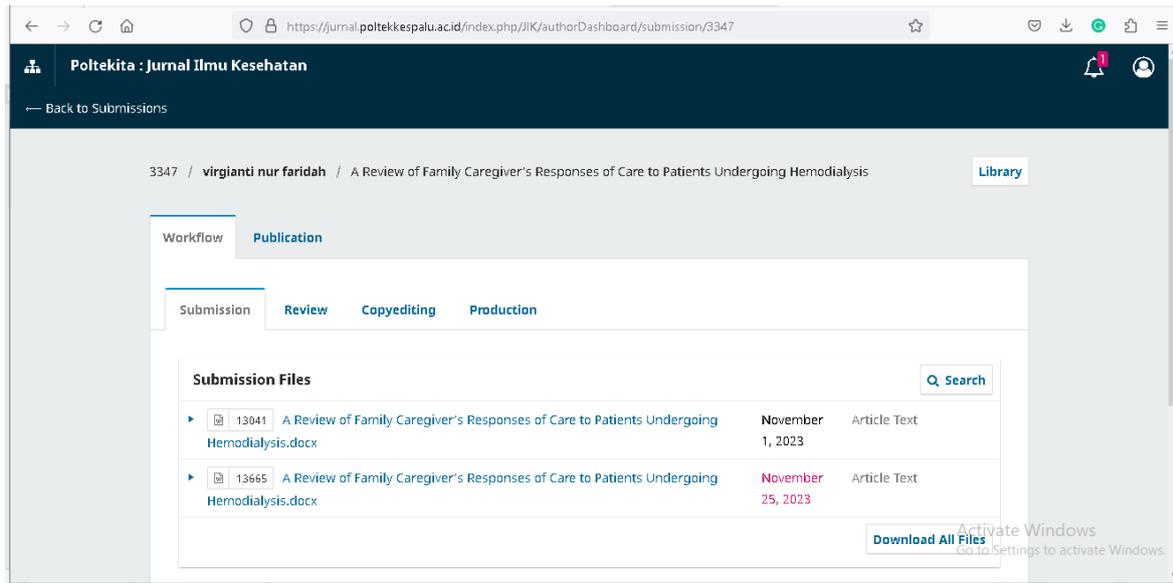


BUKTI KORESPONDENSI JURNAL POLTEKITA (SINTA 2)

Submission

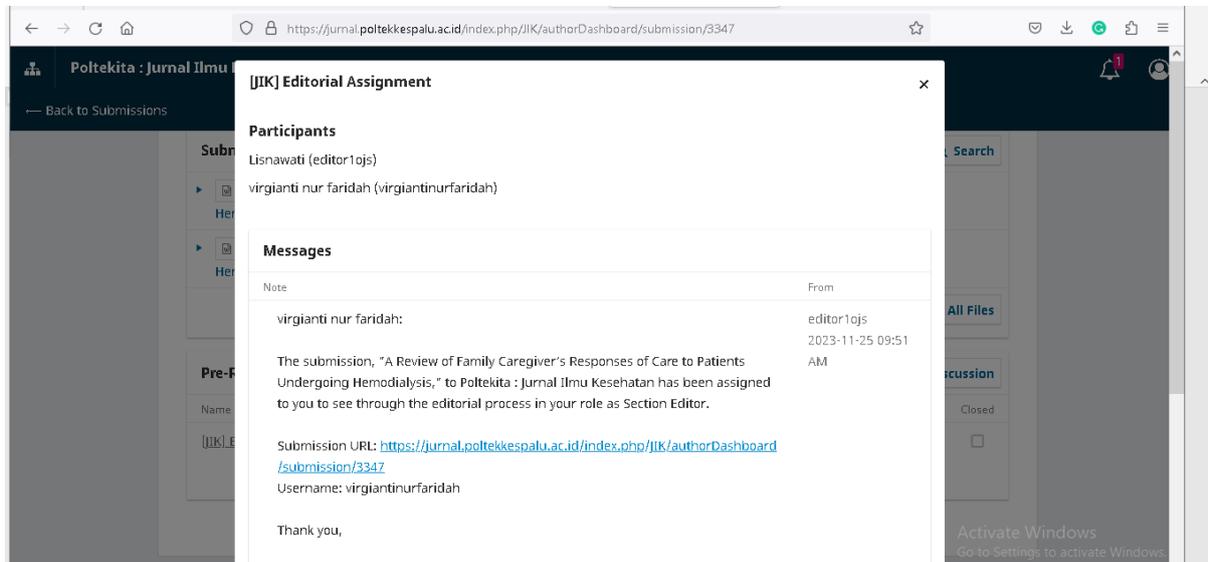


The screenshot shows the author dashboard for submission 3347. The page title is "Poltekita : Jurnal Ilmu Kesehatan". The submission title is "A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis". The submission is in the "Publication" stage. The "Submission Files" section lists two files:

File ID	File Name	Date	File Type
13041	A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis.docx	November 1, 2023	Article Text
13665	A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis.docx	November 25, 2023	Article Text

A "Download All Files" button is visible at the bottom right of the file list.

Pre Review



The screenshot shows the author dashboard with an "Editorial Assignment" modal window open. The modal contains the following information:

[JIK] Editorial Assignment

Participants

- Lisnawati (editor1ojs)
- virgianti nur faridah (virgiantinurfaridah)

Messages

Note	From
virgianti nur faridah:	editor1ojs
The submission, "A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis," to Poltekita : Jurnal Ilmu Kesehatan has been assigned to you to see through the editorial process in your role as Section Editor.	2023-11-25 09:51 AM
Submission URL: https://jurnal.poltekkespalu.ac.id/index.php/JIK/authorDashboard/submission/3347	
Username: virgiantinurfaridah	

Thank you,

Review

Poltekita : Jurnal Ilmu Kesehatan

3347 / virgianti nur faridah / A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis

Workflow **Publication**

Submission **Review** Copyediting Production

Round 1

Round 1 Status
One or more reviewers missed their deadline. The editorial team has been notified and will take action to ensure reviews are completed. You do not need to take any action at this time. You will be notified when a decision has been made.

Review Discussions [Add discussion](#)

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3347 / virgianti nur faridah / A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis

Workflow **Publication**

Submission **Review** Copyediting Production

Round 1

Round 1 Status
Revisions have been requested.

Reviewer's Attachments [Search](#)

14006	A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis_review.docx	December 2, 2023
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Publish

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3347	Faridah et al. A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis	1	Published	View	▼
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Article Review

A Review of Family Caregiver's Responses of Care to Patients Undergoing Hemodialysis

ABSTRACT

The limitations of CKD patients require that families care for family members who have CKD. The objective of this study is to describe the experiences of families in caring for family members with CKD. A systematic review involved searching six electronic databases (Scopus, PubMed, CINAHL Plus, Science Direct, Sage, and ProQuest) for previous studies published from 2015 to 2020 with qualitative designs. The Centre for Review and Dissemination and the Joanna Briggs Institute Guidelines were utilized to assess quality, and the PRISMA checklist guided the review. Titles, abstracts, and full texts were assessed for the eligibility of the studies. Data tabulation and narrative analysis of study findings were performed. Ten studies that met the inclusion criteria for the review were obtained. The included studies were divided into broad thematic areas regarding family experiences in caring for CKD patients: information seeking, coping mechanisms, decision-making, burden, social limitations, and psychological disorders.

Keywords: Caregiver, Caring, Hemodialysis

DOI:



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INTRODUCTION

Family members are often involved in treating chronic kidney disease (CKD) patients as care or treatment partners. As care partners, family members are involved in many essential activities, including administering medication, monitoring medication adherence, assisting in daily care activities, scheduling and providing transportation while attending medical appointments, monitoring patient health, advocating for patients, and offering emotional support¹. This family role benefits both patients and healthcare providers. For patients, the involvement of family members is associated with improved behavior, self-management care, and adherence to therapy, as well as improved quality of life decreased risk of mortality, reduced anxiety and depressive symptoms, and reduced chances of hospital admission. For health care providers, family members are invaluable partners in caring for patients with chronic kidney disease².

Family is integral in providing care to individuals with deteriorating health conditions. When caring for patients with worsening conditions and an increasing need

for care, the caregiver performs more complex care tasks. Thus, caregivers are essential in caring for people with illness or disabilities across disease trajectories. Family-centered care has been proposed to address this problem by meeting the needs of not only patients but also their family members³. Efforts to prepare families for hemodialysis patient care include more family-centered care, provision of appropriate education from an early age, interventions that target the readiness of care partners, communication that focuses on readiness between healthcare providers and family members of patients, and the establishment of dynamics of relationships between families and patients⁴. The formation of psycho-educational support groups can also empower families by providing the knowledge and emotional support necessary for successful treatment⁵.

Caregivers of patients on hemodialysis are at high risk for emotional development and psychological distress, poor quality of life, and increased burden. They have various psychosocial concerns because of the length of treatment⁶. Families often experience a tremendous burden associated with caring for hemodialysis patients. These

Commented [Reviewer11]: Unclear Research Objectives:

Although the abstract states that the research's objective is to describe the experiences of families caring for CKD patients, it is not detailed in the methodology or other sections. This information is crucial to understand the research context and scope.

Commented [Reviewer12]: Unproven Study Quality:

The article mentions that the quality of studies was assessed using guidelines from the Centre for Review and Dissemination and Joanna Briggs Institute, but it doesn't provide detailed results of the quality assessment for each study. Therefore, there is no clarity on the quality of each included study in the review.

challenges and burdens increase with the progression of the disease. Families experience physical, emotional, and financial difficulties ⁷.

Family burdens may also affect the patient receiving care. Indeed, it has been reported that family burdens are associated with a lack of social support and lower health-related quality of life for patients and families ⁸. Disturbances in quality of life and family burdens in hemodialysis patients place a double burden on them and disrupt the

METHOD

Search Strategy

The steps for the systematic review were based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. A literature search was conducted in the databases of Scopus, PubMed, CINAHL Plus, Science Direct, Sage, and ProQuest with the search strategies described in Figure 1 for studies published in English within the period from 2015 to 2020. The identification of research articles about the role of caregivers in the palliative care of

treatment process ⁹. This can reduce the ability of families to treat chronic kidney disease patients with hemodialysis.

Caregivers need to study family experiences in caring for hemodialysis patients so that they do not experience excessive burdens that will interfere with patient care. This systematic review aims to describe the experiences of families in caring for family members who have CKD.

hemodialysis patients was made with specific keywords, phrases, and MESH terms (caregiver, family, palliative care, palliative therapy, hemodialysis, dialysis) with the Boolean operators AND and OR.

Inclusion and Exclusion Criteria

All articles of studies in the English language that were published from January 2015 to December 2020 were included in this review. This review also included original research and excluded review articles.

Table 1. Inclusion and exclusion criteria for the review

Inclusion	Exclusion
1. English-language studies from any country	1. Studies not in English
2. Studies published in 2015 or later (to 2020)	2. Studies before 1950 or missing abstracts
3. Original research (qualitative, descriptive, cross-sectional, cohort, mixed methods, experiment)	3. Systematic reviews and literature reviews
4. Role of caregivers included in articles	4. Other/unspecified caregivers

Quality Assessment

Quality appraisal of studies was made with the validated quality appraisal checklist from the Centre for Evidence-Based Medicine (CEBM). Each full paper was assessed by one reviewer and checked for accuracy by another. The studies were assessed twice, and discrepancies were resolved by discussion. No studies were excluded regarding their quality.

Data Collection and Extraction

Data from the eligible studies were extracted using structured sheets containing information on the author/year, type, population, quality, measured outcomes, and main findings of the studies. The first author

performed data extraction, and the second author checked the extracted data.

Assessment of Study Quality and Risk of Bias

Assessment of study quality and risk of bias was performed with The JBI Critical Appraisal for Qualitative Research to analyze the quality of methodology in each study (n = 10). The checklist for suitable studies has various assessment criteria. The criteria were assessed by giving remarks of 'yes,' 'no,' 'unclear,' or 'not applicable.' Low-quality studies were excluded to ensure the validity of the results and recommendations of the review ¹⁰. In the last screening, 12 studies had scores higher than 50%, and data synthesis

Commented [Reviewer13]: Unclear Research Objectives:

Although the abstract states that the research's objective is to describe the experiences of families caring for CKD patients, it is not detailed in the methodology or other sections. This information is crucial to understand the research context and scope.

Commented [Reviewer14]: No Use of Meta-Analysis:

Despite following PRISMA guidelines for systematic reviews, no meta-analysis is performed to combine relevant study findings. This could limit the strength of synthesizing findings and presenting a more holistic picture.

Commented [Reviewer15]: Lack of Detailed Methodology:

While the article mentions that the research involved a systematic review with searches in six databases, the detailed search procedure, inclusion and exclusion criteria, and search strategy are not elaborated. This makes it challenging for readers or other researchers to replicate or criticize the research method.

could be performed on them. Unfortunately, due to the risk of biased assessment, two studies were excluded.

Data Synthesis

The results are presented in narrative form, including a table to clarify. Figure 1 shows the article selection process with the PRISMA strategy. The number of articles retrieved from the databases as studies that could be potentially selected totaled 1,577 articles. Based on Mendeley Reference Manager, 475 duplicate articles were found and removed, resulting in 1,102 articles. The next step was the selection of articles based on their titles; 236 articles were kept, while 866 articles were removed as their titles were

unrelated to the study. Then, 236 articles were screened by their abstracts; 64 articles were kept, while 172 articles were removed as their abstracts were unrelated to the study. Finally, the full texts of the 64 articles were read, resulting in 27 articles being kept and 37 articles being excluded for different reasons. Of these, 10 studies met the inclusion criteria for this review. These 10 studies were assessed for quality, data extraction, and synthesis.

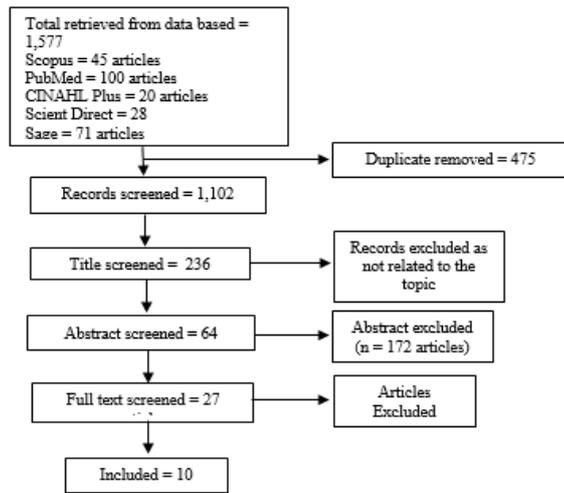


Figure 1. Article selection process

Table 2. Data Charting

No	Title, author	Population/setting	Country	Outcome	Interview/in-
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				depth/fGD	
1	Caregiver Experience in Pediatric Dialysis ¹¹	35 caregivers of children	US	<ol style="list-style-type: none"> 1. caregiver medicalization (subthemes: diagnosis and initiation, disease management, and the future) 2. emotional adjustment (initial and acute phase, acceptance, personal growth, and medical stress and psychological burden), 3. pragmatic adaptation (disruption, adaptation of life goals and sense of self, and financial impact) 4. social adjustment (relationship opportunity, relationship risk, advocacy, family functioning, and intimate relationships) 	Semi-structured interviews
2	An Interview Study of Patient and Caregiver Perspectives on Advance Care Planning in ESRD ¹²	Patients 24 and their caregivers 15	Australia	<ol style="list-style-type: none"> 1. Articulating core values (avoiding futile and undignified treatment, reevaluating terms of dialysis, framing a life worth living, and refusing to be a burden) 2. confronting conversations (signifying death and defeat, accepting inevitable death, and alleviating existential tension) 3. negotiating understanding (broaching taboos and assisting conflicted caregivers) 4. challenging patient autonomy (family pressures to continue dialysis, grief diminishing caregivers' capacity, and leveraging Support) 	Semi-structured interviews.

				5. decisional disempowerment (lacking medical transparency and disappointment with clinical disinterest).	
3	Family caregiver's Experiences of Providing Care to Patients with End-Stage Renal Disease in South-West Nigeria ¹³	15 family caregivers	Nigeria	<ol style="list-style-type: none"> 1. disconnectedness with self and others 2. never-ending burden 3. "a fool being tossed around." 4. obligation to care 5. promoting a closer relationship 	Semi-structured interviews
4	An Exploration of Palliative Care Needs of People With End-Stage Renal Disease on Dialysis: Family Caregiver's Perspectives ¹⁴	18 family caregivers	Canada	<ol style="list-style-type: none"> 1. challenges navigating the health system 2. caregiver burden 3. perceptions of palliative care 4. symptom management 5. decision-making. <p>Caregiver burdens: physical, emotional, social, and economic dimensions.</p>	In-depth
5	Dialysis or Death: A Qualitative Study of Older Patients' and Their Families' Understanding of Kidney Failure Treatment Options in a US Public Hospital Setting ¹⁵	15 patients and 6 family members	US	<ol style="list-style-type: none"> 1. do not view conservative management as a viable personal option for their own (or their family members) care 2. understand the realities of dialysis only abstractly 3. consider dialysis the only treatment option for kidney failure and any alternative as death. 	Semi-structured interviews.
6	Perspectives on decision making amongst older people with end-stage renal disease and caregivers in Singapore: A qualitative study ¹⁶	23 pasien 7 caregivers.	Singapore	<ol style="list-style-type: none"> 1. Role of Patient in decision-making 2. Role of Family in decision-making 3. Role of Doctor in Decision-making 4. Decision-making factors 	in-depth interviews
7	Social Support	Patients (n = 15)	Western	1. Social Support	Semi-structured

	in the Peritoneal Dialysis Experience: A Qualitative Descriptive Study ¹⁷	family members (n = 6) nurses (n = 11)	Canada.	<ol style="list-style-type: none"> 1. addressing emotional needs and managing emotion (emotional Support) 2. peritoneal dialysis tasks and life tasks (instrumental Support) 3. accessing information, receiving information, and learning (informational Support) 4. affirmation/external reassurance and self-confidence (appraisal support). 	interview
8	Dedication in caring for hemodialysis patients: Perspectives and experiences of Iranian family Caregivers ¹⁸	25 hemodialysis family caregivers	Iran	<ol style="list-style-type: none"> 1. heavy burden of care 2. tension in care 3. emotional exhaustion 	in-depth interviews
9	Family Members' Experiences With Dialysis and Kidney Transplantation ¹⁹	49 family members	AS	<ol style="list-style-type: none"> 1. becoming a care partner (unanticipated responsibilities and sleep disruptions), 2. adverse psychological treatment responses in patients (e.g., depression) and family members (e.g., anxiety), 3. treatment delivery and logistics (insufficient information, medication regimen logistical inconveniences) 4. patient morbidity (dialysis-related health problems and fatigue). 	Focus groups
10	Caring in an atmosphere of uncertainty: perspectives and Experiences of caregivers of People undergoing	20 hemodialysis family caregivers	Iran	<ol style="list-style-type: none"> 1. the constant struggle to learn 2. effort and adherence to the divine thread in disease's captivity 	Unstructured interviews

RESULTS And DISCUSSION

Data Characteristics

By the inclusion criteria, 10 articles were found. The analysis results indicated six themes: information seeking, coping mechanisms, decision-making, burden, social limitations, and psychological disorders. The responses of the families of patients while treating the patients with hemodialysis were found in the study articles about family experiences of treating patients (7 studies)²¹, decision-making (2 studies)²², and Support of social needs (1 study)²³. All studies that were reviewed to determine their themes utilized qualitative designs. The participants in the qualitative studies numbered more than 15, with an average of 20 participants. Regarding the origin of the studies, there were 3 studies from the United States^{24 25}, 2 studies from Canada^{26 26}, 2 research from Iran²⁸, and 1 study each from Singapore²⁹, Nigeria³⁰, and Australia³¹. Data collection in the studies utilized semi-structured interviews (5 studies), unstructured interviews (1 study), in-depth interviews (3 studies), and focus group discussions (1 study).

Family Response Information Seeking

Families will look for the correct information to determine the therapy to be given. Information from healthcare providers regarding dialysis services, procedural actions, side effects, and other vital facts will be sought to recover patients. The lack of clear information causes intense disappointment for families and patients. Families may also have reduced interest in treatment due to the need for more information. Families may choose services of alternative medicine if the obtained health information is not adequate.

Coping Mechanism

Family coping in caring for family members has different responses. Acceptance of the recognized kidney disease indicates strong coping. Families will also continue to struggle to obtain the best treatment for the recovery of patients. Family coping that is weak will be characterized by despair,

thoughts of death, and loss of spirit in caring for the family. Financial fatigue can also be a cause of families not being able to cope.

Decision-Making

Families, as well as patients, may make decisions. Patients can also make decisions regarding the sustainability of the patient therapy program. Families can discuss with patients regarding the decisions to be taken. In-depth communication with patients will affect the acceptance of patients regarding the outcome of the decisions that have been made. However, patient autonomy in decision-making must also be considered. The patient has the right to determine actions related to their health.

Burden

Families will continuously feel fatigued in treating patients. Patients with renal failure need to undergo weekly dialysis therapy. Families feel physical fatigue in performing direct treatments on patients, both at home and in hospitals. The costly treatment process can also be a factor in financial fatigue. People who do not have health insurance will feel this impact. Families of patients will also feel emotional and social fatigue in response.

Social Limitation

Patients with dialysis will experience minimal, intermediate, or even total difficulties. Families should spend much time to provide care. Families will be preoccupied with efforts to heal the patients. Communication with the surrounding environment and even peers will be reduced. Feelings of loneliness or isolation will arise and cause emotional problems.

Psychological Disorder

Physical fatigue and emotions that families experience during the treatment period of CKD patients will cause psychological responses to occur. Families can feel stress, depression, anxiety, and pressure on the conditions they face. Families need emotional Support from their surroundings. Psychological responses will increase in line with the lack of family acceptance of the condition of the treated patients.

Commented [Reviewer16]: Overly Descriptive Presentation of Findings:

Some findings are presented in a potentially overly descriptive manner without providing in-depth analysis or significant interpretation. The article should explore findings more deeply and offer broader context.

Commented [Reviewer17]: Potential Location Bias:

Most studies are from specific countries like the United States and Canada. The lack of representation from various geographical locations may limit the generalization of findings to diverse cultural and social contexts.

Commented [Reviewer18]: Lack of Bias Evaluation Details:

Although the article mentions that bias risk was evaluated, there is no detailed information on how bias risk was assessed. This leaves ambiguity about the extent to which bias risk was evaluated and how it influenced the study's outcomes.

Commented [Reviewer19]: Presentation of Unstructured Data:

The results and discussion section presents data by providing separate explanations for each finding without a clear structure. A more structured presentation, such as a table or graph, could assist readers in understanding these findings more easily.

Table 3. Constructs of Family Caregiver Responses

Construct	References									
	1	2	3	4	5	6	7	8	9	10
Information seeking										
Accessing information, receiving information, and learning (informational Support)							•			
Caregiver medicalization (subthemes: diagnosis and initiation, disease management, and the future)	•									
Treatment delivery and logistics (insufficient information, medication regimen, logistical inconveniences)									•	
Decisional disempowerment (lack of medical transparency and disappointment with clinical disinterest).		•								
Challenges navigating the health system				•						
Only abstract understanding of the realities of dialysis						•				
No consideration of conservative management as a viable personal option for their care (or that of their family members)						•				
Coping										
Affirmation/external reassurance and self-confidence (appraisal support).							•			
Articulating core values (avoiding futile and undignified treatment, reevaluating terms of dialysis, framing a life worth living, and refusing to be a burden).		•								
Confronting conversations (signifying death and defeat, accepting inevitable death, and alleviating existential tension)		•								
disconnectedness with self and others			•							
"A fool being tossed around."			•							
The constant struggle to learn										•
Effort and adherence to the divine thread in disease's captivity										•
pragmatic adaptation (disruption, adaptation of life goals and sense of self, and financial impact)	•									
Decision making										
Role of Patient in Decision-Making						•				
Challenging patient autonomy (family pressures to continue dialysis, grief diminishing caregivers' capacity, and leveraging Support)		•								
Role of Family in decision making						•				
Role of Doctor in decision making						•				
Decision-making factors						•				
Negotiating mutual understanding (broaching taboos and assisting conflicted caregivers),		•								
Consider dialysis the only treatment option for kidney failure, and any alternative is death.						•				

Construct	References									
	1	2	3	4	5	6	7	8	9	10
Burden										
Caregiver burdens: physical, emotional, social, and economic dimensions				•						
The heavy burden of care									•	
Emotional exhaustion									•	
Never-ending burden			•							
Social limitation										
Social adjustment (relationship opportunity, relationship risk, advocacy, family functioning, and intimate relationships)	•									
Obligation to care			•							
Promoting a closer relationship			•							
Becoming a care partner (unanticipated responsibilities and sleep disruptions),									•	
Psychological disorder										
Perceptions of palliative care				•						
Adverse psychological treatment responses in patients (such as depression) and family members (such as anxiety),									•	
Tension in care									•	
Symptom management				•						
Patient morbidity (dialysis-related health problems and fatigue).									•	
Addressing emotional needs and managing emotion (emotional Support)								•		
Emotional adjustment (initial and acute phase, acceptance, personal growth, and medical stress and psychological burden),	•									

The first theme of family caregiver responses was information seeking. This covered accessing information, receiving information, and learning (informational Support); caregiver medicalization (with subthemes of diagnosis and initiation, disease management, and the future); treatment delivery and logistics (insufficient information, medication regimen, logistical inconveniences); decisional disempowerment (lack of medical transparency and disappointment with clinical disinterest); challenges in navigating the health system; only abstract understanding of the realities of dialysis; and no consideration of conservative management as a viable personal option for their care (or that of their family members) ³²

³³ ³⁴ Caregivers have a significant and valuable role in caring for patients receiving kidney dialysis. Kidney health professionals must be aware of the complexity and burden

associated with this role. Assessment of needs by caregivers should be a part of routine clinical care, especially when the decision to start dialysis is made. Based on needs and concerns about care duties, kidney health professionals must perform targeted training and support sessions that provide information, guidance, and preparation for dialysis and non-dialysis tasks required at home ³⁵.

The second theme of family caregiver responses was coping. This covered affirmation/external reassurance and self-confidence (appraisal support); articulating core values (avoiding futile and undignified treatment, reevaluating terms of dialysis, framing a life worth living, and refusing to be a burden); confronting conversations (signifying death and defeat, accepting inevitable death, and alleviating existential tension); disconnectedness with self and others; “a fool being tossed around”; constant

struggle to learn; effort and adherence to the divine thread in disease captivity; and pragmatic adaptation (disruption, adaptation of life goals and sense of self, and financial impact)^{36 37 38}. Coping has been investigated on chronic diseases other than cancer, which suggests that several coping strategies can help patients overcome adverse events and reduce their suffering¹. For patients with chronic disease, a link has been found between the usage of adaptive coping strategies and increased quality of life (QoL), reduced use of escape avoidance, and increased psychological suffering. Denial is considered a coping strategy that is associated with both mental health and being concomitant to a worse quality of life with worse physical and social functioning. Therefore, there is a positive correlation between coping resources and mental health and QoL, which indicates that an individual is capable of managing and sustaining challenges in life through a sense of personal control to enjoy better mental health².

The third theme of family caregiver responses was decision-making. This consisted of the role of patients in decision-making, challenging patient autonomy (family pressures to continue dialysis, grief diminishing caregiver capacity, and leveraging Support), the role of families in decision-making; the role of doctors in decision-making; decision-making factors, negotiating mutual understanding (broaching taboos and assisting conflicted caregivers); and consideration of dialysis as the only treatment option for kidney failure and any other alternatives as death^{3 4}.

The care of CKD patients requires advanced care planning (ACP) that empowers patients to consider and communicate their future care preferences in the context of their goals and values. As part of ACP, strategies are needed to help caregivers prepare for their roles as surrogate decision-makers, with a support system available for caregivers who are unable to make end-of-life decisions because of their own grief⁵. One of the main objectives of ACP is to provide a replacement decision-maker in an advocacy role on behalf of the patient. This research consistently demonstrated that without ACP conversations, families were significantly less likely to understand the treatment preferences of patients or to make an accurate assessment

of the quality of life of patients^{6 7}

The caregiver believes that families must be present when decisions regarding care and medication are made. This approach is consistent with the palliative care model, where the patient and family are the unit of care. The decision-making process about follow-up care planning is better received informally over time and is gradually understood as awareness, not discussed at one time⁸. Managing emotions about prognosis as well as the fear of spreading, balancing the needs of caregivers themselves and of patients, considering the impact of care on employment, and making decisions in a context of uncertainty is the highest unmet needs of healthcare during the last 6 months of life of patients⁹.

The fourth theme was care burden; this term applies to caregivers or families and is a type of distress caregivers suffer due to caring for patients¹⁰. Factors that affect the burden of care include the ability level of patients for self-care, comorbid chronic diseases, education level, and ages of patients and family members. Thus, if the self-care abilities of patients are low, there may be incidences of chronic diseases with the patients, low levels of education, and increasing family age. The level of care burden on the family will increase²¹. This burden includes physical, psychological, social, and financial aspects. Increased care burdens and decreased quality of life can lead to complications such as depression. There is also a significant relationship between an increase in burdens of care and a decrease in the ability of families to care because the burdens of care can have devastating effects on individuals. The amount of stress that families experience from the experience of caring for patients with chronic diseases is a serious hidden illness²². Care burdens affect the quality of life of the families; the result may be that the provision of care is reduced and the conditions of patients with chronic illnesses worsen. The worsening of the conditions of patients can increase the burdens of care and lead to vicious cycles, and if timely intervention is not carried out, it may lead to gradual fatigue for the families²⁴.

Family caregivers for the palliative care of sufferers often experience the enormous physical, emotional, and financial responsibilities associated with providing

care. The caregiver burdens increase over time in a nonlinear manner from the initial diagnosis to the deaths of patients²⁵. Family burdens may also have effects on patients who receive care. Indeed, it has been reported that family burdens are associated with a lack of social support and lower health-related quality of life for patients and families²⁶. Disturbances in quality of life and family burdens in hemodialysis patients place a double burden on them and disrupt the treatment process²⁷. In effect, this can reduce the abilities of families to treat chronic kidney disease patients with hemodialysis. Care by family caregivers is required in all domains of quality of life (physical, psychological, social, and spiritual)²⁹.

The fifth theme of family caregiver responses was social limitation. This covered social adjustment (relationship opportunity, relationship risk, advocacy, family functioning, and intimate relationships), the obligation to care, promoting a closer relationship, and becoming a care partner (unanticipated responsibilities and sleep disruptions)^{28 30 31}. Patients and family caregivers may feel social isolation. Family caregivers describe family members with illnesses as being in self-imposed social isolation, choosing not to go out when invited by friends. Patients and family caregivers express their need for Support and other resources²³. Good holistic care helps caregivers nurture everyday life by reducing the burdens of care and helps to reduce feelings of isolation and reduced personal space³². Nurses may also facilitate the organization of psycho-educational support groups in partnership with family caregivers of CKD patients. These support groups can provide avenues for disease-specific training and Support for family caregivers³³.

The sixth and last theme was psychological disorder. Caregivers of patients on hemodialysis are at high risk for emotional development and psychological distress, poor quality of life, and increased burdens. They have various psychosocial concerns because of the lengths of treatments. They usually experience increased workloads, limited personal and social activities, and financial problems; they also feel tired, angry, depressed, helpless, guilty, isolated, deprived of freedom, afraid, and vulnerable, and neglect their health. Intervention and support

information are essential for caregivers, as these can help them improve their quality of life and their ability to cope effectively with the care of their patients. Caregivers need appropriate knowledge, special skills, education, and guidance to help patients better adhere to hemodialysis treatments³⁴.

Many patients with kidney disease have substantial unmet needs for palliative care that include physical and emotional symptoms³⁴. The palliative approach to dialysis care is undergoing a transition from a conventional orientation that focuses on dialysis as rehabilitation care, changing to an approach that prioritizes comfort as well as patient preferences and treatment goals to improve quality of life and to reduce the burden of symptoms for dialysis patients in their final years of life. The provision of palliative care can be applied to patients with severe disease at any age and stage and is not explicitly reserved for patients who have decided to discontinue therapy³⁵. To that end, early integration of palliative care into nephrological care standards can help improve informed decision-making, follow-up care planning, and end-of-life care for patients with advanced CKD and their families³⁶.

Currently, access to renal palliative care is still lacking³⁸. Renal (kidney) palliative care is a growing discipline in nephrology. Renal palliative care explicitly addresses the stress and burden of advanced kidney disease by providing symptom management, caregiver support, and follow-up care planning to optimize the quality of life of patients and their families. Integration of palliative care is needed to address the multidimensional impacts of advanced kidney disease on patients. Patients with advanced kidney disease have a higher level of care and a more excellent end-of-life experience compared to other serious chronic diseases¹.

CONCLUSION

There are six thematic areas regarding family experiences in caring for CKD patients: information seeking, coping mechanisms, decision-making, burden, social limitations, and psychological disorders. The implication for future research is to find solutions to prevent the emergence of various negative responses

Commented [Reviewer110]: Errors in Conclusion:

The conclusions of the article seem to be loosely related to the findings described. The article should provide stronger and more relevant conclusions based on the systematic review's findings.

due to the care of CKD patients with family involvement and palliative care approaches.

Limitations of the studies in this review

The studies that were involved in this systematic review have their respective drawbacks. Study weaknesses may include methods, number of samples, instruments of screening, and other aspects.

Acknowledgments: The authors of the study would like to thank the faculty of nursing and the doctoral of nursing study program for providing the opportunity to present this study

Conflicts of Interest: No conflicts of interest have been declared.

REFERENCE

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Commented [Reviewer111]: Lack of Practical Recommendations:

The article does not offer practical recommendations or implications for future research or clinical practice. This could limit the article's value for readers seeking practical guidance or advice.

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