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Dialysis Patients' and Families' Experiences in Preparing Food at Home

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Abstract *. Kidney failure is one of the diseases that increases every year and becomes a major health problem in the world, the occurrence of failure is a risk of heart and blood vessel disease and increases morbidity and mortality. The purpose of this study was to determine the experience of dialysis patients' families in helping to prepare food at home. The research method used was a qualitative descriptive study. The location of this study was carried out in the Hemodialysis Room of the Imelda Buruh Indonesia General Hospital, Medan . The time of this study conducted in March to July 2024. The number of participants in this study was 6 participants . Research data were collected through in-depth interviews with participants and analyzed thematically. The results of the study consisted of 3 (three) themes, namely: (1) Eating habits , (2) obstacles or challenges in preparing food, (3) family support for patients. The conclusion of this study is that all participants expressed that the eating patterns of patients with hemodialysis therapy showed normal eating patterns, but when hemodialysis was carried out, patients felt weak and their appetite decreased, but all patients still ate 3 times a day in small portions . Overall, participants provided strong support for patients, both moral support, material in efforts to provide patient food needs, reminding patients to eat regularly according to doctor's recommendations, and faithfully accompanying them during hemodialysis. Although obstacles and challenges were found from both patients and families in overall food management, they could be overcome.*

Keywords : Patient *Experience , Dialysis, Food*

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INTRODUCTION

Kidney failure is one of the diseases that increases every year and becomes a major health problem in the world, the occurrence of failure is a risk of heart and blood vessel disease and increases morbidity and mortality (Wiliyanarti & Muhith, 2019). According to the World Health Organization (WHO) (2019) explains that data on the incidence of kidney failure worldwide reaches 10% of the population, while kidney failure patients undergoing hemodialysis (HD) therapy are estimated at 1.5 million people worldwide. It is estimated that the incidence will increase by 8% each year (Kovesdy, 2022). The prevalence in the United States shows that up to 200,000 people per year experience HD. This means that 1,140 out of 1 million people undergo dialysis (Elisa, 2018). Since 2018, the number of hemodialysis patients in Indonesia has increased by 6,862 in 2017, 11,935 in 2018, 16,796 in 2019 and 78,281 in 2020. These data show that hemodialysis patients have increased significantly every year (Perinefri, 2018).

In Indonesia, the prevalence of chronic kidney failure based on a doctor's diagnosis was 0.38% in 2018. Data from Central Java shows that the prevalence of chronic kidney failure patients continues to increase from 0.2% in 2013 to 0.41% in 2018. Klaten Regency is one of the regencies in Central Java with a

prevalence of 0.1% (Ministry of Health, 2018). Data from the Indonesian Renal Registry (IRR) in 2019 showed that the number of hemodialysis patients in Central Java reached 1,075 new patients and 1,236 active patients. In 2020, data from the Klaten Islamic Hospital showed that 166 patients underwent routine hemodialysis, but this data increased to 191 patients in 2021. Hemodialysis by CKD patients continues to increase from year to year.). The prevalence of chronic kidney failure sufferers in Indonesia in 2018 was 132,142 people. The prevalence of chronic kidney failure sufferers in North Sumatra is 45,792 people (Riskesdas, 2018). and at the Imelda General Hospital in Medan as many as 247 in 2023. And undergoing hemodialysis therapy as many as 122 patients.

The causes of chronic kidney disease are hypertension in first place at 36%, diabetic nephropathy in second place at 29%, primary glomerulopathy 12%, chronic pyelonephritis/PNC 7%, obstructive nephropathy 4%, lupus/SLE nephropathy 1%, polycystic kidney 1%, uric acid nephropathy 1%, and unknown at 1%, and others 8%. Hemodialysis is still the main renal replacement therapy besides peritoneal dialysis and kidney transplantation in most countries in the world (Ministry of Health of the Republic of Indonesia, 2018). There are several complications of CKD, including anemia, calcium metabolism disorders, Metabolic Acidosis, malnutrition, Hyperkalemia (Lukela et al., 2019).

Chronic kidney failure is a condition where kidney function begins to decline progressively over months or even years. Generally, CKD arises from severe and permanent kidney damage (Keswari et al., 2019). Chronic kidney failure is closely related to the degenerative process as a result of damage to the function of body organs. Degenerative diseases associated with the increasing incidence of CKD include diabetes mellitus, hypertension, coronary heart disease, etc. In addition to degenerative diseases, CKD can also be caused by unhealthy lifestyles, culture and changes in socioeconomic status also have an impact on the increasing number of CKD diseases (Astuti et al., 2018).

Treatment for chronic kidney disease can be done with peritoneal dialysis, kidney transplantation, and hemodialysis. The most common treatment options for chronic kidney disease are hemodialysis and peritoneal dialysis and kidney transplantation (Junika et al., 2023). Globally, 80% of patients with end-stage chronic kidney disease undergo hemodialysis as a treatment (Saiednejad et al., 2018). Based on the Indonesian Renal Registry (IRR) in 2017, up to 98% of patients with chronic kidney disease received hemodialysis therapy and 2% received peritoneal dialysis (PD) therapy (Ministry of Health of the Republic of Indonesia, 2018).

Hemodialysis therapy is one of the therapies carried out to help the kidneys remove the end products of the body's metabolism because the kidneys cannot function due to damage to the nephrons which are the functional organs of the kidneys (Junika et al., 2023). Cho & Kang (2021) said that some patients require long-term kidney replacement, such as hemodialysis or continuous outpatient peritoneal dialysis, when kidney function deteriorates to stage 5 (end-stage kidney disease) to maintain life. Hemodialysis is carried out to remove metabolic waste or certain toxins from the human bloodstream, such as excess urea, creatinine, uric acid, and other substances through a semipermeable membrane. CKD (Chronic Kidney Disease) patients undergo hemodialysis two to three times a week, where each hemodialysis takes an average of four to five hours. Launching from (mayo clinic, 2022) there are several impacts of hemodialysis including Hypotension, Muscle cramps, itching, sleep problems, Anemia, bone density problems, excess fluid, Pericarditis, Amyloidosis (Reduced protein in the blood is stored in the joints causing joint pain), In patients undergoing hemodialysis therapy, dietary intervention plays an important role, a balanced diet is very much needed to stay fit when their kidneys are no longer functioning at full capacity. Compliance with fluid intake restrictions is very important for patients with chronic kidney failure because if you do not limit your

fluid intake it will cause edema, hypertension, left ventricular hypertrophy, and affect the patient's life expectancy, fluid will accumulate in the body (Junika et al., 2023).

Water entering the body is balanced with water coming out, either through urine or insensible water loss. In limiting fluid intake, fluid intake depends on urine output. Derived from insensible water loss plus 24-hour urine output which is allowed for patients with chronic kidney failure undergoing dialysis. Accumulation of fluid in the body causes the heart and lungs to work harder, which results in the patient's physical response to fatigue and shortness of breath, physical activity is also disrupted both during light and moderate activities (Darni & Sasmita, 2021).

LITERATURE REVIEW

1. Chronic Kidney Failure and Hemodialysis

Chronic kidney failure (CKF) is a condition of progressive decline in kidney function over a long period of time, causing a decrease in the kidney's ability to filter metabolic waste from the body (Keswari, 2019). Global data shows that the prevalence of CKF reaches 10% of the world's population, with cases increasing every year (Kovesdy, 2022). In Indonesia itself, CKF cases have also increased significantly, where the main causes of this disease are hypertension (36%) and diabetic nephropathy (29%) (Ministry of Health of the Republic of Indonesia, 2018).

Hemodialysis is the main therapy for end-stage CKD patients. Hemodialysis is performed to help the kidneys remove metabolic waste from the body such as urea, creatinine, and uric acid (Junika et al., 2023). CKD patients usually undergo hemodialysis therapy two to three times per week with a duration of four to five hours per session. Although it prolongs the patient's life expectancy, hemodialysis also carries various complications such as hypotension, muscle cramps, and sleep disorders (Mayo Clinic, 2022).

2. Hemodialysis Patient Diet Patterns

Diet is an important part of managing CKD patients undergoing hemodialysis. Patients are advised to consume high-protein foods to replace amino acid losses during the dialysis process, as well as to pay attention to limiting fluid intake to prevent complications such as edema and hypertension (Junika et al., 2023). Wina's (2020) study stated that dietary compliance greatly affects the quality of life of CKD patients.

Hemodialysis patients often experience decreased appetite which results in inadequate nutritional intake. This is caused by high levels of urea and creatinine in the blood which can stimulate excess stomach acid production, trigger nausea, vomiting, and stomach discomfort (Suharyanto & Madjid, 2013; Yunita, 2021). If this condition persists, patients are at risk of malnutrition which results in weight loss and poor quality of life (Permadani, 2022).

3. Family Obstacles in Preparing Patient Food

Food preparation for CKD patients undergoing hemodialysis requires special attention, both in the selection of food ingredients and how to process them. Financial limitations are a challenge in providing fresh food ingredients, such as fish, and in separating special menus for patients compared to other family members (Siagian, 2018).

In addition to economic factors, families also face obstacles in ensuring that patients adhere to a low-salt and low-fluid diet. Digestive disorders experienced by patients after dialysis, such as nausea and loss of appetite, also complicate dietary management (Rokhmah et al., 2017). Non-compliance with the diet can worsen the patient's health condition, increasing the risk of edema, hypertension, and shortness of breath (Pratiwi, 2019).

4. The Role of Family Support

Family support plays an important role in the success of hemodialysis therapy, especially in regulating diet and compliance with treatment. Hermawati's (2023) research shows a significant relationship between family support and dietary compliance in CKD patients. This support includes moral motivation, financial assistance, and assistance during the dialysis process.

The presence of the family helps ensure that the patient's nutritional needs are met according to medical recommendations, while also providing encouragement so that the patient continues to carry out light activities such as exercise and maintains his quality of life (Alhusaini et al., 2019). With the active role of the family, patients can be more regular in following a diet, taking medication, and attending hemodialysis sessions, thereby increasing the stability of their health condition.

METHODS

This type of research is descriptive qualitative with the aim of knowing the experiences of dialysis patients and their families in preparing food at home. The inclusion criteria in this study are: (a) Willing to participate in the study, (b) able to communicate well, (c) dialysis patients who have undergone treatment for at least 6 months, (d) family members who are actively involved in preparing food at home. Exclusion criteria: (a) Dialysis patients with treatment for less than 6 months, (b) families who are not directly involved in preparing food, (c) patients with decreased consciousness.

RESULTS

The results of the interviews in this study were conducted on 6 participants. The characteristics of the participants based on gender were 50% male and 50% female, based on age, the majority were over 35 years old as many as 4 people (66.7%), the majority of high school education as many as 3 people (50%), the majority of employees as many as 3 people (50%) and the duration of hemodialysis was 1 to 2 years. Can be seen in the table below.

Table 1 Demographic Characteristics of Participants

Participant No.	Gender	Age	Education	Work	Dialysis duration
1	Woman	45 Years	S1	civil servant	1 year
2	Woman	52 Years	S D	housewife	2 years
3	Man	37 Years	SENIOR HIGH SCHOOL	employee	1 year
4	Woman	25 years	SENIOR HIGH SCHOOL	housewife	2 years
5	Man	24 years old	SENIOR HIGH SCHOOL	employee	1 year
6	Man	47 years old	SD	employee	2 years

Based on the results of the interviews that were conducted, 3 themes were obtained, namely: (1) patient eating habits (2) obstacles or challenges in preparing food (3) family support for patients.

Theme 1: Eating habits
sub theme 1: Daily eating habits of dialysis patients
This was expressed by 6 participants, namely:
(P1) Regarding eating, it's normal, 3 times a day, nothing special, because there are no prohibitions. What is certain is that if you have an appetite, you will eat.
(P2, P6) Well, follow the doctor's advice, don't eat anything that's forbidden, it's just that sometimes you want to eat certain foods, we'll give you some, but it's still limited .
(P3) What's the pattern? For now it's normal, just don't use salt... without salt and flavoring... lahh
(P4) Yeah... it's called being sick, sometimes you have an appetite, sometimes you don't. , so if I don't have an appetite... I snack... for example sweet tea bread or anything that fits .
(P5) My eating pattern from the beginning...ohh at the beginning of dialysis it was very difficult to eat, my appetite was gone, but now it's normal, 3 times a day. For the diet, still follow the doctor's advice.

Theme 2: Obstacles or challenges in prepare food
Sub theme: patient and family strategies for preparing daily meals at home
This was expressed by 6 participants, namely:
(P1) There are no problems, it's just that because you're alone, of course you're not well looked after, especially if you've just finished dialysis , but you can prepare it yourself the next day .
there is none..because there is nothing too forbidden...always diligent in eating, this is not my mother but my sister..nee..I am from Jakarta. well..so the only challenge is my sister who has to prepare her own food

(P2) Yes, it's just like normal, but it's a little difficult to eat, but still eat 3x every day that's all...ehh it's hard to eat. then sometimes separate this food It's also troublesome...and we have to follow the doctor's advice regarding the pattern. eat for the good of mother .

(P3) there are no obstacles (mother) yes, it's money (patient laughing) because
buy special food for dad only. so the food must be separated with other families because the menu is also different, for example the fish special that is alive means fresh and challenging yes As a family, we must support in providing food that healthy and good for your health . Right..you have to choose to eat fresh fish..so it takes money .

(P4) There aren't any obstacles... it's just that... it's just difficult to eat.
the challenge... what is it... when he has just finished dialysis he doesn't want to eat, especially at night... because he feels weak and wants to sleep, but in the morning he eats again .
(P5) From the start, the problem is, salt, water, chili, whatever we mix into food, we have to differentiate it from other foods .

Well... that's what I said earlier, when preparing food it's always different from others, you can't use salt... spices, yeah... that's it .

(P6) When we are on dialysis, we are confused and feel weak. It is difficult to eat.
what should I do...ehhh, separate your father's meal from ours

Almost all participants said that there was no strategy for preparing food, they only reminded them to reduce salt, seasonings (P1, P2, P3, P4, P5) well...according to the doctor's advice. Moreover, hemodialysis patients can eat anything but there are limitations...that's all
(P6) Well... whatever... as long as you don't want to eat, let's try to have snacks... rather than not eating anything, right?

Theme 3. Family Support for Patients
Sub theme: Forms of family support for patients undergoing regular dialysis at the hospital

All participants expressed their feelings about the provision of support.

(P1) Yes... support only comes from me... my older brother is not married yet .
(P2 and P3) Well..always support...if you are a sick family, we will definitely encourage you, so when you are on dialysis we will accompany you.
(P4) Yes...family support is definitely needed, both in terms of energy, money, time and so on, encouraging people to eat a lot, not thinking too much...everything...
support for sure ,,

(P5) Family always support us, for our own good just follow the doctor's advice .

(P6) Yes, you have to be enthusiastic, follow the doctor's instructions, eat according to the rules, do light exercise such as walking in the morning. Especially we always remind you of the forbidden foods .

DISCUSSION

Theme 1: Patient's eating habits

Diet is a way or effort in regulating the amount and type of food with descriptive information including maintaining health, nutritional status, preventing or helping to cure diseases (Ministry of Health of the Republic of Indonesia, 2009). In patients undergoing hemodialysis therapy, dietary intervention plays an important role, a balanced diet is very much needed to stay fit when their kidneys are no longer functioning at full capacity. Compliance with fluid intake restrictions is very important for patients with chronic kidney failure because if fluid intake is not restricted it will result in edema, hypertension, left ventricular hypertrophy, and affect the patient's life expectancy, fluid will accumulate in the body (Junika et al., 2023).

Patients who require hemodialysis are patients who experience kidney failure. Prolonged hemodialysis can reduce the patient's enthusiasm for life, thus affecting the patient's compliance with dietary provisions. Uncontrolled intake of nutrients and fluids can be at risk of malnutrition and in more severe cases can cause death. In patients with chronic kidney failure, nutrition is important considering the adverse effects that occur if the diet does not meet their needs (Permadani. 2022). A chronic kidney disease diet with hemodialysis is a diet given to chronic kidney patients who receive kidney replacement therapy. In patients with hemodialysis, it is expected to consume foods that are sufficient in energy and consume foods high in protein to replace the loss of amino acids and other nutrients lost during the hemodialysis process. The results of a literature review show that dietary compliance affects the quality of life of patients with chronic kidney failure (Wina, 2020)

The results of the study showed that all participants shared their experiences In terms of eating habits, it is said to be normal . In general, they experience a decrease in appetite during dialysis, and the next day their eating patterns have returned to normal . This is caused by prolonged hemodialysis, gastric infection which results in an increase in amino acids in the stomach so that patients with chronic kidney failure experience a decrease in appetite and even significant weight loss (Suharyanto & Madjid, 2013). Zakiyah Aenurochmah's research (2022) stated that respondents who had a good diet.

Theme 2: Obstacles or challenges in preparing food

The obstacles faced by participants in fulfilling their nutritional needs include digestive disorders and changes in appetite . *This is in line with Siagian's research (2018) which states that some patients undergoing hemodialysis experience decreased appetite so that their eating frequency is irregular. Malnutrition is still a major problem in patients*

undergoing hemodialysis therapy so that it can cause poor nutritional status which is a predictor of death in patients with Chronic Kidney Disease (CKD). The imbalance of nutrients in CKD patients requires knowledge about things that can affect the nutritional status of hemodialysis patients . Gastrointestinal disorders in patients with chronic kidney disease are also caused by slow emptying and impaired myoelectric activity in the stomach (Rokhmahet al., 2017). So the less appetite the patient has, the more their nutritional status will decrease.

The results of Yunita's study (2021) stated that appetite and nutritional status showed a significant relationship, meaning that if appetite decreases, it can worsen the patient's condition due to lack of nutritional intake. Due to high levels of urea and creatinine in the blood of patients undergoing HD, it can stimulate the production of stomach acid, causing complaints of nausea, vomiting, heartburn and bloating. If this is felt by the patient, it will result in the patient being lazy to eat and will cause an uncomfortable feeling in the patient's stomach, which will cause the patient to refuse to eat or be unable to finish the amount of food served .

The results of the study showed that there were HD patients who experienced weight loss due to loss of appetite (participant 2). Overall , other participants expressed the same thing, namely changes in appetite after HD , including nausea, weakness throughout the body, and discomfort in the stomach. Over time, this condition gradually good appetite also increases. Due to the high levels of urea and creatinine in the blood of patients undergoing HD, it can stimulate the production of stomach acid, causing complaints of nausea, vomiting, heartburn and bloating. If this is felt by the patient, it will result in the patient being lazy to eat and will cause an uncomfortable feeling in the patient's stomach so that it will cause the patient to refuse to eat or be unable to finish a number of foods served. In addition, there are also complaints about finances considering the needs of patients who need special foods such as fresh fish, and must differentiate the patient's food from other families (participant 4)

One of the major challenges that can cause hemodialysis failure is patient compliance in undergoing a diet as recommended. Nutritional knowledge is one factor in the formation of dietary compliance behavior. Prolonged *hemodialysis can reduce the patient's enthusiasm for life* , thus affecting the patient's compliance with dietary provisions .

Pratiwi's research (2019) states that hemodialysis patient compliance is still lacking in regulating food and fluid intake. Non-compliance of hemodialysis patients in carrying out fluid and diet management can have a negative impact on the patient's health condition, including increasing blood pressure (Marsenic, Anderson, & Couloures, 2016). If hemodialysis patients cannot control fluid and diet intake, it will worsen edema, shortness of breath, itching and other symptoms.

The results of the study revealed that all participants had difficulty determining the right portion and type of food for patients, considering their weakened condition and decreased appetite. So it was found that patients who did not comply with the doctor's advice always ate according to their taste without considering their condition. Another challenge was that there were patients who were not yet married and only had one sibling (younger sibling) who lived in Jakarta . This made it very difficult for patients to manage their food (Participant 1) but overall the participants only complained about how to prepare the right food so that patients would eat both during and after hemodialysis.

Theme 3: Family Support With Patients

Family support is very necessary for recovery and maintaining the health status of patients. HD patients are very vulnerable to losing their jobs due to physical or time problems, the majority of chronic kidney failure patients do not work, and for patients on hemodialysis never return to their original activities and only depend on their families. Family support can affect dietary compliance in chronic kidney failure patients undergoing hemodialysis. The better the family support a patient has, the more compliant the patient will be in undergoing their

diet. Patients undergoing routine hemodialysis will experience malnutrition due to inadequate protein intake, low levels of albumin in the blood, gastrointestinal disorders such as nausea, vomiting, and decreased appetite. Therefore, dietary compliance is very necessary to overcome the problem of malnutrition in hemodialysis patients.

For the arrangement of patient food, the role of the family is needed so that the food served is sufficient energy and consumes high-protein foods to replace the loss of amino acids and other nutrients lost during the hemodialysis process. Diet recommendations are based on the frequency of dialysis, remaining kidney function, and body size. *Hermawati's research* (2023, shows that there is a significant and very strong relationship between family support and the right diet. The results of Alhusainidkk's research., (Alhusaini et al., 2019) that patients undergoing hemodialysis therapy are able to maintain more active social interactions and social support, with a good response so that patients are able to feel optimal physical health.

The results of the study revealed that participants felt that their families helped prepare all forms of patient needs. Overall, participants said that their families reminded patients not to be too tired, and there was a prohibition that participants should not be alone in doing their activities. The results of other patient studies also revealed that their families accompanied participants while undergoing hemodialysis therapy, and some provided material and moral support even though they went back and forth to the hospital for HD.

CONCLUSION

After conducting research on the experiences of patients and families in preparing food at home, the following conclusions were obtained: All participants stated that the eating patterns of patients with hemodialysis therapy showed normal eating patterns, but when hemodialysis was performed , patients felt weak and their appetite decreased, but all patients still ate 3 times a day in small portions. Overall, participants provided strong support for patients, both moral support and material support in efforts to provide patient food needs. Reminding patients to eat regularly according to doctor's recommendations and faithfully accompanying them during hemodialysis. Although obstacles and challenges were found from both patients and families in overall food management, they could be overcome. This means that eating patterns, obstacles and challenges, support and strategies for providing food during hemodialysis therapy until this study was carried out well.

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