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Family Issues In Caring For Patients With Chronic Kidney Failure

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ABSTRACT

Introduction: *According to the World Health Organization (WHO) and the Global Burden of Disease (GBD) project, kidney diseases significantly contribute to the global disease burden, resulting in approximately 850,000 deaths annually and 15,010,167 cases of disability, which lead to a decline in quality of life. Chronic kidney disease (CKD) patients undergoing hemodialysis face various issues that can cause biological, psychological, social, and spiritual imbalances.*
Objectives: *This study aims to explore the challenges families encounter when caring for patients with chronic kidney disease.*
Methods: *Utilizing a qualitative phenomenological research approach, the study involved in-depth interviews with a sample of five validated participants. The research identified four themes: (1) loyalty in caring for CKD patients; (2) feelings of sadness and concern regarding the patient's condition; (3) emotional burden of caregiving; and (4) acceptance of the patient's condition, with a central theme of accepting the CKD patient's status.*
Results: *The research findings revealed four themes based on data collected from participants 1 to 5: (1) commitment to caring for patients with Chronic Kidney Disease (CKD), (2) feelings of sadness and concern regarding the condition of CKD patients, (3) emotional burden associated with caring for CKD patients, and (4) acceptance of the CKD patients' condition.*
The data analysis process, based on the interview results from each participant, will be elaborated upon according to themes, sub-themes, and categories, along with excerpts from participants' statements.
Conclusions: *The findings from this study, which comprise four themes, indicate that families caring for patients with Chronic Kidney Disease (CKD) face various psychological challenges that, if not addressed with appropriate coping mechanisms, can adversely affect their mental health status.*

Introduction

Chronic Kidney Disease (CKD) presents a growing global health challenge, contributing significantly to the burden of disease worldwide. According to the World Health Organization (WHO) and the Global Burden of Disease (GBD) project, kidney diseases are responsible for approximately 850,000 deaths annually and over 15 million cases of disability, diminishing quality of life for affected individuals (World Health Organization, 2021). Chronic kidney disease, in particular, ranks 27th among the leading causes of death globally, with the incidence of kidney failure projected to increase, particularly in developing countries (Inayati, A et al., 2020). Data from Indonesia highlight this alarming trend, with Central Sulawesi reporting the highest prevalence at 0.5%, followed by other provinces like Aceh and Gorontalo, which report 0.4% (Purnamasari et al., 2022). At Bahteramas Regional Hospital, CKD cases have steadily risen from 403 in 2022 to 435 in 2023 and 102 cases in 2024, indicating a continued increase in the disease burden (Bahteramas General Hospital, 2024).

As a chronic condition requiring long-term management, CKD places a significant strain not only on patients but also on their families. Patients often require ongoing therapies such as hemodialysis, peritoneal dialysis, or kidney transplantation, which involve significant family involvement in caregiving. This responsibility can be overwhelming, leading to a range of challenges for caregivers, including psychological stress, financial strain, and interpersonal conflicts. Previous studies, such as those by (Hayulita, S et al., 2020), reveal that family members of CKD patients often face elevated levels of stress and emotional difficulties due to the physical, emotional, and financial demands of caregiving. Moreover, family conflicts can arise from the imbalance in caregiving responsibilities, especially when some family members are less involved in the care process (Purnamasari et al., 2020).

Despite the existing literature on family caregiving for CKD patients, there is a noticeable gap in research concerning the specific challenges faced by families in the context of Indonesian hospitals, particularly in relation to how these challenges affect the quality of life of both patients and caregivers. Studies have identified that CKD patients undergoing hemodialysis experience significant limitations in their physical, social, and psychological well-being (Nazaruddin et al., 2022). These challenges are compounded by inadequate family support systems that fail to meet the multifaceted needs of patients, leading to poor quality of life (Nazaruddin et al., 2021).

Therefore, this study aims to explore the specific challenges faced by families who care for patients with chronic kidney disease, particularly in terms of the emotional, social, and financial burdens they endure. By examining this gap, this research seeks to contribute to a deeper understanding of the caregiving experience and to inform strategies that can better support both patients and their families in managing CKD.

Methods

The type of research conducted in this study is qualitative, utilizing a phenomenological design through an interpretative phenomenological approach. This research was carried out in the Hemodialysis Unit of Bahteramas Hospital in Southeast Sulawesi Province. The population refers to the generalization area comprising objects or subjects with specific qualities and characteristics relevant to the research (Sugiyono, 2015). The focus of this study is on families caring for patients with chronic kidney disease.

The sample in this study consists of patients receiving treatment in the hemodialysis unit at Bahteramas Hospital in Southeast Sulawesi Province. Respondents were selected using purposive sampling techniques, which involve choosing samples from the population that align with the researcher’s objectives or research questions. This method ensures that the selected sample adequately represents the previously identified characteristics of the population (Nursalam, 2013). The study included a total of five participants.

Inclusion Criteria:

1. Patients diagnosed with chronic kidney disease undergoing therapies such as hemodialysis, peritoneal dialysis, or conservative treatment

2. Family members actively involved in the care of the patient (e.g., spouse, children, or close relatives).
3. Families who have been caring for CKD patients for at least six months

Exclusion Criteria:

1. Family members who are only occasionally involved in the care of the patient, such as occasional visitors without direct caregiving responsibilities
2. Respondents with severe physical or mental health conditions that could affect their ability to provide objective information
3. The study focuses solely on chronic kidney disease; therefore, patients with acute kidney failure are excluded

Results

Participants in this study comprised family members (spouses, children, siblings), with a total of five individuals who met the inclusion criteria. All participants were adolescents and adults residing in various locations; some were from the city of Kendari, while others were from Konawe Regency. The research findings revealed four themes based on data collected from participants 1 to 5: (1) commitment to caring for patients with Chronic Kidney Disease (CKD), (2) feelings of sadness and concern regarding the condition of CKD patients, (3) emotional burden associated with caring for CKD patients, and (4) acceptance of the CKD patients' condition.

The data analysis process, based on the interview results from each participant, will be elaborated upon according to themes, sub-themes, and categories, along with excerpts from participants' statements. The findings will then be presented in the form of descriptive accounts and diagrams aligned with the specific research objectives.

a. Theme 1: Commitment to Caring for Patients with Chronic Kidney Disease (CKD)

The Indonesian dictionary (KBBI, 2024), defines commitment as steadfast adherence to one's principles and obedience to ongoing tasks, even in the face of difficulties. According to the research findings, this theme reveals that participants consistently demonstrate loyalty in caring for CKD patients under any circumstances, even when lacking assistance from others and needing to resign from their jobs or educational pursuits. Participants never leave CKD patients alone at home and ensure all their needs are met, both at home and during hospital visits for dialysis. Furthermore, participants faithfully wait for CKD patients during their dialysis sessions in the hospital, which typically last approximately four to five hours.

Theme 1 comprises several sub-themes, including: **(1) Always Accompanying Patients During Illness**. Participants reported that they consistently accompany patients during illness, both at home and during routine visits to the hospital for dialysis. This is illustrated by the following statement from a participant:

> *"...when admitted to the hospital, I am the one who accompanies them; I always stay by their side. There is no one else to care for my parents." (P1)*
>
> *"...it has been almost two years since they began to fall ill, so I have been taking care of them continuously." (P4)*
>
> *"...I am the only one who looks after them because there is no one else to do so." (P2)*

The second sub-theme is: **(2) Preparing Daily Needs for the Patient**. Participants indicated that when the elderly patients fall ill, they prepare all of their daily needs, including food, beverages, clothing, and any tasks that the patients can no longer perform themselves. For instance, they manage the patients' diets, which are carefully regulated and restricted, as well as the patients' fluid intake to prevent swelling. This is illustrated by the following participant statements:

> *"...I handle everything, sometimes his wife helps, but she rarely comes because she just gave birth and has to take care of the baby. So, it's mostly me. I take care of his meals and everything else he needs. If he complains about feeling unwell or if something hurts, I take care of that as well. I prepare his food and all the other necessities; it's all on me." (P2)*

b. Theme 2: Feelings of Sadness and Worry Regarding the Condition of Patients with Chronic Kidney Disease (CKD)

The Indonesian Language Dictionary (KBBI, 2024), defines sadness as a profound emotional pain, while worry refers to feelings of fear or anxiety about uncertain situations. In the context of this study, Theme 2 indicates that participants experience sadness, worry, and compassion for both the health condition of the patient and themselves, as they endure the challenges of chronic kidney disease with severe symptoms and unpredictable occurrences. This theme comprises two sub-themes and eight categories. The first sub-theme is: **(1) Feeling Sad and Frequently Crying Due to the Patient's Condition**. In the context of this study, this signifies that participants often cry out of sadness when observing the patient's health, which can change at any moment. The following are quotes from participants:

> *"...Sometimes we feel sad and pity when we see them. At times, I also get frustrated with my parents when they are difficult to manage, but I feel sad for them too" (P1).*

> *"...There are moments when I cry alone out of pity, especially when I think about my own situation, but I feel even sadder for the patient" (P2).*

The second sub-theme is: **(2) Feeling pity for oneself and the patient**. In the context of this research, sub-theme 2 explains that, in addition to feeling pity for the health condition of the patient as a loved one, participants also feel sorry for themselves while caring for the patient. This is due to the mixed emotions of anger, annoyance, and stress, yet they must remain patient with the current situation they are experiencing. The following quotes illustrate this:

> *"...it's like we feel sad and angry, it's frustrating, but what can we do for our parents? We feel sad for ourselves, but we feel even sadder for the patient" ("...I feel sad, frustrated, and angry, but I still take care of them because they are my parents; I feel sad for myself, but I feel even sadder for the patient") (P1)*

> *"...yes, it's like we want to fight, and it stirs up emotions, but what can we do? They are family..." ("...yes, it's similar; it's as if we want to fight, but they are still family") (P3)*

c. Theme 3: Emotional Burden in Caring for Patients with Chronic Kidney Disease (CKD)

The Indonesian Dictionary (KBBI, 2024), defines "burden" as something heavy (difficult) that must be undertaken, while "emotional" refers to a state of psychological and physiological reactions that are subjective in nature. In the context of this research, Theme Four discusses the participants' reactions to patients' behaviors while caring for individuals with chronic kidney disease, expressed through both physiological and psychological experiences felt by the participants. These include feelings of irritation, displeasure, anger, fatigue, stress, and dizziness. Despite these burdensome feelings, the participants continue to care for patients with chronic kidney disease. Theme Three consists of two sub-themes, namely: (**1) Experiencing irritation, annoyance, and boredom**. According to the research, these feelings arise from patients' difficult behavior, such as occasionally disregarding advice from the participants, sudden outbursts of anger, and actions that cause irritation and frustration, ultimately leading to feelings of boredom in caregiving. This is reflected in the participants' expressions as follows:

> *"...hmmm it's normal, yes I feel irritated and annoyed, but <u>I'm used to being scolded</u>... so when they get angry, I just stay silent." (P1)*
>
> *"...<u>sometimes I feel emotional, annoyed</u>... you know how parents can be, they often make you angry..." (P5)*

Subtheme two is: (**2) experiencing fatigue and exhaustion while caring for the patient**. In the context of the research, this subtheme explains that participants feel exhausted from providing care because they do so alone, without assistance from others, and this care is required every day at all times, leading to their fatigue. Some participants even expressed feeling weary and bored due to the demands of caring for the elderly. This is illustrated in the following participant quotes:

> *"...<u>when I feel tired, yes, I am tired. That's just how it is when taking care of someone; it can be exhausting</u>, especially when receiving constant reminders" (P3).*
>
> *"...<u>I also often experience tightness and chest pain when I'm too tired; I frequently feel fatigued</u>" (P2).*

d. Theme 4: Acceptance of Chronic Kidney Disease (CKD) Patient's Condition

The Indonesian Dictionary (KBBI, 2024), defines "acceptance" as welcoming or agreeing to something, while "condition" refers to a state of being. Therefore, the intent of Theme 4 is that participants willingly accept the patient's condition. Participants perceive the compromised health of the patient as a fate that must be accepted, expressing a sense of surrender to the situation. They also convey that they find meaning in this state, which motivates them to continue caring for patients with chronic kidney disease. Theme 4 consists of two sub-themes, namely: **(1) Surrendering to the Condition of the Chronic Kidney Disease Patient**. This first sub-theme indicates that participants feel the need to accept the current health issues of the patient as something to be faced and managed to the best of their ability, since patients with chronic kidney disease are their beloved ones who require care and protection. Consequently, participants express a sense of resignation regarding the patient's condition while striving to provide care within their capabilities. This is reflected in the following excerpts from participants:

> *"...there's nothing we can do; it is what it is, so we just have to accept it. Even if I feel angry, she is still my mother, and that won't change" ("...<u>no matter what, it is just like that, so we enjoy it</u>; even if I get angry, she is still my parent, so it's just like that") (P1) (referring to mother; the chronic kidney disease patient).*

> *"...what can we do? This is how it is. I can't change anything because she is my parent, so we just have to accept it" ("...there's nothing I can do; it's already like this, what can I do because she is my parent, so that's just how it is") (P2).*

Sub-theme two is: **(2) Feeling sincere acceptance of the condition of chronic kidney disease patients**. Contextually, this sub-theme explains that regarding the health condition of patients with chronic kidney disease, participants feel sincere and accept the situation while remaining committed to caregiving. Participants have resigned themselves to the circumstances and continue to seek treatment in the hope that the patient can regain their health. This is reflected in the following participant quotes:

> *"...It's okay; I accept it with compassion." ("...I'm fine; I sincerely accept it.") (P2)*

> *"...She is just like that, as you can see; that's her condition now." ("...she is as you see her; that is her current state.") (P3) (referring to the chronic kidney disease patient)*

> *"...What can we do? The situation is as it is." ("...what can we do? The situation is already like this.") (P5)*

Discussion

Commitment to Caring for Patients with Chronic Kidney Disease (CKD)

Families caring for patients with CKD over extended periods require effective coping mechanisms. This necessity arises from the often unpredictable behaviors of patients, which can lead to frustration and caregiver burnout (Chairani, A, 2017). Nevertheless, families demonstrate unwavering commitment to caring for CKD patients in all circumstances. Field research indicates that families experience levels of exhaustion that vary, depending on the differing challenges posed by the patients' behaviors. However, the fatigue and frustration felt by family members are understood as part of the process linked to the fluctuating health status of the patient.

(Carolina, P & Zia, A. A, 2019), emphasize that prevention and management of CKD patients can be facilitated through social support from family and the surrounding community, alongside regular care and treatment. For instance, dialysis treatment, which lasts approximately four to five hours, is symptomatic and supportive, tailored to the specific issues presented by the patient.

Feelings of Sadness and Worry for Patients with Chronic Kidney Disease (CKD)

Changes in health status for CKD patients inevitably have psychological impacts on their families, particularly for those who have cared for the patient prior to illness and now must facilitate routine dialysis sessions. One significant psychological effect experienced by families is prolonged sadness and worry. Research findings indicate that the sadness and anxiety felt by families caring for CKD patients stem from uncertainty regarding the patient's health condition, given that the patient is often a cherished family member who has lived with them for an extended time (Dila, R. R., & Yuanita, P., 2019).

Feelings of Sadness and Worry in Families. The sadness experienced by families is intertwined with feelings of anxiety, as they contemplate the patient's advancing age and numerous physical complaints (Wahyuni et al., 2024). Additionally, one patient may be the head of the household and the family's primary breadwinner; when this individual develops chronic kidney disease, their ability to earn a living is hindered. In some cases, family members are compelled to resign from their jobs to care for the CKD patient and accompany them during dialysis sessions at the hospital. This situation further deepens the family's sadness, as they must not only care for an elderly person experiencing depression but also devise ways to meet daily living needs. (Mait, G et al., 2021) states that individual behaviors are often dominated by emotions—both positive and negative—which can lead to psychological discomfort.

1. Emotional Burden in Caring for Patients with Chronic Kidney Disease (CKD)

Families serve as the support system for patients, yet they can also experience burnout that becomes an emotional burden when caring for CKD patients. The caregivers are consistently present with the patient, facing various behaviors that may cause feelings of annoyance, anger, and exhaustion. This emotional strain can persist over extended periods.

The range of emotions felt by family members can significantly impact their quality of life. The stressors they encounter are physical, psychological, social, and financial. Family members often experience reduced sleep, diminished social interactions, and feelings of annoyance, anxiety, stress, anger, and shame, leaving little time for leisure activities. (Sousa et al., 2022), asserts that family caregivers caring for patients with chronic illnesses can influence the family's quality of life. A decline in the family's quality of life can lead to an increased emotional burden, potentially resulting in neglect of the patient.

2. Acceptance of the Condition of Patients with Chronic Kidney Disease (CKD)

Every family desires the best care for their sick members, particularly those with chronic kidney disease, and they continually seek treatment options to facilitate recovery. (Imamah & Lin, 2021) explains that one important social skill individuals possess, including family members, is the ability to assist in problem-solving by involving others to foster collaboration and obtain support, thus enhancing control over their lives. This is precisely what families do when caring for CKD patients. The care provided by families reflects social skills and social support for the patient. These social skills constitute a personal ability that families utilize in caregiving and serve as a coping resource, allowing them to accept the patient's condition and facilitate treatment acceptance.

Nazaruddin et al (2022), state that social conditions refer to the state or situation within a specific community that influences social dynamics. Social conditions encompass all individuals whose interactions affect us. The dimension of social relationships includes personal relationships, social support, and social activities. Personal relationships refer to the connections individuals have with others. Sousa et al (2022), further notes that families that support care and treatment demonstrate attitudes, actions, and acceptance of the patient's health condition. This statement implies that families accept the condition of CKD patients as a form of social support. Families can also serve as collaborators in managing and treating elderly individuals experiencing depression. Healthcare professionals should value family empowerment as a vital component of caregiving, as families play an essential role in deciding the treatment options acceptable to CKD patients. Thus, families are better equipped to accept the conditions of CKD patients (Chen et al., 2024).

Conclusion

The findings from this study, which comprise four themes, indicate that families caring for patients with Chronic Kidney Disease (CKD) face various psychological challenges that, if not addressed with appropriate coping mechanisms, can adversely affect their mental health status. The overarching theme derived from this research is the acceptance of the condition of CKD patients. This theme illustrates that families experience significant physical, psychological, social, and financial burdens while still demonstrating patience and willingness to accept the health condition of the patient.

It is hoped that this research will educate families about long-term care for those who have accepted the condition of CKD patients, thereby enhancing their understanding of chronic kidney disease. Additionally, it aims to reduce the stress and burdens felt by families during caregiving, ultimately improving their coping strategies and quality of life over the long term as they care for CKD patients.

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