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

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ABSTRACT

Because patients with chronic kidney disease (CKD) have restrictions, family members must assume responsibility for caring for their afflicted loved ones. The primary purpose of this study is to conduct a thorough examination of the challenges that families face when caring for a family member with chronic kidney disease (CKD). Six online databases were exhaustively searched in order to locate qualitative research publications published between 2015 and 2020 (Scopus, PubMed, CINAHL Plus, Science Direct, Sage, and ProQuest). The Joanna Briggs Institute and the Center for Review and Dissemination made recommendations, which were implemented in the study's quality assessment. Furthermore, the PRISMA criteria were strictly followed throughout the review procedure. A thorough study of the abstracts, titles, and entire texts was performed to determine the research eligibility. The study's findings were evaluated using narrative analysis and data tabulation. In ten studies that met the inclusion criteria were gathered for the review. The study looked at the interactions of families who care for individuals with chronic kidney disease (CKD) and was divided into broad subject categories. The setting encompasses a variety of aspects such as data collection methods, problem-solving strategies, decision-making procedures, caregiver responsibilities, societal restraints, and psychological barriers.

Keywords: Caregiver, Caring, Hemodialysis

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INTRODUCTION

Family members often cooperate to provide care or medical treatment for those afflicted with chronic kidney disease (CKD). Family members, in their role as caregivers, bear a crucial responsibility in activities such as administering medication and ensuring compliance, aiding in daily care duties, arranging and facilitating transportation for medical appointments, overseeing the health of the patient, advocating on behalf of the patients, and providing emotional support¹. This familial responsibility confers advantages to both patients and healthcare professionals. The participation of family members in patient care is linked to enhanced behavior, self-care,

and Compliance with medical therapy, along with improved quality of life, lowered risk of death, alleviated symptoms of anxiety and sadness, and reduced probability of hospitalization. Family members are essential in supporting healthcare practitioners in the treatment of patients with chronic renal illness².

The presence of family is essential in providing care to individuals with deteriorating health conditions. As patients' health declines and their need for care becomes more demanding, caregivers are tasked with performing increasingly complex care responsibilities. Hence, caregivers assume a vital role in delivering care to individuals with illnesses or impairments

throughout the progression of their conditions. Family-centered care has been proposed as a viable solution for this issue, since it aims to meet the requirements of both patients and their relatives³. The preparation of families for the care of hemodialysis patients entails several key components: the adoption of a family-centered approach, the provision of comprehensive education beginning in infancy, the utilisation of interventions that prioritise the preparedness of carers, and the facilitation of effective communication between healthcare practitioners and family members and fostering strong connections between families and patients⁴. Creating psycho-educational support groups can empower families by providing them with crucial information and emotional assistance necessary for successful therapy⁵.

Individuals responsible for the care of patients undergoing hemodialysis face a significant likelihood of experiencing emotional and psychological difficulties, reduced quality of life, and heightened load. Due to the extended duration of treatment, they experience a range of psychosocial issues⁶. Family members frequently bear a significant weight when it comes to taking

care of individuals undergoing hemodialysis. The problems and burdens escalate as the disease advances. Families have various challenges encompassing physical, emotional, and financial hardships⁷.

The patient getting care may also be impacted by familial responsibilities. Research has indicated that family responsibilities are linked to a dearth of social assistance and diminished quality of life in terms of health for both patients and their families⁸. The existence of disturbances in the quality of life and the stressors faced by families of hemodialysis patients impose a dual load on the patients and impair the treatment process⁹. This can diminish the capacity of families to provide hemodialysis treatment for patients suffering from chronic renal disease.

An analysis of family experiences in the management of hemodialysis patients is crucial for caregivers to avoid encountering overwhelming loads that may hinder patient care. The goal of this systematic study is to give a complete assessment of the obstacles that families confront in providing care for relatives with chronic kidney disease (CKD).

2.7. METHOD

Search Strategy

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) standards were followed for the systematic review.

A thorough literature review was undertaken using numerous databases, including PubMed and Scopus. The databases Sage, CINAHL Plus, and Science Direct, and ProQuest. The search parameters outlined in Figure 1 were utilised. The search was restricted to academic research conducted in the English language and published between the timeframe of 2015 to 2020. The procedure of A systematic search was undertaken using

specific keywords and phrases to identify research papers on the involvement of caregivers in the palliative care of hemodialysis patients, and MESH terms (caregiver, family, The terms "palliative care," "palliative therapy," "hemodialysis," and "analysis" can be used in combination with the Boolean operators "AND" and "OR."

Inclusion and Exclusion Criteria

This review encompassed all English language research published between January 2015 and December 2020. This review encompassed primary research and excluded articles that were solely reviews.

Table 1 outlines the criteria used to determine whether information was included and excluded in 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

The studies were assessed for quality using the validated quality rating criteria provided by the Centre for Evidence-Based Medicine (CEBM). Each complete manuscript was evaluated by one reviewer and verified for precision by another. The research underwent two assessments, and any inconsistencies were resolved by discussion. All studies were included regardless of their quality.

Data Collection and Extraction

The data from the eligible studies were obtained by using structured sheets that included details on the author/year, kind, population, quality, measurable outcomes, and main findings of the investigations. The initial author conducted data extraction, while the subsequent author verified the extracted data.

Evaluation of Study Quality and Assessment of Bias

The JBI Critical Appraisal for Qualitative Research was utilized to assess the quality of research and the potential for bias in each of the 10 investigations, specifically focusing on the quality of procedure. The checklist for appropriate investigations encompasses multiple evaluation criteria. The criteria were evaluated by providing assessments of 'yes,' 'no,' 'unclear,' or 'not applicable.' To maintain the integrity of the findings and recommendations of the study,

papers of inferior quality were eliminated. Out of the total number of studies screened, 12 obtained scores exceeding 50%, allowing for data synthesis to be conducted on these research. Regrettably, two studies were removed because they posed a possibility of biased judgment.

Data Synthesis

The findings are presented in a logical and descriptive manner, with a table for added clarification. Figure 1 displays the PRISMA approach article selection process. As candidate studies for selection, 1,577 papers were collected from databases. Using Mendeley Reference Manager, a total of 475 duplicate articles were identified and subsequently eliminated, resulting in a final count of 1,102 articles. Subsequently, papers were chosen by evaluating their titles, resulting in the retention of 236 articles, while 866 articles were excluded due to their names being irrelevant to the study. Subsequently, a total of 236 publications underwent screening based on their abstracts. Out of these, 64 papers were deemed relevant and retained, while 172 articles were excluded due to their abstracts being unrelated to the study. Ultimately, all 64 papers were thoroughly examined, leading to the retention of 27 articles and the exclusion of 37 articles due to various causes. Out of these, 10 studies met the criteria for inclusion in this review. An assessment was conducted on the quality, data extraction, and synthesis of these 10 investigations.

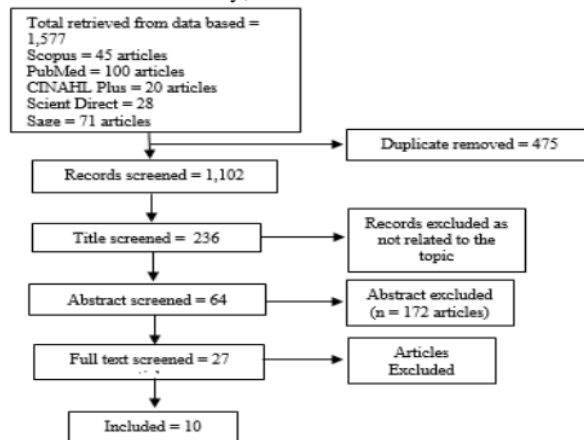


Figure 1. Article selection process

Table 2. Data Charting

No	Title, author	Population/setting	Country	Outcome	Interview/in-depth/FGD
1	Caregiver Experience in Pediatric Dialysis 11	35 caregivers of children	US	<ol style="list-style-type: none"> 1. The process of medicalizing caregiving, which includes aspects such as diagnosing and initiating treatment, managing the sickness, and considering future possibilities. 2. Emotional adjustment (including the initial and intense stage, acceptance, personal growth, and medical strain) 3. Pragmatic adaptation involves making practical modifications in different areas of life, such as dealing with disruptions, changing life goals and self-perception, and managing the financial implications that result from these adaptations. 4. Social adjustment encompasses various aspects such as the potential for forming relationships, the possibility of encountering risks in relationships, the act of advocating for oneself, the functioning of one's family, and the quality of personal relationships. 	Semi-structured interviews
2	An inquiry was conducted employing interview approaches to explore the viewpoints of individuals suffering from end-stage renal disease (ESRD) and their carers regarding	There are 24 patients and 15 carers.	Australia	<ol style="list-style-type: none"> 1. The act of expressing fundamental principles (such as avoiding pointless and demeaning care, reassessing the conditions of dialysis, defining a meaningful existence, and declining to become a source of inconvenience). 2. Engaging in discussions that 	Semi-structured interviews.

	advance care planning ¹²			<p>address topics such as mortality, surrendering to the unavoidable reality of death, and relieving existential anxiety.</p> <ol style="list-style-type: none"> 3. Facilitating comprehension (addressing sensitive topics and aiding caregivers in dispute) 4. Factors that pose difficulties to patient autonomy include familial influence to prolong dialysis treatment, reduced caregiving ability due to grieving, and utilizing support systems. 5. Experiencing decisional disempowerment due to a lack of medical transparency and feeling disappointed by the clinical disinterest. 	
3	Family caregivers in South-West Nigeria who offer assistance to individuals suffering from end-stage renal disease recount their personal encounters ¹³	15 family caregivers	Nigeria	<ol style="list-style-type: none"> 1. Alienation from oneself and others 2. Perpetual onus 3. "a person exhibiting foolish behavior and being subjected to constant manipulation or instability." 4. duty to provide care 5. fostering a more intimate connection 	Semi-structured interviews
4	An investigation into the perceptions of family carers regarding the palliative care requirements of individuals undergoing dialysis for end-stage renal disease ¹⁴	18 family caregivers	Canada	<ol style="list-style-type: none"> 1. Difficulties encountered in navigating the healthcare system. 2. Responsibilities and challenges faced by caregivers 3. Perspectives on palliative care 4. Management of symptoms 5. The process of making decisions. Challenges faced by caregivers encompass various aspects, including physical, emotional, social, and economic factors. 	In-depth

5	An investigation was done in an American public healthcare facility to measure the level of knowledge about treatment choices for renal failure among elderly patients and their family members. The study's goal was to measure people's understanding of dialysis and the implications of not receiving treatment ¹⁵	A collective of 21 people were present, consisting of 15 patients and 6 members of their families.	US	<ol style="list-style-type: none"> 1. They doubt the feasibility of adopting a conservative approach to safeguarding their own or their family members' welfare. 2. Develop a thorough conceptual understanding of the fundamental principles of dialysis. 3. Dialysis is the sole feasible remedy for renal failure, as any other option would lead to mortality. 	Semi-structured interviews.
6	A research investigation was carried out in Singapore to examine the viewpoints on decision-making among elderly individuals suffering from end-stage renal disease and their carers ¹⁶	23 pasien 7 caregivers.	Singapore	<ol style="list-style-type: none"> 1. The patient taking part in the decision-making process. The significance of the family in the decision-making process. The decision-making process heavily weighs the doctor's opinion. 2. Elements that impact the process of making decisions 	in-depth interviews
7	To determine the significance of social support in the setting of peritoneal dialysis, a study was started. A qualitative descriptive strategy was employed to gather data for the investigation. Method or methodical process ¹⁷	The study had a cohort of 15 patients and 6 family members. There were 11 nurses included in the study.	Western Canada.	<ol style="list-style-type: none"> 1. Emotional support refers to social assistance that specifically addresses emotional needs and facilitates the successful management of emotions. 2. Peritoneal dialysis tasks and tasks associated with everyday life (instrumental support) 3. Gaining information, receiving information, and acquiring knowledge (informational support) 4. Confirmation/external Self-assurance and self-belief aid in the assessment of one's capabilities. 	Semi-structured interview

8	Iranian family caregivers' viewpoints and first-hand encounters in the specialized treatment of hemodialysis patients ¹⁸	25 hemodialysis family caregivers	Iran	<ol style="list-style-type: none"> 1. Overwhelming responsibility of caregiving 2. Carer stress 3. Feeling emotionally drained or depleted. 	in-depth interviews
9	Experiences of Family Members Regarding Dialysis and Kidney Transplantation ¹⁹	49 family members	AS	<ol style="list-style-type: none"> 1. Assuming the role of a care partner involves unforeseen obligations and disturbances to sleep patterns. 2. Unfavorable psychological reactions in patients (such as depression) and family members (such as anxiety) in response to treatment. 3. Insufficient information and logistical inconveniences regarding the delivery and logistics of therapy, including medication regimen. 4. patient morbidity refers to the occurrence of health problems and exhaustion specifically associated to dialysis treatment. 	Focus groups
10	An investigation into the viewpoints and firsthand encounters of caregivers responsible for persons undergoing hemodialysis in Iran: Examining the provision of care within a context characterized by uncertainty ²⁰	20 hemodialysis family caregivers	Iran	<ol style="list-style-type: none"> 1. The perpetual endeavor to acquire knowledge. 2. Dedication and commitment to the spiritual connection while being held captive by illness. 	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 Canada²⁶, 2 research from Iran²⁸, and 1 study each from Singapore²⁹, Nigeria³⁰, and Australia³¹. The studies employed various methods of data collecting, including semi-structured interviews (5 studies), unstructured interviews (1 research), in-depth interviews (3 studies), and focus group talks (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 Mortality and the depletion of one's vitality while tending to the needs of the family. Financial exhaustion might contribute to families' inability to manage.

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.

Table 3. Constructs of Family Caregiver Responses

Construct	References									
	1	2	3	4	5	6	7	8	9	10
Information seeking										
Obtaining data, acquiring knowledge, and gaining insights (informational support)							•			

Construct	References									
	1	2	3	4	5	6	7	8	9	10
Medicalization of caregiving (with subthemes: diagnosis and beginning, disease management, and future prospects)	•									
Issues related to treatment administration and organization, include lack of information, drug schedule, and practical challenges.									•	
Lack of medical clarity and unhappiness with clinician disinterest might lead to decisional disempowerment.		•								
Difficulties encountered when navigating the healthcare system				•						
Limited comprehension of the practical aspects of dialysis						•				
There is a lack of acknowledgment about the possibilities for conservative management as a realistic choice for one's self or their family members' health.						•				
Coping										
Validation from others and belief in oneself (endorsement and self-assurance).								•		
Expressing fundamental principles (such as avoiding ineffective and disrespectful care, reassessing the conditions of dialysis, defining a meaningful existence, and rejecting the notion of becoming a burden).		•								
Engaging in discussions that involve topics such as mortality, surrendering to the certainty of death, and easing existential anxiety.		•								
Alienation from oneself and others				•						
"A person displaying foolish behavior and being subjected to being thrown or moved around."				•						
The perpetual endeavor to acquire knowledge										•
Dedication and commitment to the spiritual connection with the experience of illness										•
Pragmatic adaptation refers to the process of making practical adjustments in response to disruptions, such as changes in life goals, sense of self, and financial consequences.	•									
Decision making										
The patient's participation in the process of making decisions.						•				
Factors that provide a challenge to patient autonomy include familial pressures to continue dialysis, the decreased capacity of caretakers due to grieving, and the use of support as a means of influence.		•								
The significance of familial involvement in the process of determining decisions						•				
It is essential to include the doctor in the decision-making process.						•				
Factors influencing the process of making decisions						•				
By promoting mutual understanding (by tackling tough subjects and assisting carers in resolving conflicts),		•								

Construct	References									
	1	2	3	4	5	6	7	8	9	10
Exclusively consider dialysis as the sole therapeutic option for renal failure, as any other choice would result in mortality.					•					
Burden										
Caregiver burdens: physical, emotional, social, and economic dimensions				•						
The heavy burden of care								•		
Emotional exhaustion								•		
Never-ending burden			•							
Social limitation										
Social adjustment encompasses various aspects such as the potential for forming relationships, the potential risks involved in relationships, the act of advocating for oneself, the functioning of one's family, and the quality of personal relationships.	•									
Duty to provide care			•							
Fostering a more intimate connection			•							
Assuming the role of a care partner involves unforeseen duties and disturbances to one's sleep.									•	
Psychological disorder										
Views on palliative care				•						
Psychological treatment can lead to negative reactions in patients, such as sadness, and in family members, such as worry.									•	
Caregiver stress								•		
Management of symptoms				•						
Incidence of patient morbidity, including dialysis-related health complications and weariness.									•	
Providing assistance for emotional needs and effectively handling emotions (emotional support)							•			
Emotional adaptation (early and intense stage, acceptance, personal development, and the stress of medical treatment and psychological strain).	•									

The primary trend identified in the responses from family caregivers was their proactive quest for information. The study encompasses the examination of obtaining information, receiving information, and learning, which is sometimes referred to as informational assistance the medicalization of caregivers (including themes of diagnosis and initiation, disease management, and future prospects); the delivery and logistics of treatment (including insufficient information, medication regimen, and logistical inconveniences); feeling disempowered in decision-making (due to a lack of medical transparency and disappointment with clinical

disinterest); challenges in navigating the health system; limited understanding of the realities of dialysis; and a lack of Considering Conservative management is a feasible choice for taking care of oneself or one's family^{32 33 34}. Caregivers play a vital and irreplaceable role in delivering care for patients undergoing kidney dialysis. Healthcare professionals specialized in nephrology must possess a thorough comprehension of the complex nature and substantial obligations associated with this role. Integrating caregivers' evaluation of needs into routine clinical care is essential, especially when deciding when to start dialysis. Specialized training and support sessions should be offered by kidney health professionals to address specific care

responsibilities, imparting information, aid, and readiness for both dialysis and non-dialysis tasks that must be carried out at home³⁵.

The second issue examined in regards to the reactions of family caregivers was coping. This includes the elements of seeking validation and confidence from external sources, as well as developing a strong belief in oneself (appraisal support). It also entailed articulating core concepts (such as the avoidance of fruitless and undignified therapy, reassessing the conditions of dialysis, defining a meaningful existence, and declining to be a source of hardship). Furthermore, it involved participating in challenging discussions that recognize the reality of mortality and failure, embracing the unavoidable nature of death, and alleviating existential anxiety. Additionally, it entailed experiencing a sense of detachment from oneself and others, comparable to being tossed around in a foolish manner. Moreover, it entailed a perpetual endeavor to get knowledge and expertise, alongside following a spiritual or celestial journey while confronting the obstacles of disease. Ultimately, it required a practical response to disturbances, the modification of life objectives and one's perception of self, and the handling of the financial repercussions of the situation^{36 37 38}.

Research has explored coping mechanisms in chronic illnesses other than cancer, indicating that various tactics can assist patients in overcoming negative occurrences and alleviating their distress¹. A correlation has been discovered between the utilization of adaptive coping mechanisms and improved quality of life (QoL), decreased reliance on escape avoidance, and heightened psychological distress among individuals with chronic illnesses. Denial is a coping mechanism that is linked to both mental health and a lower quality of life, accompanied by poorer physical and social functioning. Hence, there exists a direct relationship between coping resources and mental health and quality of life (QoL), suggesting that an individual's ability to handle and endure life's difficulties through a feeling of personal agency leads to improved mental well-being.²

The study also examined the decision-making process as a third part of family

caregiver reactions. This entailed patients engaging in the decision-making process, taking into account patient autonomy (including the impact of familial pressures to continue dialysis, the decrease in carer capacity due to grief, and the utilisation of support systems), Facilitating family involvement in decision-making, comprehending the physician's role in decision-making, analysing the factors influencing decision-making, fostering mutual understanding (including addressing sensitive subjects and aiding conflicted carers), and assessing dialysis as the sole treatment for kidney failure and any alternative choices that may lead to mortality^{3 4}.

To optimise care for individuals afflicted with chronic kidney disease (CKD), the implementation of advanced care planning (ACP) is of paramount importance. This empowers individuals to reflect carefully and express their future care preferences in alignment with their goals and values. Advance Care Planning (ACP) necessitates the development of strategies that effectively support carers in adequately preparing for their role as surrogate decision-makers. Furthermore, it is imperative to build a support structure for caregivers who are incapable of making end-of-life decisions as a result of their own profound sorrow. The numeral 5. The primary objective of ACP is to designate a surrogate decision-maker who will actively support and represent the interests of the patient.

This study consistently demonstrated that without engaging in Advance Care Planning (ACP) discussions, families had a significantly reduced probability of understanding patients' treatment preferences or appropriately assessing patients' quality of life^{6 7}.

The carer stresses the critical importance of family involvement in the care and medication decision-making process. This approach aligns with the palliative care model, which prioritises the patient and their family in the provision of care. The process of deciding on follow-up care planning is more effectively communicated through informal means over a period of time, gradually increasing awareness rather than being discussed all at once⁸. The most significant unmet needs in healthcare during the final six months of a patient's life include effectively managing emotions related to prognosis and the fear of spreading, finding

a balance between the needs of caregivers and patients, taking into account the impact of care on employment, and making decisions in a context of uncertainty⁹.

The fourth subject explored in the study was the concept of care burden, which refers to the anguish experienced by caregivers or families as a result of providing care for patients¹⁰. The burden of care is influenced by various factors, such as the patients' self-care capabilities, the presence of concomitant chronic diseases, the educational background of individuals involved, as well as the ages of both patients and family members. Consequently, patients with limited self-care abilities may have a higher prevalence of chronic diseases, lower educational attainment, and an aging family population. The family's caregiving responsibilities will intensify²¹. This load encompasses physical, psychological, social, and financial dimensions. The heightened responsibilities of providing care and the diminished quality of life might give rise to difficulties, such as the emergence of depression. There is a strong correlation between an increase in caregiving responsibilities and a decline in families' capacity to provide care, as the duties associated with caregiving can have profound and detrimental impacts on individuals. The magnitude of stress that families experience when providing care for patients with chronic diseases is a substantial and frequently disregarded affliction²². The presence of care burdens has a detrimental impact on the well-being of families, perhaps leading to a decrease in the level of care provided and a deterioration in the health conditions of individuals with chronic illnesses. The deterioration of patients' illnesses can exacerbate the caregiving obligations and give rise to self-perpetuating cycles. Without appropriate intervention, it may result in progressive exhaustion for the families²⁴.

Family caregivers of palliative care patients frequently bear significant physical, emotional, and financial burdens in their role as caregivers. The responsibilities of the caregiver progressively escalate in a non-linear fashion from the moment of the initial diagnosis until the eventual demise of the patients²⁵. Patients who get treatment may also be impacted by the responsibilities and obligations of their family. Research has indicated that family responsibilities are

linked to a dearth of social assistance and diminished quality of life in terms of health for both patients and their families²⁶. The occurrence of disturbances in the quality of life and the obligations placed on families encountered by hemodialysis patients creates a dual burden on them and obstructs the treatment process²⁷. In essence, this can reduce the ability of families to administer hemodialysis treatment for those suffering from chronic renal illness. Family caregivers bear the responsibility of providing comprehensive care that encompasses several dimensions of well-being, such as physical, psychological, social, and spiritual components²⁹.

The sixth aspect of family caregiver reactions revolved around societal constraints. This encompassed aspects of social adaptation (including opportunities and risks in relationships, advocacy, family functioning, and personal connections), the duty to provide care, fostering a stronger bond, and assuming the role of a caregiver (unexpected obligations and disturbances in sleep patterns)^{28 30 31}. Patients and their family caregivers may feel socially isolated. Family caregivers perceive family members with illnesses as actively choosing to isolate themselves socially, deliberately declining offers from peers to socialize. Patients and family caregivers articulate their requirement for assistance and additional resources²³. Effective holistic care enables caregivers to support daily living by alleviating the responsibilities of caregiving and mitigating emotions of loneliness and limited personal autonomy³². Nurses can also engage in collaboration with family carers of individuals suffering from chronic kidney disease (CKD) to organise psycho-educational support groups. These support groups offer specialized information and assistance to family caregivers of individuals with certain diseases³³.

The final issue explored was psychological disorder. Caregivers of patients undergoing hemodialysis face a heightened susceptibility to emotional and psychological challenges, diminished quality of life, and amplified responsibilities. Due to the extended duration of therapies, they experience a range of psychosocial issues. Typically, they encounter heightened work demands, restricted personal and social engagements, and financial difficulties.

Additionally, they endure fatigue, Feelings experienced by individuals may include rage, melancholy, helplessness, guilt, loneliness, lack of independence, fear, vulnerability, and disrespect for their health. Access to intervention and support information is crucial for caregivers, as it can enhance their quality of life and their capacity to successfully manage the care of their patients. Effective caregiving for hemodialysis patients necessitates caregivers possessing adequate knowledge, specialized skills, education, and supervision in order to facilitate improved adherence to treatment protocols³⁴.

A significant number of individuals suffering from renal disease experience considerable unaddressed requirements for palliative care, encompassing both physical and mental symptoms³⁴. The palliative approach to dialysis care is shifting from a traditional focus on dialysis as a form of rehabilitation care to an approach that emphasizes both patient comfort and their individual preferences and treatment goals. This change aims to enhance the Enhance the overall well-being and mitigate symptoms for end-stage dialysis patients. Palliative care can be administered to patients of all ages and stages who are suffering from serious illnesses, and it is not just restricted to persons who have opted to discontinue treatment³⁵. In order to achieve this objective, the incorporation of palliative care into the protocols of nephrological treatment at an early stage could enhance the capacity to make informed decisions, plan To ensure proper care after therapy and offer support to individuals suffering from advanced chronic kidney disease (CKD) and their families in the terminal phase of their lives³⁶.

Presently, there is a deficiency in the availability of renal palliative care ³⁸. Palliative care for renal (kidney) patients is an expanding field within the realm in the field of nephrology. Renal palliative care is a specialized approach that aims to alleviate the physical and emotional difficulties associated with severe kidney disease. It aims to enhance the well-being of patients and their families by managing symptoms, offering support to caregivers, and developing plans for ongoing care. Integrating palliative care is essential for addressing the complex impacts of advanced renal illness on patients. Individuals suffering from advanced renal disease receive

superior medical treatment and experience a more positive end-of-life journey in comparison to those with other severe chronic illnesses¹.

CONCLUSION

The study identifies six thematic areas related to family experiences in caring for CKD patients: information acquisition, coping strategies, decision-making, burden, social constraints, and psychological illnesses. The future study should focus on developing strategies to mitigate the occurrence of adverse reactions resulting from the engagement of family in the treatment of CKD patients and the use of palliative care approaches.

Limitations of the studies in this review

The papers included in this systematic review each have their own limitations. Weaknesses in the study may encompass factors such as research methodologies, sample size, screening instruments, and other related issues.

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