Indicators Tool (SPICT) to assess these needs. SPICT is valuable in this context because it uses objective, general, and clinical indicators to identify patients with life-limiting conditions, facilitating a more proactive approach compared to traditional prognosis-based assessments (18).

This study, focusing on North Sulawesi, a region with a high CKD burden, aims to determine the prevalence and characteristics of palliative care needs among ESKD patients. The findings are intended to support the integration of routine palliative care assessments into standard hemodialysis care, thereby advancing a more holistic and patient-centered approach to disease management.

Methods

A descriptive observational design was implemented in 2024 at a hemodialysis center in North Sulawesi, Indonesia. A total of 150 patients with end-stage kidney disease (ESKD) undergoing hemodialysis were recruited using purposive sampling.

Eligibility criteria included: 1) diagnosis of ESKD with willingness to participate; 2) ability to speak Indonesian and complete questionnaires; and 3) diagnosis of ESKD for at least six months. Exclusion criteria were: 1) presence of communication barriers; 2) repeated treatment with previously collected data; and 3) incomplete questionnaire responses.

Data collection instruments included a sociodemographic questionnaire and the Supportive and Palliative Care Indicators Tool (SPICT). The sociodemographic questionnaire collected information on age, gender, education level, marital status, duration of chronic kidney disease (CKD) diagnosis, and duration of hemodialysis. The SPICT assessed palliative care needs in ESKD patients, comprising six general indicators, twenty-three clinical indicators, and eight life-limiting conditions. Patients were classified as requiring palliative care if they met at least 2 general indicators and 1 specific indicator. The Indonesian version of the SPICT demonstrated validity and reliability, with a Cronbach's alpha of 0.97 (18).

Ethical approval was obtained from the ethics committee of Prof. Dr. R. D. Kandou Hospital (No. 102/EC/KEPK-KANDOU/V/2024), and written informed consent was secured from all participants. Statistical analyses were conducted using SPSS version 29.0. Continuous variables were summarized as means and standard deviations, while categorical variables were presented as frequencies and percentages. Univariate analysis was used to identify palliative care needs among ESKD patients.

Result and Discussion

Respondent Characteristics

Table 1 shows that the average age of respondents was 52.6 (SD=12.7) years, with 49 (32.7%) respondents being male, 77 (51.3%) respondents having a high school education level was high school which was 78 (52%) respondents, and 131 (87.3%) respondents being married. In addition, the average time from diagnosis to chronic kidney disease was 3.2 (SD= 2.9) years, the average duration of hemodialysis was 3.4 (SD= 3.01) years, and most respondents had comorbidities, accounting for 134 (89.3%) respondents.

Table 1. Distribution of Respondent Characteristics (n =150)

Characteristics	n (%) or Mean±SD (min-max)
Age (year)	52.6±12.7(18-85)
Gender	
Male	77 (51.3)
Female	73 (48.7)
Education level	
Elementary school	12 (8)

Junior high school	22 (14.7)
Senior high school	78 (52)
Diploma III	1 (0.7)
Bachelor's degree	37 (24.7)
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Marital Status	
Married	131 (87.3)
Unmarried	19 (12.7)
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Duration of being diagnosed with CKD (year)	3.2±2.9 (0.5-14)
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Duration of haemodialysis (year)	3.4±3.01 (0.5-14)
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Comorbidity	
Yes	134 (89.3)
No	16 (10.7)

Table 2 shows that most respondents (146, 97.3%) were identified as having palliative care needs, with the majority presenting 2 general indicators (104, 69.3%) and 2 clinical indicators (136, 90.7%).

Table 2. Palliative Care Needs according to the SPICT (n= 150)

Variables	Category	n (%)
Needing palliative care	Needs no palliative care	4 (2.7)
	Needs palliative care	146 (97.3)
SPICT general indicator	0	1 (0.7)
	1	3 (2)
	2	104 (69.3)
	3	32 (21.3)
	4	5 (3.3)
	5	5 (3.3)
SPICT clinical indicator	1	14 (9.3)
	2	136 (90.7)

DISCUSSION

Demographic Characteristics

The findings of this study indicate that the average age of respondents was 52.6 years, with a predominantly male population. This is in line with a previous study, which showed that most patients with end-stage kidney disease undergoing hemodialysis were in the age group of 50–59 years (19). Likewise, other studies by Effendy, Silva (18), Yodang, and Nuridah (20) reported that most participants were aged 50 years or older. This finding is also consistent with global evidence showing that CKD prevalence increases with age due to cumulative exposure to metabolic and cardiovascular risk factors such as hypertension and diabetes. CKD currently affects more than 10% of the global population and continues to rise, particularly among aging populations (21, 22). In terms of gender, the majority of respondents were male, which is in accordance with the findings of a previous study, which found that 58% of CKD patients undergoing hemodialysis were male. Men tend to have a greater risk of CKD, which is associated

with lifestyles such as smoking habits, drinking alcohol, and higher levels of exposure to hypertension and diabetes than women (23).

Additionally, the majority of respondents had a high school education level (52%), which may influence health literacy and self-management abilities. Patients with lower or moderate education levels often face challenges in understanding complex treatment regimens such as hemodialysis, dietary restrictions, and medication adherence potentially affecting disease outcomes (22).

The high proportion of married respondents (87.3%) suggests that patients are likely to have access to spousal or family support. Social support is a critical factor in chronic illness management, particularly in CKD, where long-term treatment adherence and psychological adaptation are essential. Previous studies have shown that strong family support can improve coping mechanisms, treatment compliance, and overall quality of life among hemodialysis patients. This is particularly relevant given the demanding nature of dialysis therapy, which typically requires multiple weekly sessions and significant lifestyle adjustments (24).

The relatively similar duration between CKD diagnosis and hemodialysis suggests that many patients may present late in the disease trajectory, a phenomenon commonly reported in low- and middle-income countries (25). Furthermore, the long duration of hemodialysis underscores the substantial burden experienced by patients (14). Studies have shown that prolonged dialysis is associated with declining functional status, increased comorbidities, and reduced quality of life. Patients undergoing maintenance hemodialysis often experience multidimensional challenges, including physical discomfort, emotional distress, and social limitations, which require comprehensive and multidisciplinary management approaches such as palliative care (26).

As demonstrated by the demographic data, this study reflects a typical population of CKD patients undergoing long-term hemodialysis, characterized by middle-to-older age, a moderate level of education, and prolonged disease duration.

Prevalence and Characteristics of Palliative Care Needs

The findings of this study demonstrate that, based on the Supportive and Palliative Care Indicators (SPICT) Tool, almost all respondents (97.3%) were identified as having palliative care needs. This high proportion highlights the substantial burden experienced by patients with ESKD undergoing hemodialysis and reinforces the growing recognition that ESKD should be approached as a life-limiting condition requiring integrated palliative care.

The high prevalence of palliative care needs observed in this study is consistent with recent evidence indicating that patients undergoing maintenance hemodialysis experience significant multidimensional symptom burden. Physical symptoms such as fatigue, pain, pruritus, and sleep disturbances are highly prevalent, accompanied by psychological distress, including anxiety and depression. These symptoms often occur simultaneously and persist over time, substantially reducing quality of life (26, 27).

The SPICT results further revealed that the majority of respondents had at least two general indicators (69.3%) and two clinical indicators (90.7%). The presence of multiple general indicators, such as declining functional status and increased healthcare utilization, suggests a progressive deterioration in overall health. Similarly, the dominance of clinical indicators reflects the severity of disease progression, including complications and frequent exacerbations commonly seen in end-stage kidney disease (28). These findings align with global literature emphasizing that patients on long-term dialysis often experience worsening clinical conditions that meet criteria for palliative care assessment and intervention (29).

Importantly, the predominance of two indicators (both general and clinical) suggests that most patients are not in the very terminal stage but are already in a vulnerable phase where early palliative care integration is highly beneficial (30). Current evidence strongly supports the early introduction of palliative care in CKD, as it improves symptom control, enhances quality of life, and reduces unnecessary hospitalizations (31). A recent systematic review found that integrating palliative care into routine hemodialysis management improves patient-centered outcomes, particularly symptom relief and psychosocial support (32).

Furthermore, the high proportion of patients identified with palliative care needs reflects the concept of “unmet needs” in dialysis populations. The high SPICT scores observed in this study, therefore, not only reflect clinical severity but also suggest an increased risk of adverse outcomes if comprehensive supportive care is not provided. Studies have shown that despite the heavy symptom burden, many CKD patients do not receive adequate palliative care services due to limited awareness, insufficient integration within nephrology care, and misconceptions that palliative care is only appropriate at the end of life. This gap may be even more pronounced in developing countries, where healthcare resources and specialized palliative care services are limited (14).

These findings emphasize the importance of routine screening for palliative care needs, as most respondents identified as needing palliative care. The presence of multiple general and clinical indicators reflects significant disease burden and highlights the importance of early, proactive, and multidisciplinary care strategies.

This study has several limitations. The sample was collected at a single site, limiting generalizability, and the analysis relied on univariate methods, precluding the identification of independent predictors of palliative care needs. To minimize the potential bias, strict inclusion and exclusion criteria were applied, and a validated questionnaire with clear instructions was provided to reduce recall bias. Future studies are suggested to expand data collection across multiple hospitals or regions to reduce site-specific bias and to utilize multivariate analysis to adjust for covariates, thereby identifying true independent predictors of palliative care needs in ESKD patients.

Conclusion

Nearly all patients with end-stage kidney disease (ESKD) undergoing hemodialysis are identified as having palliative care needs. The findings of this descriptive study

highlight the importance of integrating routine palliative care assessments and services for ESKD patients, particularly those receiving hemodialysis, to ensure comprehensive and patient-centered management of physical, psychosocial, and spiritual needs. Future research should investigate factors associated with the palliative care needs of patients with end-stage kidney disease.

Declaration of Conflict of Interest

None

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Author Contributions

FF, AI, JT designed research; FF, RW conducted research; FF, AI analyzed data; FF, JT wrote the first draft of manuscript; FF, AI had primary responsibility for final content. All authors read and approved the final manuscript.

Data Availability Statement

The dataset generated and analysed during the current study is available from the corresponding author upon reasonable request.

Declaration of the Use of AI in Scientific Writing

The authors declare that artificial intelligence (AI) tools were used solely to assist in language refinement and improving the clarity of the manuscript. The AI did not contribute to the study design, data analysis, or interpretation of results.

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