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

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A B S T R A C T

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.

Kata kunci:

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A B S T R A K

Latar Belakang: Penyakit gagal ginjal kronis merupakan penyakit kronis yang membutuhkan perhatian khusus dan menjadi salah satu penyebab kematian tertinggi di dunia. Pasien dengan gagal ginjal kronis tidak dapat mengatasi dan memenuhi kebutuhan fisik, psikologis dan finansialnya sendiri, sehingga menjadi beban keluarga/caregiver. Tujuan: Penelitian mengkaji melalui telaah literatur tentang pengalaman keluarga dalam merawat anggota keluarga yang menderita gagal ginjal kronis. Metode: Penelusuran Literatur menggunakan database search enginer PubMed, EBSCO, Scopus, dan ProQuest pada November 2022 menggunakan kata kunci experience, family caregiver, dan chronic renal failure. Peneliti mengambil artikel tahun 2012-2022 dengan melihat judul, abstraks, dan teks lengkap untuk menilai kelayakan jurnal. Sebanyak 5 artikel dan 249 responden dari 2289 artikel ditemukan dan digunakan. Hasil: Peneliti menemukan dan menyimpulkan pentingnya peran keluarga dalam membantu kebutuhan fisik, pemberi dukungan emosional dan psikologi, pendukung kebutuhan ekonomi, advokasi dan navigasi. Kesimpulan: Tekanan/beban keluarga meliputi kelelahan fisik, kelelahan dan beban emosional, ketegangan dan kecemasan. Keluarga juga mengalami gangguan peran pengambilan tanggung jawab serta peran perawatan pada anak dan anggota keluarga.

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 data bases, 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.

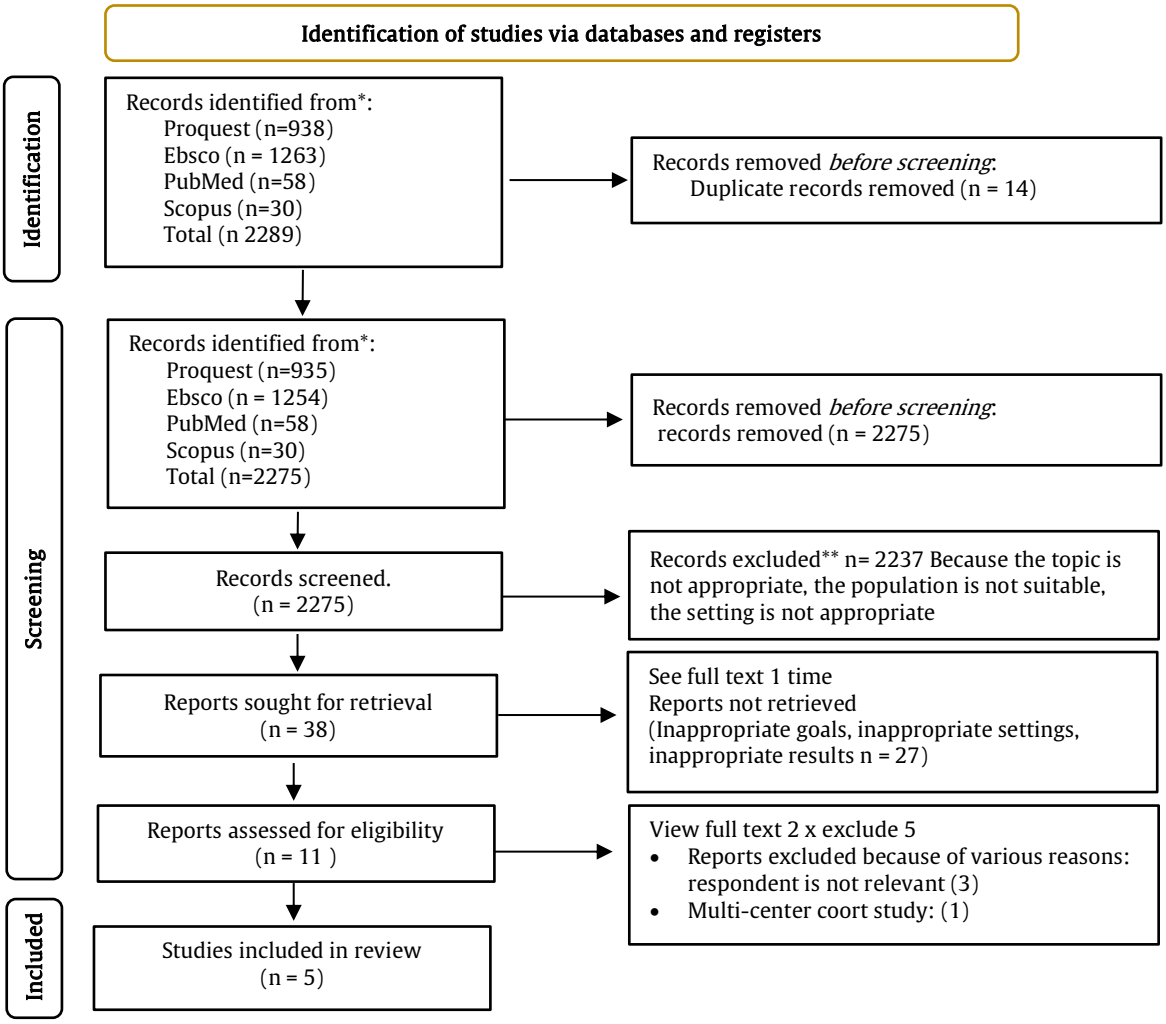

Figure 1. Prisma Diagram

Table 1. Article Characteristics

Article characteristics		Results	Amount
Design Studies		Qualitative Research	5
Continent	America	Canada	1/5
		America	1/5
	Europe	English	1/5
		Portugal	1/5
	Asia	Iran	1/5
Number of respondents		Families caring for patients with chronic kidney failure	249 Respondents
Findings: The role of the family in caring for family members with chronic kidney failure		Physical support provider	3 articles/5 articles
		Emotional support provider	4 articles/5 articles
		Economic support	3 articles/5 articles
		Advocate	2 articles/5 articles
		Navigation provider	2 articles/5 articles
Findings: Burden of caring for families caring for family members with chronic kidney failure		Experiencing physical exhaustion	3 articles/5 articles
		Experiencing fatigue and emotional burden	3 articles/5 articles
		Experiencing tension and anxiety	3 articles/5 articles
Findings: Psychosocial disorders and roles experienced by the family		Taking responsibility for care of a child or family member	1 article/5 articles
		Changes in the roles of family members	3 articles/5 articles

Table 2. Article reviews

No	Journal title	Author	Research design	Results
1	Patient, Caregiver, and Provider Perspectives on Challenges and Solutions to Individualization of Care in Hemodialysis: A Qualitative Study	Sass, R., Finlay, J., Rossum, K., Soroka, KV, McCormick, M., Desjarlais, A., ... Bohm, C. (2020)	Design: Qualitative Research Sample: 113 respondents Place: Canada	Conducted eight focus groups and 44 interviews with a total of 113 people. The focus group consisted of 47 patients and 18 caregivers (total n=65; Winnipeg, n=29; Halifax, n=19; Edmonton, n=13; Ottawa, n=4). Focus group participants ranged from 4 to 13 for her. Calgary used patient interviews instead of focus groups (n=13) and Edmonton used patient interviews instead of focus groups (n=4). Overall, 21 (33%) of her HD participants and 13 (72%) of her caregivers who participated in the focus group and interview were female. The mean ages of participating patients and caregivers were 60 (interquartile range [IQR] 51.74) and 65 (IQR 56.68), respectively. At this institution, he had a median time to onset of HD of 3 (IQR 1.6) years. Additionally, 31 HCPs (Winnipeg, n=13; Halifax, n=4; Edmonton, n=3; Calgary, n=8; Ottawa, n=3) participated in the interviews. 77% of healthcare providers were female (n=24) and had worked in the healthcare industry for an average of 13 years (IQR 6.16). We have identified his four main themes in his work; Session settings: transportation and parking. socio-economic and emotional well-being. Location and schedule of HD sessions (Sass et al., 2020). Diploma: Participants were particularly interested in patient comfort and safety during HD sessions, affordable and reliable transportation to and from HD sessions, increased financial burden due to changing functional status, and combating HD. I had Challenges in individualizing HD care were identified. This allows for greater individualization of treatment goals and greater flexibility in medication and self-care planning. These results will inform future research aimed at improving patient-centered care in HD.
2	The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: Contested discourses of aging	Low, J., Myers, J., Smith, G., Higgs, P., Burns, A., Hopkins, K., & Jones, L. (2014).	Design: Qualitative Research Sample: 26 respondents Place: England	Used data to explore how participants caring for someone on conservative treatment coped with issues of medication, aging and death. For analysis purposes, we divided the data into four specific domains related to accounts. These are (a) awareness of the emergence of CKD, (b) CKM, (c) discussion of aging in the context of health and social care, and (d) negotiation of discussion of aging and death (Low et al., 2014).
3	Dedication in caring for hemodialysis patients: Perspectives and experiences of Iranian family caregivers	Eslami, AA, Rabiei, L., Shirani, M., & Masoudi, R. (2018).	Design: Qualitative Research Sample: 25 respondents Place: Iran	Of the caring relatives, 15 (60%) were female and 10 (40%) were male. Participants' ages ranged from 20 to 69 years old (mean ± standard deviation = 47 ± 3.9 years). Twelve (48%) are married and the rest are single. Patient-caregiver relationships consisted primarily of spouses (n=15) or daughters (n=10). In addition, the average hospital stay is 10 hours per day, and patients are treated for up to 7 years. Several codes and themes emerged from the interview results, consisting of 3 main themes and 9 sub-themes. Relevant topics were then explained to supervisors, who were able to corroborate them with further explanations. Analysis of the data revealed three major themes suggesting that caregivers face challenges such as high caregiver stress, caregiver overload, and mental fatigue. Diploma: Treatment of hemodialysis patients always presents challenges and concerns in terms of effectively treating the patient. Providers need to address this issue based on a patient- and caregiver-centered approach, rather than just a patient-centered approach, in order to develop blueprints and plans to support patients and their caregivers. I have. (Eslami et al., 2018).
4	The Experience of Primary Caregivers of Undocumented Immigrants with End-Stage Kidney Disease that Rely on Emergency-Only Hemodialysis	Cervantes, L., Carr, AL, Welles, CC, Zoucha, J., Steiner, JF, Johnson, T., ... Hasnain-Wynia, R. (2020)	Design: Qualitative Research Sample: 66 respondents Place: America	The 20 primary caregivers had a mean age (SD) of 46 (17), 13 (65%) were female, 7 (35%) were caregivers of adult children, 13 (65%) were was a partner. Five themes and 17 sub-themes (in brackets) were identified. (1) the caregiver role (providing mental, physical, and financial support, advocacy, and direction of care); diseases, problems, etc.) economy, self-care, redefinition, etc.). (3) unpredictable her EOHD (episodes of acute illness leading to emergencies, stress when patient is denied dialysis, impact on work and sleep, emotional relief after EOHD session); Impact (dropout or truancy, psychosocial

				pressure) (Cervantes et al., 2020).
5	Caring for patients with end-stage renal disease during COVID-19 lockdown: What (additional) challenges to family caregivers?	Sousa, H., Frontini, R., Ribeiro, O., Paúl, C., Costa, E., Amado, L., ... Figueiredo, D. (2022).	Design: Qualitative Research Sample: 19 respondents Place: Portugal	Four major themes were identified. (1) Mental stress. (2) Changes in Parental Responsibilities. (3) education and support needs; (4) Coping strategies. Each topic and its corresponding subtopics are described below. Table 2 shows the main theme, sub-themes, and frequency of occurrence of each sub-theme in nurse stories. Diploma: To our knowledge, this is the first study to report that caregivers of ESRD patients have additional care responsibilities due to COVID-19. Therefore, more attention should be paid to caregiver burden during lockdown. This is because ensuring patient care, adherence and support is extremely important. The results also provide foundational data to assist dialysis teams in developing training and support strategies for family caregivers of patients undergoing hemodialysis at centers during the COVID-19 pandemic. Future research needs to assess whether such interventions by family caregivers are acceptable during the pandemic (Sousa et al., 2022).

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).

Sub-theme 2: Emotional support providers

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.

Sub theme 3: Economic support

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). Lilin & Indriono (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. Ae-Ngibise et al (2015) in Lilin & Indriono (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 & Setyawan (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 & Setyawan, 2018).

Sub-theme 2: Experiencing fatigue and emotional burden

According to Golics 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). Tableeão, 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 & Woferst (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. Caregivers/families who provide care cannot participate in activities in their surroundings such as social gatherings, recitations, gathering with school friends. All these activities are very limited because caregivers have to help patients a lot. Caring for family members with chronic kidney failure can lead to disruption of social roles. The caregiver, in this case the caring family member, has limited activities due to physical weakness, so they mostly stay at home. As a result, family members who provide care cannot carry out their roles in the family and the surrounding community. Family members should play a role in accordance with the structure in the family and social roles (Nugraha, 2011).

Sub-theme 2: Changes in the roles of family members

In his research Sonenberg (2010) mentions that lifestyle changes occur due to caring for sick family members and will have an impact on family members who care for sick families such as the need for body energy and time management, changes in family roles and responsibilities, pressure/stressors from inside and outside (family). The Family Caregiver Alliance reports that there are financial problems for caregivers who care for their family members. The existence of limited time and opportunities to work causes caregivers to experience a burden. Whereas caregivers still need costs such as care, clothing, housing, and education (Nugraha, 2011).

Apart from being financially burdened, the family also has a psychological burden. The psychological burden is that the family must be willing to take family members to a health service while waiting for hemodialysis therapy which can lead to burnout. The time needed between 4-5 hours can also be used by the family for other things. The impact that occurs if supportive therapy is not given to the family is the disruption of family structure and roles such as disharmony, feeling neglected and feeling uncared for and unable to meet the needs of the family. The client will also experience a psychological burden, which means that the client feels a burden on the family (Wahyuningsih, 2011).

STUDY LIMITATIONS

This review study draws on limitations of papers published between 2012 and 2022 by collecting data on patient family experiences. However, evaluation has limitations. Researchers searched and included only literature published in English, which may exclude relevant information from studies published in languages other than English. In addition, the date and language restrictions we set may affect the generalization of the study and exclude some topics. .

CONCLUSIONS AND RECOMMENDATIONS

Based on the research conducted and the review of the literature, we have found descriptions and phenomena that occur in families caring for patients with chronic renal failure. This description or phenomenon can be summarized as follows: the role of the family in providing care is needed in various ways such as helping the patient's physical needs, as a provider of emotional and psychological support, as a supporter of economic needs, advocating and directing (navigation). Families experience various pressures/burdens

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.

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