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Psychological and Social Support Among Chronic Kidney Disease Patients: A Qualitative Study

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ABSTRACT
Chronic kidney disease is one of the chronic diseases that can affect mental health because the patient must undergo dialysis in addition to kidney transplantation to survive. Purpose of this study ***was*** *to explore the perspectives of chronic kidney disease patients undergoing dialysis regarding mental health and social support. This study used a qualitative method with a descriptive phenomenological approach. The population in this study was 30 patients with chronic kidney disease, 10 patients became participants were interviewed with semi-structure. Samples were captured by the purposive sampling method. The results of the study were analyzed by the Colaizzi method. Based on interviews regarding the perspectives of patients with chronic kidney disease, two main themes were identified, namely psychological state and social support. Chronic kidney disease patients undergoing dialysis face challenges and difficulties related to their psychological state.*

Keywords: *Chronic Kidney Diseases, Dialysis, Psychological Conditions, and Social Support*.

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INTRODUCTION

Kidney failure is a non-communicable disease with various causes that result in a rapid decline in kidney function and ends with chronic kidney failure. Kidney failure is a global health issue that affects minority and low-income communities. Based on data from the WHO Global Burden of Disease (GBD), it is stated that 5-10 million people die each year due to kidney disease (1). The prevalence of kidney failure in Taiwan is the highest in the world due to a longer life expectancy and a growing population. The high life expectancy accompanied by old age is a major concern for the government because it creates a large social and financial burden for individuals, society, and the health system (2). In 2018, data obtained from patients with kidney failure ranked 3rd in Indonesia, following heart disease and cancer (3). Furthermore, according to Infodatin in 2017, the province with the highest prevalence is Central Sulawesi at 0.5%, followed by Aceh, Gorontalo, and North Sulawesi at 0.4% each, and South Sulawesi at 0.3% (4).

Patients with chronic kidney disease cannot be separated from mental health disorders, such as depression and anxiety. Depression affects about a quarter of people with CKD, which is 3 times higher compared to people with other chronic conditions (5). The prevalence of depression in patients receiving dialysis was nearly 15% higher than in those who did not receive renal replacement therapy or a kidney transplant, suggesting that treatment-related factors may further contribute to mental stress (6). Dialysis measures can affect mental health in patients characterized by an increased risk of hospitalization, morbidity and mortality, and an increased risk of death by 29-42% (7). In addition, kidney failure patients undergoing dialysis have a significant burden physically, mentally, depressed, and quality of life due to

decreased physical and psychological well-being (8). Stage 5 chronic kidney disease patients undergoing dialysis face a high comorbidity load both physically, mentally, and quality of life disorders (9). Therefore, this study aims to explore mental health in kidney failure patients and who provides support to sufferers because as it is known that kidney failure is called incurable disease, but patients can undergo hemodialysis.

METHOD

The research method used was qualitative, with descriptive phenomenology study methods with the aim of interpreting and explaining experiences by participants as patients with chronic kidney diseases in this life including experiences when interacting with other people and the surrounding environment.(10). This research was conducted in the hemodialysis room of Stella Maris Hospital Makassar in August 2022. The sampling technique used was purposive sampling (11). Participants in this study included up to ten patients with chronic kidney disease who underwent dialysis. Participants in this study were patients who met the inclusion criteria of the study and patients with kidney failure who underwent dialysis six months to two years later because in general, patients who are sentenced to suffer from the disease experience a grieving phase due to a decrease in health conditions according to (12) which reveals that a person will complete the grieving stage perfectly in a period of 6 months to 1 year. Meanwhile, the exclusion criteria in this study are (a) patients of pediatric; (b) patients who develop fever, tightness, and other special conditions after undergoing hemodialysis; (c) patients who have multiple diseases. Informed consent was provided to the participants before the interview.

Data collection is carried out by interviewing each participant who has met the criteria. Interviews were stopped when the data results had reached saturation where there was no more new information from participants or could be considered saturated. Interview guidelines were developed by the researchers based on research questions and objectives, as well as research concepts and phenomena. The semi-structured questions given to participants such as "*how do you feel when you are sentenced to CKD and have to undergo dialysis?*". The collection process was carried out by identifying the number of kidney failure patients undergoing hemodialysis, then researchers gave informed consent to prospective participants. If the participants agree, the interview process continues. The researcher conducted interviews with each participant 3 times. The first interview was conducted with the aim of building a trusting relationship between the researcher and the participant. The second interview, which lasted 45-60 minutes, was designed to explore mental health in patients with renal failure and who provides support to people with chronic renal failure. The third interview was conducted after all the data from the second interview had been generated and lasted 20-30 minutes. During this interview, the participant is asked to determine themes inferred from the interview that relate to the participant's feelings. At this time, the researcher can also make corrections if there are gaps in the data obtained in the second interview. It is also important to conduct a third interview to give participants the opportunity to verify and add to the description of their feelings to further add

Table 1. Participant Characteristics (n=10**)**

Demographic Characteristic	n	%
Age (year)		
17 – 25	1	10
26 – 35	2	20
36 – 45	4	40
46 – 55	2	20
>55	1	10
Sex		
Male	7	60
Female	3	30
Educational Background		
High school	6	60
D3 Midwifery	1	10
Bachelor	3	30
Duration of Dialysis		
1-6 month	1	10
7-12 month	6	60
13-24 month	3	30

Table 2. Results of Theme Analysis

Theme	Subtheme
Psychological Conditions	1. Feeling worried imagining kidney failure and dialysis. 2. Imagining death. 3. Dialysis is the end of everything
Social support	1. Informative support. 2. Emotional support. 3. Instrumental support. 4. Appreciation support.

to the accuracy of the data from this study. Data analysis was based on the Colaizzi method (13) which consisted of 7 stages: transcribing of interviews, extracting significant statements, formulating meanings from significant statements, organizing the aggregate formalized meanings into theme clusters, writing an exhaustive description of the phenomenon, identifying the fundamental structure, and validating the exhaustive description with each participant.

RESULT AND DISCUSSION

Characteristics of the participants

Participants in this study were patients with chronic kidney disease undergoing dialysis. Each participant was interviewed in depth using Indonesian. The characteristics of the participants can be seen in table 1.

Themes and Subthemes

This research focused on two main themes that were composed of seven sub-themes. The two themes identified in this study were psychological conditions and social support, these two themes are obtained from the results of the Colaize method analysis process with seven stages which can be seen in table 2.

Theme 1: Psychological Condition

Theme 1 consists of three sub-themes. The first sub-theme is the feeling of being worried about imagining kidney failure and dialysis. This is illustrated in the following quotes:

"*My feelings that I experienced at that time were certainly a little.. one is anxious, the second is also how is it, is it dizzy*?" (P1)

"*Anxious, dizzy with fear... what is it called? discouraged, lost the spirit of life*" (P1)

"*Yes, resigned*" (P2)

This sub-theme was also supported by the statement of participants who expressed that they were afraid, anxious, and disappointed about their health condition. This is illustrated in the following quotes by the participants:

"*It's because that's how we used to be afraid of dialysis*" (P2)

"*Yes, frustrated, sad, disappointed those are all things that I can't accept*" (P3)

"*Well, I'm usually afraid that it won't be long*" (P3)

"*There is indeed a feeling of fear, especially when installing the first CDL, policemino. Indeed, there is a feeling of fear, ahh, how about this, but let's just go with the one that is good"(P6)*

"There is a fear" (P8)

"*E.. how is it.. I feel so nervous.. e.. so surprised*"(P9)

"*It's scary, isn't it, I'm a health worker, but I mean it's like I'm afraid*" (P10)

"*So maybe this is a temptation..a test from God..so..yes, pray more. Hopefully, there is still a miracle that God has given to heal. That's all*"

Next, the second sub-theme is imagining death stated by the participants in the following quotes:

"*I am worried because all this time I have heard that people who do dialysis sometimes die quickly*" (P1)

"*At first I refused to do dialysis because of the information. Circulating in the community saying that dialysis causes people to die quickly*" (P1)

"*I feel like dying, close to death… always sweating, my feet are cold*" (P8).

Then, the third sub-theme was the feeling that dialysis is the end of everything, which is stated by the participants in the following quotes:

"*I think that with kidney failure there is no hope anymore, no one can survive, have a long life, continue... limited activities can't do anything*" (P1)

"*I am influenced by the words of people who say that people who do dialysis do not*

survive.. if I do dialysis yah..wait for death" (P2)

"*What appeared in my heart at that time was that I no longer had a long life*" (P2)

"*Other people told me that dialysis is the end of everything*" (P6)

"*I thought that I could still survive, but I can't*" (P7)

Theme 2: Social Support

This theme consists of four sub-themes. The first sub-theme is informative support, which is expressed by participants in the following quotes:

"*At that time, my brother and I went around the state hospital to see some patients undergoing dialysis, oh it turned out like this, so at that time I intended to undergo dialysis because at that time I was feeling short of breath, fluid had accumulated, my legs and face were already swollen*" (P1).

"*I got excited again after being explained by the nurse about dialysis, which can prolong life*" (P1).

"*The doctor said to just go ahead.. Praise God you are healthy" (P9).*

Next is emotional support received by the participants, which is stated in the following quotes:

"Thank God, over time I was able to adjust to dialysis. My relationship with friends and family is even better." (P1).

"*Yes, the family is very supportive of doing dialysis, if I go through the dialysis time they will get annoyed. They said they are still enthusiastic about undergoing dialysis*" (P1).

"*My parents said I had to if I had to be patient*." (P4).

"*Usually I get a visit from the prayer team, my brother says to be patient, they seem to give advice, always asking me what I want to eat*" (P5).

"*My pastor always comes to visit to pray every Tuesday, Thursday, and Saturday*"(P7).

"*My family is very supportive ...they are very supportive ...currently I do dialysis routinely ...they say it's good ...dialysis is not scary*"(P9).

Furtherly, the instrument support sub-theme obtained by the participants is stated in the following quotations:

"*My father often took me to the hospital for dialysis. If my father doesn't have time, my brother usually replaces him*" (P4).

Fourth, the appreciation support obtained by the participants is stated in the following quotation:

"*Even though I was sick, many friends gave me encouragement, even my friends who were overseas were extraordinary, they did not leave me"(P5)*

"But coincidentally, there were two patients who gave support. So I said yes. The nurse also said keep the spirit, sir, there is no need to be afraid, the important thing is to come according to the schedule for dialysis, so I do it continuously, I see the hospital as my second home" (P7)

"By chance, my brother and family encourage me...must be strong" (P9)

This theme was formulated from the results of interviews with each participant

to determine the psychology condition of patients with chronic kidney failure. In this study, the eight participants expressed nearly identical feelings of worry about their health condition when they were declared to have kidney failure and had to undergo hemodialysis. Feelings of worry or anxiety are common neurobehavioral correlations of various stressors, and exposure to acute and chronic stress can trigger anxiety disorders (14). Meanwhile, anxiety is a clinical condition that requires treatment, mainly because of its association with mortality in end-stage renal disease patients and its negative impact on the perceived quality of life. Several participants in this study expressed their feelings of anxiety, fear, and frustration after being declared to suffer from chronic kidney failure and having to undergo hemodialysis. From the participant's statements, it can be implied that there is a fear of participants accepting changes in health status. Fears and worries occur in response to living with a chronic disease, or so-called “health anxiety” (15). This health anxiety has an impact on affective, cognitive, behavioral, perceptual, and especially emotional states such as fear of danger or health threats. This is supported in the by (16) who stated that treatment is urgently needed in renal failure patients who are dependent on hemodialysis or kidney transplantation, as hemodialysis is most often used due to insufficient kidney donors. During dialysis, several psychological conditions can occur in patients with kidney failure related to finances, depression, and anxiety, which are the most common and serious conditions. Furthermore, anxiety in patients with kidney failure is a comorbid psychological state that affects the patient's quality of life (17).

Based on the results obtained by researchers, six participants experienced the fear of death and thought that dialysis was the end of everything. Death is a life process that cannot be avoided for every individual (18); moreover, death anxiety generally occurs in advanced cancer patients associated with closely related psychological disorders such as depression, demoralization, and fear of worsening the disease (19). Death anxiety is a fear caused by a person's awareness of death and feelings of fear because they are not creatures. The results showed that death anxiety is closely related to physical and psychological conditions. In addition, chronic kidney failure can cause complications both physically, psychosocially, spiritually as well as affect the quality of life and reduce survival rates, thus triggering thoughts about death. Thinking too much about death can lead to death anxiety. This is supported by the results of a research, which reveals that individuals suffering from CKD with low socioeconomic status have less control over disease progression and experience death anxiety as well as existential stress (20).

From the results of this study, it was found that the participants received social support from family, health workers, and colleagues, family support includes providing motivation, financial assistance, and daily assistance that can be provided by other family members. The family is also a source of intrinsic motivation for self-care, as patients with chronic kidney failure express the desire to do dialysis in order to recover and survive their illness so they can see the success of their children (21). In addition, some patients rely on family members for moral support and assistance related to dialysis procedures. Patients also contact friends

who suffer from chronic kidney failure and have had experience with dialysis to obtain information about dialysis as well as to help improve the coping process and influence patients in making decisions about dialysis (22). However, family support can have both positive and negative effects on self-care. Family motivation includes support in the form of eating healthy food and nutritional intake as well as seeking or accessing medical care that affects the patient's self-care behaviors (23). Then, the negative effect of family support based on a study says that a patient reported they only use insulin when reminded by his sister and as a form of respect for his sister for giving him advice.

Furthermore, participants in this study continued with dialysis after receiving support from health workers. This statement is supported by research which states that 55% of patients chose dialysis even though the patient previously did not have a picture of what dialysis is and had never heard about dialysis because the patient thought it was irrelevant to consider the treatment as long as there were no clinical signs, but eventually the patient decided to do dialysis after receiving sufficient guidance from the nephrologist or nurse and support from relatives, which is the most important support. In addition, support from health workers in the form of information provided to patients by doctors about the development, prevention, and treatment of disease significantly increases positive self-care behavior (24). It is also showing the results of a research conducted in rural areas of Indonesia, where hypertensive patients were given information about reducing salty and sweet foods, as well as from the research, which explains that some patients received information about physical activity from the village midwife and ways to manage their illness.

Peer support has been used to improve joint decision-making regarding treatment in patients with kidney failure, cancer, and cardiovascular disease. Research showed that peer support has a good effect on the self-management of patients with chronic diseases, especially cancer, diabetes, hypertension, and other diseases. It can have a positive impact on patients with chronic diseases, it can influence decision-making by offering practical advice, sharing experiences and normalizing renal replacement therapy for people with kidney failure (25). Similar to the results of research, it is stated that peer support also appears to be a major source of support for some Indonesians living with chronic diseases in Indonesia. In one study (26), for example some patients cited experiences with patients living with similar conditions who shared information about symptoms and treatment with each other. Similar to the results of this study, one of the participants said "there are two patients who gave support, it's okay" if the disease is so, dialysis must be done". Likewise, in other studies, some male patients quit smoking on the advice of friends who also suffer from the same disease and have been advised by their doctors to stop smoking to lower their blood pressure (27).

Medication adherence, fluid restriction, dialysis sessions, and dietary restrictions in patients with chronic kidney failure were associated with social support. Therefore, social support is closely related to good health outcomes because chronic kidney failure patients can meet clinical requirements and make lifestyle changes. However, social support has a stronger influence on self-management behavior

than health literacy, for example, the support of health care providers has the greatest influence on patient self-management behavior (28). Participants show satisfaction with social support such as the availability of listeners, attention, information, friendships, and emotional support obtained from partners or girlfriends, friends, family members, health professionals, religious institutions, and others.

LIMITATIONS

The limitation of this study was some participants did not want to be interviewed because they experienced changes in conditions during and after dialysis such as fever and tightness.

RESEARCH ETHIC

To guarantee the ethical consideration for this study, research ethical approval from the Faculty of Public Health of Hasanuddin University in Indonesia was required, with the number 10330/UN4.14.1/TP.01.02/2022.
Anonymity, beneficence, justice, and no harm were practiced by researchers in the data-gathering process.

CONFLICT OF INTERST

There is no a conflict of interest.

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CONCLUSION

Patients with kidney failure feel worried, anxious, and even afraid to undergo dialysis, to the point of fearing they will of face death. Patients with chronic kidney failure also think that dialysis is the end of everything. However, although kidney failure patients have psychological burdens, support from family, colleagues, and health workers can balance the situation and ease the difficulties faced by patients. This research can be used to advise health workers and families that patient care is not only physical but the presence of family and health workers is needed to provide emotional support, information, instruments and appreciations. Furthermore, it takes a spiritual approach to strengthen resilience to the patient's condition.

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