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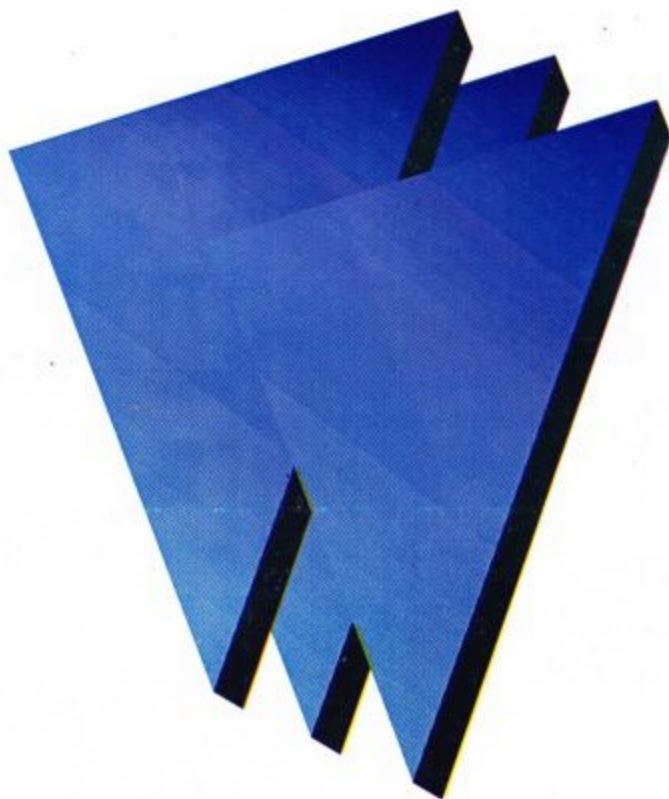
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# JURNAL ILMU KESEHATAN

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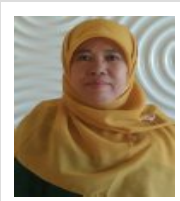
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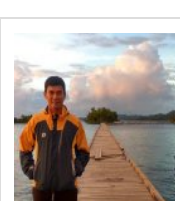
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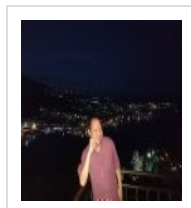
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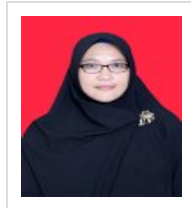
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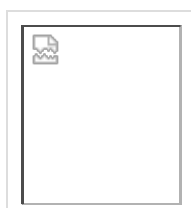
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Article Review

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

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**ABSTRACT**

*The limitations of CKD patients require families to care for family members who suffer from CKD. This research analyzes family experiences in caring for family members with CKD. This research method uses a descriptive design with a scoping review approach. Article searches used four journal databases: PubMed, ScienceDirect, EBSCO, and Google Scholar. Articles that met the inclusion criteria, including a publication range from 2015 to 2022 in English and Indonesian and free access to the full-text PDF, were evaluated before selection. The research results based on a review of 10 articles show that family members have different responses in caring for CKD sufferers. Acceptance of known kidney disease indicates coping with solid efforts. The family will also continue to fight to get the best treatment for the patient's recovery. Apart from that, the family and the patient can make decisions regarding the continuation of the patient's therapy program. Families need emotional support from the surrounding environment. Psychological responses will increase along with the lack of family acceptance of the condition of the patient being treated.*

**Keywords:** Caregiver, Caring, Hemodialysis

<https://doi.org/10.33860/jik.v17i4.3347>



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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 support <sup>1</sup>. 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 illness <sup>2</sup>.

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 relatives<sup>3</sup>. 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 utilization of interventions that prioritize the preparedness of carers, and the facilitation of effective communication between healthcare practitioners and family members and fostering strong connections between families and patients<sup>4</sup>. Creating psycho-educational support groups can empower families by providing them with crucial information and emotional assistance necessary for successful therapy<sup>5</sup>.

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 issues<sup>6</sup>. 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 hardships<sup>7</sup>.

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 families<sup>8</sup>. 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 process<sup>9</sup>. 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).

## METHOD

The author intends to use Scoping Review research as a research design. A scoping review is used as an introduction to a systematic review, aiming to identify the types of evidence available on the topic discussed, providing an overview of how research is conducted on a particular subject or field, and identifying essential characteristics or factors associated with a study. Study. Concepts, and explains systematic reviews. Two from the same educational institution, one lecturer and one student, wrote this scoping review<sup>12</sup>.

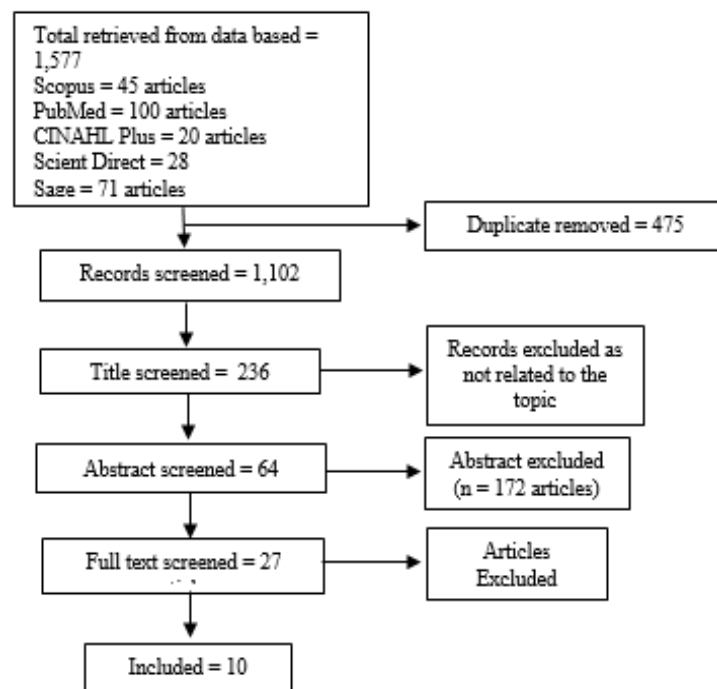
The preparation of this scoping review used guidance from the expanded Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) in the scoping review checklist. A customized review includes (1) Identification of documents through systematic search, (2) Filtering articles based on title and abstract, (3) Assessment of the suitability of the

article in full text, (4) Critical Appraisal, (5) inclusion of related articles.

Publications exploring the impact of acupressure on increasing breast milk production were one of the inclusion criteria for this study. Other criteria are publications published between 2015 and 2022, articles written in Indonesian and English, complete and easily accessible reports, and essays published in two languages. Meanwhile, the exclusion criteria are gray literature in newspapers, news, etc. There are ten articles among the 64 original articles. After this first screening, 236 of 1,577 articles were removed due to inappropriate titles or abstracts. Ten of the original fourteen publications were found to be applicable and consistent with this study after a second round of screening using established inclusion criteria.

**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



**Figure 1. PRISMA Flowchart**

**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"> <li>The process of medicalizing caregiving, which includes aspects such as diagnosing and initiating treatment, managing the sickness, and considering future possibilities.</li> <li>Emotional adjustment (including the initial and intense stage, acceptance, personal</li> </ol>	Semi-structured interviews



				<p>growth, and medical strain)</p> <p>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.</p> <p>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.</p>	
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 advance care planning <sup>12</sup>	There are 24 patients and 15 carers.	Australia	<p>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).</p> <p>2. Engaging in discussions that address topics such as mortality, surrendering to the unavoidable reality of death, and relieving existential anxiety.</p> <p>3. Facilitating comprehension (addressing sensitive topics and aiding caregivers in dispute)</p> <p>4. Factors that pose difficulties to patient autonomy include familial influence to prolong dialysis treatment, reduced caregiving ability due</p>	Semi-structured interviews.

				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 <sup>13</sup>	15 family caregivers	Nigeria	<ol style="list-style-type: none"> <li>1. Alienation from oneself and others</li> <li>2. Perpetual onus</li> <li>3. "a person exhibiting foolish behavior and being subjected to constant manipulation or instability."</li> <li>4. duty to provide care</li> <li>5. fostering a more intimate connection</li> </ol>	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 <sup>14</sup>	18 family caregivers	Canada	<ol style="list-style-type: none"> <li>1. Difficulties encountered in navigating the healthcare system.</li> <li>2. Responsibilities and challenges faced by caregivers</li> <li>3. Perspectives on palliative care</li> <li>4. Management of symptoms</li> <li>5. The process of making decisions. Challenges faced by caregivers encompass various aspects, including physical, emotional, social, and economic factors.</li> </ol>	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	A collective of 21 people were present, consisting of 15 patients and 6 members of their families.	US	<ol style="list-style-type: none"> <li>1. They doubt the feasibility of adopting a conservative approach to safeguarding their own or their family members' welfare.</li> <li>2. Develop a thorough conceptual understanding of the fundamental principles of dialysis.</li> <li>3. Dialysis is the sole feasible remedy for renal failure, as any other option would lead to mortality.</li> </ol>	Semi-structured interviews.

	implications of not receiving treatment <sup>15</sup>				
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 <sup>16</sup>	23 pasien 7 caregivers.	Singapore	<ol style="list-style-type: none"> <li>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.</li> <li>2. Elements that impact the process of making decisions</li> </ol>	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 <sup>17</sup>	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"> <li>1. Emotional support refers to social assistance that specifically addresses emotional needs and facilitates the successful management of emotions.</li> <li>2. Peritoneal dialysis tasks and tasks associated with everyday life (instrumental support)</li> <li>3. Gaining information, receiving information, and acquiring knowledge (informational support)</li> <li>4. Confirmation/external Self-assurance and self-belief aid in the assessment of one's capabilities.</li> </ol>	Semi-structured interview
8	Iranian family caregivers' viewpoints and first-hand encounters in the specialized treatment of hemodialysis patients <sup>18</sup>	25 hemodialysis family caregivers	Iran	<ol style="list-style-type: none"> <li>1. Overwhelming responsibility of caregiving</li> <li>2. Carer stress</li> <li>3. Feeling emotionally drained or depleted.</li> </ol>	in-depth interviews
9	Experiences of Family Members Regarding Dialysis and Kidney Transplantation <sup>19</sup>	49 family members	AS	<ol style="list-style-type: none"> <li>1. Assuming the role of a care partner involves unforeseen obligations and disturbances to sleep patterns.</li> <li>2. Unfavorable psychological reactions in patients (such as depression) and family members</li> </ol>	Focus groups

				(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.	
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 <sup>20</sup>	20 hemodialysis family caregivers	Iran	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

### 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.

### 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) <sup>21</sup>, decision-making (2 studies) <sup>22</sup>, and Support of social needs (1 study) <sup>15</sup>. 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<sup>19,20</sup>. 2 studies from Canada <sup>23,24</sup>, 2 research from Iran <sup>25</sup>, and 1 study each from Singapore <sup>25</sup>, Nigeria <sup>20</sup>, and Australia <sup>20</sup>. 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).

**Table 3. Constructs of Family Caregiver Responses**

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

Construct	References									
	1	2	3	4	5	6	7	8	9	10
<b>Coping</b>										
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.	•									
<b>Decision making</b>										
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),		•								
Exclusively consider dialysis as the sole therapeutic option for renal failure, as any other choice would result in mortality.							•			
<b>Burden</b>										
Caregiver burdens: physical, emotional, social, and economic dimensions				•						
The heavy burden of care								•		
Emotional exhaustion								•		
Never-ending burden			•							
<b>Social limitation</b>										
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.	•									



Construct	References									
	1	2	3	4	5	6	7	8	9	10
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.									•	
<b>Psychological disorder</b>										
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 <sup>16,20</sup>. 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 home <sup>26</sup>.

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 foolishly. 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 <sup>19, 25, 27</sup>.

Research has explored coping mechanisms in chronic illnesses other from cancer, indicating that various tactics can

assist patients in overcoming negative occurrences and alleviating their distress<sup>1</sup>. 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.<sup>2</sup>

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 utilization of support systems), Facilitating family involvement in decision-making, comprehending the physician's role in decision-making, analyzing 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<sup>3,4</sup>.

To optimize 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<sup>5</sup>. 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<sup>6,7</sup>.

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 prioritizes 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 once<sup>8</sup>. 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 uncertainty<sup>9</sup>.

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 patients<sup>10</sup>. 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 intensify<sup>21</sup>. 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 affliction<sup>22</sup>. 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<sup>15</sup>. 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 families<sup>20</sup>.

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 patients<sup>19</sup>. 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 families<sup>23</sup>. 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 process<sup>24</sup>. 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 components<sup>25</sup>.

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)<sup>20,28</sup>. 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 requirements for assistance and additional resources<sup>15</sup>. Effective holistic care enables caregivers to support daily living by alleviating the responsibilities of caregiving and mitigating emotions of loneliness and

limited personal autonomy<sup>16</sup>. Nurses can also engage in collaboration with family carers of individuals suffering from chronic kidney disease (CKD) to organize psycho-educational support groups. These support groups offer specialized information and assistance to family caregivers of individuals with certain diseases<sup>20</sup>.

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 protocols<sup>13</sup>.

A significant number of individuals suffering from renal disease experience considerable unaddressed requirements for palliative care, encompassing both physical and mental symptoms<sup>13</sup>. 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 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 treatment<sup>26</sup>. 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 lives<sup>27</sup>.

Presently, there is a deficiency in the availability of renal palliative care<sup>25</sup>. 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 illnesses<sup>1</sup>.

#### **Limitations of the studies in this review**

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

#### **CONCLUSIONS**

Based on a review of 10 articles, the research results show that family members have different responses in caring for CKD sufferers. Acceptance of known kidney disease indicates a solid effort to address it. The family will also continue to fight to get the best treatment for the patient's recovery. The family will continue to feel tired in caring for the patient. People with kidney failure need to undergo weekly dialysis therapy. Families feel physically exhausted from providing direct treatment to patients at home and in the hospital. The family and patient can also decide to continue the patient's therapy program. The family will look for the correct information to determine the therapy to be given. Input from healthcare providers regarding dialysis services, procedural procedures, side effects, and other vital facts will be sought to help the patient recover. Families need emotional support from the

surrounding environment. Psychological responses will increase along with the lack of family acceptance of the condition of the patient being treated.

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#### **CONFLICTS OF INTEREST**

The authors declare no conflict of interest

#### **REFERENCES**

1. Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. Towards a universal model of family-centered care: A scoping review. *BMC Health Serv Res.* 2019;19(1). <https://doi.org/10.1186/s12913-019-4394-5>
2. Gerogianni G, Polikandrioti M, Babatsikou F, et al. Anxiety–depression of dialysis patients and their caregivers. *Medicina (Lithuania).* 2019;55(5). <https://doi.org/10.3390/medicina55050168>
3. Sherman DW. A review of the complex role of family caregivers as health team members and second-order patients. *Healthcare (Switzerland).* 2019;7(2). <https://doi.org/10.3390/healthcare7020063>
4. Ebadi A, Sajadi SA, Moradian ST, Akbari R. Suspended Life Pattern: A Qualitative Study on Personal Life Among Family Caregivers of Hemodialysis Patients in Iran. *Int Q Community Health Educ.* 2018;38(4):225-232. <https://doi.org/10.1177/0272684X18773763>
5. Baghcheghi N, Koohestani HR. Designing and psychometric properties of coping strategies scale for family caregivers of hemodialysis patients. *Acta Facultatis Medicae Naissensis.* 2021;38(3):257-269. <https://doi.org/10.5937/afmnai38-29501>
6. Abed MA, Khalifeh AH, Khalil AA, Darawad MW, Moser DK. Functional health literacy and caregiving burden

- among family caregivers of patients with end-stage renal disease. *Res Nurs Health*. 2020;43(5):529-537. <https://doi.org/10.1002/nur.22060>
7. Alnazly E. Predictors of the burden on family carers of patients on hemodialysis in Jordan. *Eastern Mediterranean Health Journal*. 2020;26(5):565-572. <https://doi.org/10.26719/emoji.19.097>
  8. Mahmoudian A, Chafjiri RT, Alipour A, Shamsalinia A, Ghaffari F. The design and evaluation of psychometric properties for a questionnaire on elderly abuse by family caregivers among older adults on hemodialysis. *Clin Interv Aging*. 2018;13:555-563. <https://doi.org/10.2147/CIA.S149338>
  9. Surendran P, Venugopal V, Dongre A, Paninjukunnath R. Perceived challenges faced by family caregivers of chronic kidney disease patients and suggested solutions: A qualitative study. *Int J Med Sci Public Health*. Published online 2018:1. <https://doi.org/10.5455/ijmsph.2018.0307819032018>
  10. Abebe A, Arba A, Paulos K, et al. The Lived Experience of Primary Family Caregivers of Patients on Hemodialysis Treatment in Southern Ethiopia: A Phenomenological Study. *Int J Nephrol Renovasc Dis*. 2022;15:41-52. <https://doi.org/10.2147/IJNRD.S353191>
  11. Wightman A, Zimmerman CT, Neul S, Lepere K, Cedars K, Opel D. Caregiver Experience in Pediatric Dialysis. *Pediatrics*. 2019;143(2). <https://doi.org/10.1542/peds.2018-2102>
  12. Sellars M, Clayton JM, Morton RL, et al. An Interview Study of Patient and Caregiver Perspectives on Advance Care Planning in ESRD. *American Journal of Kidney Diseases*. 2018;71(2):216-224. <https://doi.org/10.1053/j.ajkd.2017.07.021>
  13. Oyegbile YO, Brysiewicz P. Family caregiver's experiences of providing care to patients with End-Stage Renal Disease in South-West Nigeria. *Journal of Clinical Nursing*. 2017;26(17-18):2624-2632. doi:10.1111/jocn.13689
  14. Maddalena V, O'Shea F, Barrett B. An Exploration of Palliative Care Needs of People With End-stage Renal Disease on Dialysis: Family Caregiver's Perspectives. *Journal of palliative care*. 2018;33(1):19-25. <https://doi.org/10.1177/0825859717747340>
  15. Karlin J, Chesla CA, Grubbs V. Dialysis or Death: A Qualitative Study of Older Patients' and Their Families' Understanding of Kidney Failure Treatment Options in a US Public Hospital Setting. *Kidney medicine*. 2019;1(3):124-130. <https://doi.org/10.1016/j.xkme.2019.04.003>
  16. Han E, Haldane V, Koh JJK, et al. Perspectives on decision making amongst older people with end-stage renal disease and caregivers in Singapore: A qualitative study. *Health expectations : an international journal of public participation in health care and health policy*. 2019;22(5):1100-1110. <https://doi.org/10.1111/hex.12943>
  17. Fox DE, Quinn RR, James MT, Venturato L, King-Shier KM. Social Support in the Peritoneal Dialysis Experience: A Qualitative Descriptive Study. *Canadian Journal of Kidney Health and Disease*. 2020;7. <https://doi.org/10.1177/2054358120946572>
  18. Eslami A, Rabiei L, Shirani M, Masoudi R. Dedication in caring of hemodialysis patients: Perspectives and experiences of Iranian family caregivers. *Indian Journal of Palliative Care*. 2018;24(4):486-490. [https://doi.org/10.4103/IJPC.IJPC\\_204\\_17](https://doi.org/10.4103/IJPC.IJPC_204_17)
  19. DePasquale N, Cabacungan A, Ephraim PL, Lewis-Boyer L, Powe NR, Boulware LE. Family Members' Experiences With Dialysis and Kidney Transplantation. *Kidney Medicine*. 2019;1(4):171-179. <https://doi.org/10.1016/j.xkme.2019.06.001>
  20. Rabiei L, Eslami AA, Abedi HA, Masoudi R, Sharifirad GR. Caring in an atmosphere of uncertainty: perspectives

- and experiences of caregivers of peoples undergoing hemodialysis in Iran. *Scandinavian journal of caring sciences*. 2016;30(3):594-601. <https://doi.org/10.1111/scs.12283>
21. Bansal AD, O'Connor NR, Casarett DJ. Perceptions of hospitalized patients and their surrogate decision-makers on dialysis initiation: A pilot study. *BMC Nephrol*. 2018;19(1). <https://doi.org/10.1186/s12882-018-0987-1>
  22. Salehi-tali S, Ahmadi F, Zarea K, Fereidooni-Moghadam M. Commitment to care: the most important coping strategies among family caregivers of hemodialysis patients. *Scand J Caring Sci*. 2018;32(1):82-91. <https://doi.org/10.1111/scs.12432>
  23. Grubbs V, Moss AH, Cohen LM, et al. A palliative approach to dialysis care: A patient-centered transition to the end of life. *Clinical Journal of the American Society of Nephrology*. 2014;9(12):2203-2209. <https://doi.org/10.2215/CJN.00650114>
  24. Morris SM, King C, Turner M, Payne S. Family carers providing Support to a person dying in the home setting: A narrative literature review. *Palliat Med*. 2015;29(6):487-495. <https://doi.org/10.1177/0269216314565706>
  25. Hoang VL, Green T, Bonner A. Informal caregivers' experiences caring for people receiving dialysis: A mixed-methods systematic review. *J Ren Care*. 2018;44(2):82-95. <https://doi.org/10.1111/jorc.12235>
  26. Jafari H, Ebrahimi A, Aghaei A, Khatony A. The relationship between care burden and quality of life in caregivers of hemodialysis patients. *BMC Nephrol*. 2018;19(1). <https://doi.org/10.1186/s12882-018-1120-1>
  27. Eirini G, Georgia G. Caregivers of Patients on Haemodialysis. In: *Caregiving and Home Care*. InTech; 2018. <https://doi.org/10.5772/intechopen.72400>