Family Experience in Caring for Patients with Chronic Renal Failure: Literature Review

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ABSTRACT

Background: Chronic kidney failure is a chronic disease that requires special attention and is one of the highest causes of death in the world. Patients with chronic renal failure are unable to cope with and meet their own physical, psychological and financial needs, thus becoming a burden on the family/caregiver. Objective: The study examines through a literature review of family experiences in caring for family members suffering from chronic renal failure. Method: Literature Search using PubMed, EBSCO, Scopus, and ProQuest search engine databases in November 2022 using the keywords experience, family caregiver, and chronic renal failure. Researchers took 2012-2022 articles by looking at titles, abstracts, and full text to assess the journal’s feasibility. Result: A total of 5 articles and 249 respondents out of 2289 articles were found and used. Researchers discover and conclude the importance of the role of the family in helping physical needs, providing emotional and psychological support, supporting economic needs, advocacy and navigation. Conclusion: Family stress/burdens include physical exhaustion, fatigue and emotional baggage, tension and anxiety. Families also experience impaired roles of taking responsibility as well as roles of care in children and family members.

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INTRODUCTION

Chronic Kidney Disease in the world is currently increasing and becoming a serious health problem, the results of 2010 Global Burden of Disease study, chronic kidney disease was the 27th leading cause of death in the world in 1990 and increased to 18th in 2010. Read More of the 2 million people in the world receive treatment with dialysis or kidney transplant and only about 10% actually experience this treatment. Ten percent of the world's population suffer from chronic kidney disease and millions die every year because they do not have access to treatment (Kemenkes RI, 2021). According to Riskesdas (2018) the prevalence of Indonesian with chronic kidney failure (CKD) is 0.38%, an increase from 2013 was 0.2%. The prevalence rate for patients with chronic kidney failure in DI Yogyakarta is 0.43% (Kementrian Kesehatan RI, 2018).

Families play an important role and have great responsibility in the care of patients with chronic renal failure. People with chronic kidney disease are typically unable to manage and meet their own physical, psychological, and financial needs, which are a burden on families and caregivers. Different families face different experiences when caring for patients with chronic renal failure. Nursing and caring for patients with chronic renal failure is a great responsibility with help, hands-on care and emotional support. According Trisnasari (2017) a caregiver is someone who provides medical, social, economic, or environmental resources to an individual who is partially or completely dependent on the illness that the individual is facing. Family caregivers are defined as individuals who provide continuous nursing care seriously every day for a long period of time to care for family members who suffer from chronic illnesses (Trisnasari, 2017).

The family as a caregiver will experience several problems while caring for hemodialysis patients, both from psychological, social and economic aspects. Families living together and providing care to hemodialysis patients can create tension in the entire family unit (Halawati, DFA, & Kusuma, 2017). Care of hemodialysis patients can also have a significant impact on the family system, especially family roles. The family's role in family care, from remediation to prevention, treatment and rehabilitation, is very important. (Thomas, 2019). Diseases suffered by one family member will affect all family members, and will affect the interaction between family members in a healthy and sick condition, namely on family functions that have previously been formed in a family (Thomas, 2019). Changes in this interaction can provide an overview of the family’s response in dealing with the health and illness ranges of family members. This is marked by a change in the role of a sick family member, for example the role of a sick father will be replaced by a mother. Role changes that occur can have a stressful effect on partners and other family members (Halawati, DFA, & Kusuma, 2017).

In accordance with research conducted by Malu (2020) Chronic renal failure patients may lose their freedom during treatment, he said, because there are taboos and rules they must follow to prevent their condition from worsening. In this context, the succession of family functions is of great importance for treatment continuity and patient quality of life. Factors that can affect the quality of life of patients with renal failure include physical, psychological, social, economic and environmental factors. Family support is one factor that influences patients on hemodialysis treatment. One of the factors that underpins the success of nursing services is the involvement of the patient’s family in the care and meeting the needs of patients with chronic kidney disease (Malu, 2020).

When caring for sick family members, caregivers encounter a variety of issues that lead to stress. The many tasks, responsibilities, and stresses caregivers experience in providing care can negatively impact themselves and sick family members. The stress faced by caregivers poses challenges as they prepare to care for sick family members. Nursing skills are very important when caring for a sick family member (Anizar & Pudjiastuti, 2017).

Based on the background and review of the literature conducted by researchers, the researchers are interested in conducting research with the theme “Family Experience in Caring for Patients with Chronic Kidney Failure; Literature Review”. It is the hope of the researchers that the results of this study can add insight in the field of nursing, learning media and as a media for consideration to enrich knowledge about family experience in providing care to family members who suffer from chronic kidney failure. Researchers also hope that this research is expected to provide benefits for further researchers and become a reference that can assist in carrying out further research.

METHODS

The method used in this research is literature review. The article selection process begins by using predetermined keywords, then it is analyzed on the search engine database PubMed, EBSCO, Scopus, and ProQuest first then the number of article results will appear, after that enter the time limit for article publication 2012 – 2022 (last 10 years), and in English, a limited number of article search results will appear. Then the selected relevant articles are exported to the bibliographic application, namely Mendeley for a more in-depth full text review of whether the article meets the inclusion and exclusion criteria of this literature review. Figure 1 shows the process of searching and reviewing literature.

Researchers review articles independently and then discuss them to reach agreement. Selection of articles using prism guidelines. Provides an overview of the search identification and filtering process and the results of the selected articles

RESULTS

In the literature review, literature or article searches were carried out in 4 databases, namely PubMed, EBSCO, Scopus, and ProQuest using search keywords or keywords that had been compiled based on research questions based on PICo. The results of the literature search found 2289 articles that match the search keywords. Articles taken are limited to the period from 2012 to 2022 using English, with hospital and out-of-hospital service settings, and for free full text article retrieval.

The next researcher carried out the selection process using the steps according to the PRISMA diagram. Beginning with the selection stage of the article duplication stage, and found 14 articles that were duplicated so that the remaining 2275 articles. After carrying out the duplication selection, the researcher selected 2275 existing journals by identifying them based on the accuracy of the title and abstract, then identifying each article based on its quality and filtering it.
Based on the inclusion and exclusion criteria that the researcher had compiled based on the PICo and the researcher’s research questions. Based on the results of the selection based on this, the researcher found 5 articles which were used as material for the research review literature.

![Prisma Diagram](image)

**Figure 1. Prisma Diagram**

**Table 1. Article Characteristics**

<table>
<thead>
<tr>
<th>Article characteristics</th>
<th>Results</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design Studies</td>
<td>Qualitative Research</td>
<td>5</td>
</tr>
<tr>
<td>Continent</td>
<td>America</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Canada</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Europe</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Asia</td>
<td>1/5</td>
</tr>
<tr>
<td>Number of respondents</td>
<td>Families caring for patients with chronic kidney failure</td>
<td>249 Respondents</td>
</tr>
<tr>
<td>Findings: The role of the family in caring for family members with chronic kidney failure</td>
<td>Physical support provider</td>
<td>3 articles/5 articles</td>
</tr>
<tr>
<td></td>
<td>Emotional support provider</td>
<td>4 articles/5 articles</td>
</tr>
<tr>
<td></td>
<td>Economic support</td>
<td>3 articles/5 articles</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
<td>2 articles/5 articles</td>
</tr>
<tr>
<td></td>
<td>Navigation provider</td>
<td>2 articles/5 articles</td>
</tr>
<tr>
<td>Findings: Burden of caring for families caring for family members with chronic kidney failure</td>
<td>Experiencing physical exhaustion</td>
<td>3 articles/5 articles</td>
</tr>
<tr>
<td></td>
<td>Experiencing fatigue and emotional burden</td>
<td>3 articles/5 articles</td>
</tr>
<tr>
<td></td>
<td>Experiencing tension and anxiety</td>
<td>3 articles/5 articles</td>
</tr>
<tr>
<td>Findings: Psychosocial disorders and roles experienced by the family</td>
<td>Taking responsibility for care of a child or family member</td>
<td>1 article/5 articles</td>
</tr>
<tr>
<td></td>
<td>Changes in the roles of family members</td>
<td>3 articles/5 articles</td>
</tr>
<tr>
<td>No</td>
<td>Journal title</td>
<td>Author</td>
</tr>
<tr>
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</tr>
<tr>
<td>1</td>
<td>Patient, Caregiver, and Provider Perspectives on Challenges and Solutions to Individualization of Care in Hemodialysis: A Qualitative Study</td>
<td>Sass, R., Finlay, J., Rossum, K., Soroka, K., McCormick, M., Desjarlais, A., – Bohm, C. (2020)</td>
</tr>
<tr>
<td>2</td>
<td>The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: Contested discourses of aging</td>
<td>Low, J., Myers, J., Smith, G., Higgs, P., Burns, A., Hopkins, K., &amp; Jones, L. (2014).</td>
</tr>
<tr>
<td>3</td>
<td>Dedication in caring for hemodialysis patients: Perspectives and experiences of Iranian family caregivers</td>
<td>Eslami, AA, Rabiei, M., Shirani, M., &amp; Masoudi, R. (2018).</td>
</tr>
<tr>
<td>4</td>
<td>The Experience of Primary Caregivers of Undocumented Immigrants with End-Stage Kidney Disease that Rely on Emergency-Only Hemodialysis</td>
<td>Cervantes, L., Carr, AL, Welles, CC, Zoucha, J., Steiner, J.F., Johnson, T., Hasnain-Wynia, R. (2020)</td>
</tr>
</tbody>
</table>
treatment of hemodialysis patients requires good motivation according to (Vina, 2022), it is established that family and being heard expressed in the form of affection, trust, a emotions. Aspects of emotional support include support you can rest and relax, and it helps you control your family should do. A family is a safe and peaceful place where one family member experiences health problems, other family members play a role in providing motivation, support and providing assistance both physically and psychologically so as to improve the quality of life of problematic family members. This is also in accordance with (Vina, 2022) it is described that the family has a very important role in caring for and maintaining the health status of its family members.

As stated by (Iriani et al., 2020) which outlines a theory about family development put forward by Friedman that is if one family member experiences health problems, other family members play a role in providing motivation, support and providing assistance both physically and psychologically so as to improve the quality of life of problematic family members. This is also in accordance with (Vina, 2022) it is described that the family has a very important role in caring for and maintaining the health status of its family members. Consistent with Milligan's (2004) statement that caregiving responsibilities include physical care, social care, mental care, and quality care, caregivers bear the burden of this type of work. Often experienced. Caregiver stress is defined by Tantono (2006) as the multidimensional stress experienced by caregivers. The experience of caregiving is associated with multifaceted responses to physical, psychological, emotional, social, and economic stress. According to Anneke (2009), there are three factors that influence the burden on caregivers (family members who care for sick family members). These are the impact on the caregiver's personal and social life, psychological distress, and guilt (Trisnasari, 2017).

Emotional support is one of the most important things a family should do. A family is a safe and peaceful place where you can rest and relax, and it helps you control your emotions. Aspects of emotional support include support expressed in the form of affection, trust, attention, listening, and being heard (Iriani et al., 2020). On the other hand, according to (Vina, 2022), it is established that family treatment of hemodialysis patients requires good motivation and acceptance on the part of the family. This is because family members are the closest to the patient in their treatment, especially at home.

### DISCUSSIONS

Based on the study and review of the journals conducted, 3 themes and 10 sub-themes were found based on the experiences experienced by families in caring for family members with chronic kidney failure. The themes and sub-themes that can be discussed are as follows:

**Theme 1: The role of the family in caring for family members with chronic kidney failure**

Sub-theme 1: provide physical support

As stated by (Iriani et al., 2020) which outlines a theory about family development put forward by Friedman that is if one family member experiences health problems, other family members play a role in providing motivation, support and providing assistance both physically and psychologically so as to improve the quality of life of problematic family members. This is also in accordance with (Vina, 2022) it is described that the family has a very important role in caring for and maintaining the health status of its family members. Consistent with Milligan's (2004) statement that caregiving responsibilities include physical care, social care, mental care, and quality care, caregivers bear the burden of this type of work. Often experienced. Caregiver stress is defined by Tantono (2006) as the multidimensional stress experienced by caregivers. The experience of caregiving is associated with multifaceted responses to physical, psychological, emotional, social, and economic stress. According to Anneke (2009), there are three factors that influence the burden on caregivers (family members who care for sick family members). These are the impact on the caregiver's personal and social life, psychological distress, and guilt (Trisnasari, 2017).

### Table 2

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring for patients with end-stage renal disease during COVID-19 lockdown: What additional challenges to family caregivers?</td>
<td>Sub theme 1: Emotional support providers</td>
<td>Emotional support is one of the most important things a family should do. A family is a safe and peaceful place where you can rest and relax, and it helps you control your emotions. Aspects of emotional support include support expressed in the form of affection, trust, attention, listening, and being heard (Iriani et al., 2020). On the other hand, according to (Vina, 2022), it is established that family treatment of hemodialysis patients requires good motivation and acceptance on the part of the family. This is because family members are the closest to the patient in their treatment, especially at home.</td>
</tr>
</tbody>
</table>

The National Alliance for Caregiving Foundation (2010) states that caregivers provide physical, emotional, and often financial assistance to others who are unable to care for themselves because of illness, injury, or disability stated that it is responsible for providing (Agustina, Kartika; Dewi, 2018). Lin & Indrino (2021) also states that some caregivers will work or sell their belongings and other resources such as personal clothing, livestock, until their possessions run out. Caregivers also involved in manual labor to survive the economic downturn. Some caregivers are unable to work because they have to stay at home and care for sick people. Carers who are unable to work rely mostly on other distant relatives for financial support. Ase-Ngbise et al. (2015) in Lin & Indrino (2021) stated that some caregivers expressed desperation in making a job economically profitable while caring for their sick relative.

**Sub-theme 4: Advocate**

According to Beandlands et al in Nugraha (2011), there are five family caregiver activities that are interrelated in providing assistance to family members suffering from chronic kidney failure who are undergoing hemodialysis, including: assessing, advocating, entertaining, providing routine/daily assistance, and providing exercises. The family caregiver also specifically describes their duties including activities related to hemodialysis, namely: managing diet/nutrition, knowing existing medications and symptoms, and caring personally (Agustina, Kartika; Dewi, 2018).

Patients with chronic kidney failure with hemodialysis will experience disturbances in bodily functions causing patients to have to adapt for the rest of their lives, besides that hemodialysis patients will appear several problems such as weakness, physical limitations, psychological, economic, social and even death (Nugraha, 2011 in Putri & Maghfirah, 2018). Based on this, the role of the family is very important in caring for patients with chronic kidney failure.

**Sub theme 5: Navigation givers**

Based Agustina et al (2018) explained in his research that patients with end-stage kidney disease often rely on caregivers, in this case family members who care for them to...
help them in their daily lives and assist with medical needs. The tasks performed by caregivers (families who provide care) include arranging medication administration, accompanying patients for hemodialysis and other medical needs, maintaining personal hygiene, and providing food. Caregivers or family members who care for patients also provide emotional and psychosocial support in everyday life (Agustina et al., 2018).

**Theme 2: Burden of care/care for families caring for family members with chronic kidney failure**

Sub theme 1: Experiencing physical exhaustion

In line with what was conveyed by Setiawan (2014) in Naufal & Setyawani (2018) families who treat patients with chronic diseases in this case are chronic kidney failure suffer from physical, psychological and social problems, this was also conveyed by Pinquart & Sörensen (2003) that the activities of parenting or caring for the patient by the family can interfere with the daily routine of the carer/caring family, namely; causing physical, emotional, and financial strain; and ends up draining the energy of the family caring for the patient (Naufal & Setyawani, 2018).

Sub-theme 2: Experiencing fatigue and emotional burden

According to Colics et al. (2013), family members caring for chronically ill patients were affected by aspects of mental state, daily activities, family relationships, sleep and health, vacation, participation in medical care, support provided to family members, work and study, can have a significant impact on, economic impact, health, life, schedule (Vina, 2022). Tableao, Tomasi & Quevedo (2014) also conveyed in Lilin & Indriono (2021) Raising and caring for children is a time-consuming responsibility that causes social, emotional, behavioral and economic problems for caregivers and limits their personal lives. Caregivers and family members who care for family members are often referred to as forgotten patients. Caregivers often suffer psychological stress, such as mood swings, fatigue, headaches, joint and muscle pain, and marital and family discord (Lilin & Indriono, 2021).

Sub theme 3: Experiencing tension and anxiety

Based on research conducted by Rahayu & Sujiati (2014) in Utami (2014) states that families who care for patients with chronic kidney failure will experience severe anxiety when their family members are carried out on hemodialysis in the first 2 to 6 months. This is of course the family will experience stress that can cause anxiety. Families who experience anxiety in the long term will experience cognitive decline including loss of short term memory which will hinder one's function in life (Putri & Maghfirah, 2018). This is in line with what was stated by Arosa & Wofest (2014) that families also experience mild to severe anxiety in care of patients with chronic renal failure receiving hemodialysis (Vina, 2022).

**Theme 3: Psychosocial disorders and roles experienced by the family**

Sub-theme 1: Taking care of children or family members.

In line with what was conveyed by Beandlands et al (2005) in Nugraha (2011), namely a change in participating in social activities due to limited association.
including: physical exhaustion, emotional exhaustion and burden, tension and anxiety. The family also experiences role disturbance in the form of a role of taking responsibility and the role of caring for children and family members.

ETHICAL CONSIDERATIONS

Funding Statement.

The author does not receive financial support from any party.

Conflict of Interest Statement

The authors state that they have no disputes with other parties related to this study.

REFERENCES


