

ORIGINAL RESEARCH

The Fluid Management Experience in Patients with Chronic Kidney Disease Undergoing Hemodialysis in Indonesia: A Qualitative Study



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Abstract

Background: Fluid management can reduce mortality, severe comorbidities, and debilitating symptoms in patients on hemodialysis. Therefore, a restricted fluid intake plan is crucial for patients with chronic kidney disease (CKD). Little evidence has been found to date on exploring the experience in fluid management of CKD patients in Indonesia.

Purpose: This study aimed to explore the fluid management experience of adults with chronic kidney disease participating in hemodialysis treatment in Indonesia.

Methods: A qualitative study with a phenomenological approach was conducted. Purposive sampling was used to recruit 14 adults patients with CKD undergoing hemodialysis in a tertiary hospital in Padang between July and September 2020. Manual content analysis using the Colaizzi approach was used to identify themes.

Results: Data analysis revealed four themes with 12 sub-themes. The four major themes include the challenge of thirst control, fluid/diet restriction management, inadequate information, and the support system.

Conclusion: The result showed the severe suffering and sadness experienced by CKD patients who conform to fluid restrictions. It is important to provide clear information on the fluid prescription or the exact consumable amount per day. Structured education with a personal approach is recommended to ensure detailed information regarding "fluid prescribing". The support obtained from family, friends, and dialysis staff is a significant factor in promoting acceptance and adherence.

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1. Introduction

Chronic kidney disease (CKD) is a complex condition in which the kidneys are unable to function properly as a result of structural or functional damage that leads to excessive fluid and waste accumulation in the blood (Thomas, 2019). Nowadays, the prevalence of CKD is rising significantly. The estimated number of affected people ranges from 11% to 13% globally (Hill et al., 2016). Indonesia is characterized by a high incidence rate of chronic kidney disease, alongside a steadily increasing number of people participating in hemodialysis yearly. The Indonesian Renal Registry (IRR) reported 77,892 active hemodialysis users in 2017, which significantly increased to 132,142 in 2018, where 66,433 new patients were recorded at the end of 2017 alone. In 2019, the number increased to 185,901 with new patients of 69,124. Moreover, West Sumatra is amongst the top 5 Provinces with the highest number of patients in 2018, with 1,334 patients actively participating in hemodialysis therapy (Indonesian Renal Registry, 2018).

Food and fluid intake restrictions have been identified as the most frequent stressor expressed by chronic kidney disease patients with hemodialysis (Hong et al., 2017). Also, the fluid restriction was considered to be the most difficult, due to the persistent feeling of thirst (Nazly et al., 2013), especially after ingesting drugs with the capacity to dry out the mucous membrane, e.g., diuretics. At the intrapersonal level, the most frequently discussed barrier to fluid restriction adherence was physiological symptoms, such as thirst and dry mouth (Lee et al., 2020). Moreover, food intake also elevates sodium, causes thirst, and influences water intake, leading to interdialytic weight gain (Maimani et al., 2021). Therefore, dietary regulation is also a critical aspect to consider while limiting patient fluid intake (Thomas, 2019).

The success of CKD treatment is highly dependent on the patient following the recommended fluid restriction and diet. The patient's ability to manage fluid restriction is related to the patient's knowledge, ability, and willingness to manage their own health care. It is related to interventions that encourage positive adherence behavior (Carman et al., 2013). Patients committed to fluid restriction have been shown to have fewer hospitalizations, lower morbidity, improved survival and better clinical outcomes (Carman et al., 2013). Therefore, patient commitment to fluid and dietary restriction is essential to improve poor adherence among CKD patients (Theofilou, 2013).

However, CKD patients' compliance to fluid restriction is still low. The previous research showed that none of the participants achieved high levels of engagement with fluid restriction. Eleven percent (11%) had moderate levels and the majority (88.9%) had low levels of engagement with fluid restriction (Chironda & Bhengu, 2016). Many factors influence patients' adherence to the therapy, including patient-related factors, such as patients demographics, physical and mental function, disease and treatment perception, and disease-related factors such as laboratory parameters, comorbidities, and the stage of chronic kidney disease (Seng et al., 2020). Some of the reasons for unsuccessful management of the hemodialysis treatment regimen include poor attendance, itching, uncontrolled glucose, catheter infections, work, holidays, and weekends (Ford-Anderson, 2011). However, non-adherence has been implicated in increased interdialytic weight gain (IDWG), and excessive IDWG has been linked with unfavorable clinical consequences and is considered an independent predictor of all-cause and cardiovascular mortality in patients undergoing long-term HD (Lindberg, 2010; Maimani et al., 2021). Patient non-adherence to fluid restriction also contributes to severe complications, including intradialytic cramping and episodes of hypotension, medication-related fatigue, and dizziness, lower extremity edema, ascites, left ventricular hypertrophy, and congestive heart failure, hypertension, shortness of breath, and pulmonary vascular congestion or acute lung edema (Lindberg, 2010).

The act of proper dieting and limiting fluid intake reduces patient complaints, especially for those with depression potentials (Cox et al., 2017). Therefore, a restricted fluid intake plan is crucial for patients with chronic kidney disease. Systematic review of qualitative studies by Palmer et al. (2015) showed significant confusion between nutritionists and nurses on the hemodialysis unit's fluid prescriptions. This makes most patients make personal dietary decisions undermining the recommendation. Dietary limitations and a lack of credible dietetic advice frustrate patients with CKD who want to take a proactive approach to preventing CKD progression and maintaining their health (Kelly et al., 2017).

CKD patients often use multiple coping strategies. A study showed that various factors such as treatment modality, time since diagnosis, presence of other chronic comorbidities, and self-perceived limitations contribute to types of coping strategies used by CKD patients (Subramanian et al., 2017). Although some patients have self-management strategies to "take control" of their own symptom management to improve their quality of life, such as managing fluid and dietary restrictions, managing fatigue, and managing depression, adherence to fluid intake limitation is significant to reduce complaints (Cox et al., 2017).

Several studies have revealed numerous strategies for overcoming thirsts, such as sucking on frozen gauze, ice cubes, gargling with menthol liquid, chewing gum, acupressure, using a thin straw, or saliva substitutes (Garcia et al., 2016; Yang et al., 2010). However, success is influenced by several factors, including respondent characteristics, demographics, patient habits, and culture (Garcia et al., 2016). Previous research revealed that patients' perspectives regarding the management of fluid restriction in chronic hemodialysis were diverse and were likely influenced by various patient characteristics, including their experience with hemodialysis. Having good knowledge with accurate self-assessment and positive psychological factors were also described as having a beneficial role for adherence for fluid restriction. Social networks such as family and friends, dialysis providers, and peers sometimes facilitated and sometimes were barriers to attaining fluid restriction goals (Smith et al., 2010). By considering these patient perspectives on the importance of issues in the management of fluid restriction, we hope to guide future interventions to be patient-centered and culturally sensitive.

On the other hand, Indonesia is a tropical country, especially Padang, West Sumatra province, which is located on the coast. The tropical climate in Indonesia poses a challenge for chronic kidney disease patients expecting to limit fluid intake. Previous research has also shown

the contributory role of season or weather in fluid restriction (Thomas, 2019). Patients predominantly from the Minangkabau ethnicity tend to like spicy and salty dishes. This also causes increased thirst and high fluid intake. Therefore, it is required to explore fluid management experience in CKD patients in Padang, Indonesia. Also, to the author's knowledge, no study to date has focused on exploring experiences of CKD patients in fluid management in Indonesia. Therefore, the purpose of this study was to explore fluid management experiences of chronic kidney disease patients participating in hemodialysis therapy in Indonesia.

2. Methods

2.1 Research design

A qualitative study with a phenomenological approach was conducted, where this method was used to obtain firsthand experience on fluid management from chronic kidney disease patients participating in hemodialysis therapy. This phenomenological approach describes a person's knowledge structure and attempts to capture the main themes and the individual's interpretation. Therefore, in-depth information is obtained regarding this phenomenon, and an opportunity is also provided for patients to freely express feelings about their fluid management experiences (Creswell & Poth, 2016).

2.2 Setting and samples

In phenomenological studies, it is important that all participants experience the phenomenon being studied (Creswell & Poth, 2016). Thus, a purposive sampling strategy was used to recruit participants. The CKD patients undergoing hemodialysis were recruited from the hemodialysis units of one public hospital in Padang, West Sumatra, Indonesia. The inclusion criteria included: (1) patient age ≥ 18 years, (2) chronic kidney disease patients undergoing hemodialysis for over six months, (3) able to narrate personal experiences, (4) willing to be interviewed, (5) and capable of speaking Indonesian or Minangkabau language. The researchers approached and delivered information to the head nurses at the research location about the objectives and the research procedures. The researchers asked them for help to obtain data on patients in their units to identify potential participants. Together with the head nurses, the researchers identified potential patients as participants based on the established inclusion criteria. Recruitment was ceased when data saturation was reached (Creswell & Poth, 2016). The total participants were 14 patients.

2.3 Data collection

This study was conducted between July and September 2020 by first and second researchers. Semi-structure interview guides were used to explore the experiences and perceptions of participants. The interview guidelines were made based on theory of fluid and diet restrictions on CKD patients (Daugirdas et al., 2015). The interview venues were selected to suit the participants' preferences, whether during the hemodialysis process or while in the hospital waiting room. All patients were recruited during the treatment time, approximately 30 minutes after the commencement of the hemodialysis. On average, each in-depth interview lasted for 30 to 60 minutes. Participants might answer questions using Indonesian or Minang language. The interview guide was developed from three open-ended questions, "Tell us your experience with limiting fluid intake?", "How do you deal with thirst?", and "How do you avoid foods with high fluid content?". Probing questions such as: "Please, can you give some examples on how you deal with these feelings ...?", and "what were your actions?" were also asked to elicit more information about their experiences and the significance attached to those experiences. Other probing questions were dependent on the flow from the participant's narrations. However, the interview was recorded with an audio-recorder and directly transcribed verbatim by the first and second researcher. Data saturation was confirmed when there were no new codes found to culminate into properties of another theme for the experience of fluid management in the subsequent in-depth interview sessions (Mason, 2010) after the number of 14 participants.

2.4 Data analysis

Each audio-recorded interview was transcribed verbatim within 24 hours after the interview to avoid any recall biases and begin the initial data analysis process, which used thematic

analysis with the Colaizzi approach. All data processes were handled manually by first and second researcher. Furthermore, the following steps were involved: (1) Reading and copying all interview descriptions disclosed by participants, (2) Extracting significant statements (directly related to the phenomenon under investigation), (3) Describing the respective meaning, (4) Combining the denotations into groups and themes, (5) Developing a complete theme description (a comprehensive depiction of participant's experiences of fluid management), (6) Identifying the structural basis of the phenomenon, and (7) finally, returning the findings to the participants for validation (Creswell & Poth, 2016). The example of theme developing process for the second theme can be seen from Table 1. At the final validation, the data verification was sought through co-researcher validation and sharing the findings with the participants to verify that these findings reflected the participants' actual meaning. For publication, the transcripts were translated into English from the original Indonesian.

Table 1. Example of theme developing process

Significant Statement	Category	Sub-Theme	Theme
<p>"I take a medium-high glass in the morning, and a little after eating before taking the prescribed medication with a sip. Also, I take another during lunch only when eating. However, what important is achieving a wet throat."</p> <p>"I only drink when ready to eat and after ingesting the medicine. The collective quantity is often a bottle during the day and one at night, accumulating to 600 ml."</p>	<p>Drink after eating and ingesting medicine</p>	<p>Set drinking time/schedule</p>	<p>Fluid/diet restriction management</p>
<p>"Warm water effectively eases my thirst and makes the stomach feel good."</p> <p>"I have a preference for chilled water; hence I freeze frequently and drink the melted content in little bits."</p>	<p>Drink warm or chilled water</p>	<p>Modifying the temperature of the drink</p>	

2.5 Rigor and trustworthiness

The credibility, dependability, confirmability, and transferability criteria were used to attain trustworthiness in this study (Polit & Beck, 2008). Triangulation and member check were used to provide high data trustworthiness for the study's findings. Data source triangulation was achieved by comparing the interview results with three nursing staffs and four patients' relatives/ caregivers, direct observations, and field notes. To determine the acceptability of the data gathered from participants, the interview findings were sent to all participants in the form of transcripts. Participants were asked to provide their feedback resulting in that all the participants agreed with the transcripts. It was also done to validate the results, as it is the most critical technique to establish credibility and allow participants to reflect on experiences (Mays & Pope, 2020). The dependability in this study was maintained by involving an expert in qualitative research to audit and analyze a series of research processes. Confirmability was done by debriefing the study results with all research team to ensure that there was no bias in analyzing and developing the themes. All researchers were agreed with all findings. Finally, the researchers tested transferability by summarizing the study's findings and then providing a narrative explanation of the interview results. It was done to help readers clearly understand the results of the research, and could use and apply the results of the study elsewhere.

2.6 Ethical considerations

The data collection process commenced after ethical clearance was obtained from the Health Research Ethics Commission with a reference number of 209/KEPK/2020. This research was in line with the principles stipulated in the Declaration of Helsinki (World Medical Association, 2013). The participants were contacted according to the predetermined criteria, and study objectives were explained. Therefore, content containing information related to the research was provided after obtaining patient consent, which explained the research objectives, procedures, discomfort, risks, benefits, and expectations. The study was performed following

the hospital's health protocols. The transcribed data were saved in a password-protected parent folder in a Microsoft Word document that was anonymized and pseudonymized. Folders in use were kept safe, while anonymity ensured that none of the participants would be linked to their narrated stories. Only the researchers were privy to the data of this study.

3. Results

3.1 Characteristics of the participants

The characteristics of participants are described in Table 2. The participants consisted of 7 women (50%) and 7 men (50%). Most of them were 46-60 years old (57.1%), bachelor's degree (35.7%), married (78.6%), not employed (57%), and 1-3 years undergoing hemodialysis (50%). All participants were Minang ethnicity.

Table 2. Characteristics of participants

Characteristics of participants	f	%
Age (years)		
26-45	5	35.7
46-60	8	57.1
>60	1	7.1
Gender		
Male	7	50
Female	7	50
Ethnicity		
Minang	14	100
Education		
Elementary school	1	7.1
Junior High School	4	28.6
Senior High School	4	28.6
Bachelor's degree	5	35.7
Marital Status		
Married	11	78.6
Separated or divorced	2	14.3
Single	1	7.1
Employment Status		
Full time	4	28.6
Part-time	2	14.2
Not employed	8	57
Duration of Hemodialysis therapy		
<1 years	3	21.4
1-3 years	7	50
>3 years	4	28.6

3.2 Fluid management experiences

Data analysis revealed four themes and 12 sub-themes that showed patients' experiences managing fluid for adults with CKD undergoing hemodialysis. The challenge of controlling thirst control, managing dietary/fluid limitations, inadequate information, and social support were four main themes extracted from the data. Table 3 illustrates the themes and sub-themes.

3.2.1 The challenges of thirst control

A majority of the participants acknowledged being tormented by the fluid's limitations. This was due to the inevitable thirst experienced during numerous activities, weather conditions, and the inner desire to drink. The challenges in controlling the thirst include feeling torture of thirsty and combating bodily need for hydration.

3.2.1.1 Feeling torture of thirsty

Participants stated that holding back the craving to drink water was identified as the most excruciating part of chronic kidney disease. This experience was highlighted from the participants' statements:

“Holding back from drinking water is the most challenging aspect. This has made me contrive various tips, including buying small drinking bottles to limit my intake. However, I eventually tend to drink repeatedly.” (P11, female, 31 years)

Table 3. The developed thematic map of experience on fluid restriction

Theme	Sub-theme
The challenge of thirst control	Feeling torture of thirsty Combating bodily need for hydration
Fluid/diet restriction management	Setting drinking time/schedule Modifying the temperature of the drink Distraction technique Healthy eating for CKD Management of edema
Inadequate information	Unspecific fluid prescription Inaccurate perception/ Misconceptions
The support system	Family as source of strength Peer support Professional advice

Moreover, other participants also stipulated similar torturous events, with the following statement excerpts:

“... but it is tough to avoid water. This thirst is highly torturous ...” (P14, female, 57 years)

3.2.1.2 Combating bodily need for hydration

Increased fluid intake is also associated with outdoor activities. Some participants also insinuated the impact of hot weather as a reason for the thirst as observed with the following statements:

“...I barely become thirsty at home because I predominantly relax and sleep, except I am involved in outdoor activities. However, it is difficult to hold thirst on occasions involving relatively high activities.” (P13, female, 52 years).

“The weather around my home is scorching. This makes it difficult to ignore thirst.” (P7, male, 63 years).

These conditions, as stated above, were implicated to increased thirst, and the individual's body needs to lead to an increased demand for fluids.

3.2.2 Fluid/ diet restriction management

The present theme is further explained as five sub-themes of setting drinking time/schedule, modifying the temperature of the drink, distraction technique, healthy eating for CKD, and management of edema.

3.2.2.1 Setting drinking time/schedule

All participants attempted to set drinking time/schedule to limit the daily fluid intake, based on the following statements:

“I take a medium-high glass in the morning and a little after eating before taking the prescribed medication with a sip. Also, I take another during lunch only when eating. However, what is important is achieving a wet throat.” (P8, female, 55 years).

“I only drink when ready to eat, and after ingesting the medicine. The collective quantity is often a bottle during the day and one at night, cumulated to 600 ml.” (P10, female, 58 years).

3.2.2.2 Modifying the temperature of the drink

The drinking water temperature of most participants was purposely modified to speed up thirst reduction. However, a warmer variant was preferred, based on the following statements:

“Warm water effectively eases my thirst and makes the stomach feel good...” (P1, male, 32 years).

Conversely, some participants preferred using cold water or ice cubes.

“I have a preference for chilled water, hence, I freeze frequently and drink the melted content in little bits.” (P11, female, 31 years)

3.2.2.3 Distraction technique

Some participants adopt the distraction technique to reduce thirst. A total of two participants actively participated in Muslim worship activities with the Sunnah fasting on Monday and Thursday. Moreover, some other respondents took showers or rested in an air conditioner room as a form of distraction.

“Therefore, I participate in blood dialysis on Tuesday and Friday. Most times, I am doing Sunnah fasting three days after Friday ‘s HD (hemodialysis) to Tuesday because I feel too heavy from excess drinking on Monday. This is one way to avoid gaining additional weight and is followed by having a little drink after breaking the fast.” (P10, female, 58 years).

“... I anticipate taking frequent baths before prayer time as a means to reduce drinking or fluid intake. This approach is helpful because of the hot weather in my residential area, which increases thirst. Also, my children put on the air conditioner in my bedroom to help me rest appropriately while sleeping, avoid overheating and dehydration.” (P7, male, 63 years).

3.2.2.4 Healthy eating for CKD

All participants acknowledged the types of foods to be avoided by patients with chronic kidney disease. Some participants also ingested superfoods/multivitamins to increase endurance and stamina, in addition to the vitamins prescribed at the hospital. These are evidenced by the statements:

“...I avoid eating fruits with high water and potassium content; hence I only consume papaya. (P12, female, 38 years).

“I drink honey mix with water and also consume tea imported from abroad (Regina tea), termed ‘the Bunga’, for improved appetite. Furthermore, I cut garlic into pieces and soak them in water to achieve a black color before adding sugar and drinking. Also, I eat Habatussaudah, a lot of fish oil, including those from Kling, aqufish or fishqua.” (P3, male, 58 years).

3.2.2.5 Management of edema

Body edema was one of the significant challenges that participants experienced after consuming excess fluid from food or drink. This manifestation predominantly occurs in the extremities and on the face, based on the statements:

“...I pay attention when my legs become swollen, particularly after exceeding the stipulated drinking limit. Also, the sensation of cramps at the feet is imminent after taking excess liquid during hemodialysis.” (P13, female, 53 years).

Edema management required certain activities, including the regulation of daily fluid intake, performing sweat emission-related activities, including walking, and sunbathing. Also, the participants reported managing fluid by regulating the intake, as stated in the following statements:

“...I also like to sunbathe in the morning, and possibly take a walk to sweat out the fluid.” (P3, male, 58 years).

“... I tend not to drink in the absence of thirst and when the tongue is not dry, but only when eating. At this point, just one bottle (pointing to 1 330 ml bottle of aqua) is sufficient all through to the night, especially on days when I did not run out.” (P9, male, 33 years).

3.2.3 Inadequate information

All participants acclaimed to have been provided with education by doctors and nurses upon diagnosis. The information shared was based on foods to be avoided, fluid intake limitation, and the potential impact of non-adherence. However, the knowledge shared by dialysis staff was not detailed, as doctors and nurses stipulate the need to reduce fluid intake. The present theme is further explained as two sub-themes of unspecific fluid prescription and inaccurate perceptions/ misconception.

3.2.3.1 Unspecific fluid prescription

The participants reported that the clinicians do not inform in detail the quantity to be reduced or consumed per day. This decision is left to the respondent's discretion, as stated below:

“... There is no detailed explanation stipulating the amount of liquid to be taken, as the health care provider simply asks the respondents to drink less. This is particularly the case after I gain much weight.” (P5, male 54 years)

“.. In the beginning, the clinicians said to me to limit fluid consumption, so, I must drink a little, as well as fruits such as bananas, but the amount is not conveyed...” (P11, female ,31 years)

Based on the choice of fluid, participants often objectively estimate a personal dose, as indicated by the following responses:

“... I estimate my fluid intake by monitoring the tendency for swellings.” (P5, male 54 years).

“...We develop personal limits by self-evaluation for body comfort. Therefore, this is the quantity I can afford daily (pointing to a 330ml aqua bottle).” (P9, male, 33 years).

3.2.3.2 Inaccurate perception/ Misconception

Most participants had an inaccurate perception in interpreting the body symptoms due to inadequate education. In addition, one of the participants assumed it is alright to eat and drink at will on the day before hemodialysis therapy. This was because of the misconception that the fluids and toxins from food are expected to be filtered out during the treatment, as observed with the following statement:

“... I usually drink one 600 ml bottle of aqua a day. However, I consume as much and as possible on the days before scheduled dialysis because I expect the fluids and toxins to be sucked out when dialyzed.” (P11, female, 31 years).

3.2.4 The support system

This critical theme that emerged from the interviews reflects another dimension of participants' support from family, peer, and professional advice.

3.2.4.1 Family as source of strength

The support from family members, including husband/wife, and children had a significant impact on participants during hemodialysis, as stated below:

“... My child always reminded me not to drink excess water. This activity helps in maintaining my weight gain at 1kg between dialysis. However, a rise by 2kg is possible in some instances, therefore making the range of 1-2kg.” (P14, female, 57 years)

“... my wife is very kind, as she is always there somehow in my life to remind me not to drink too much, also to eat healthily...” (P5, male, 54 years).

3.2.4.2 Peer support

Participants also acknowledged the support and attention received from friends in the hemodialysis unit, sharing knowledge on how to limit fluid intake, based on the following statements:

“... when I gain about 4 kg, Yaya (her name) ... monitor this appetite and drink, or you become bigger... joking.” (P11, female, 31 years)

“...my friend said when he was thirsty, he tried to divert to other activities such as chatting with friends, watching television, or take a bath, he thinks it works.” (P9, male, 33 years).

3.2.4.3 Professional advice

The participants reported that they receive supports from dialysis staffs like nurses, doctors, and technicians, based on the following statements:

“The nurses tend to admonish me, saying, you should not drink a lot... drink less, or you become tight, you know ...” (P11, female, 31 years)

“...when the doctor visits, he always said to limit fluid intake and organize my diet intake because my interdialytic weight gain always over 3 kg, and I have edema in my leg.” (P5, male, 54 years)

4. Discussion

This study aimed to explore the fluid management experience of adults with chronic kidney disease participating in hemodialysis treatment in Indonesia. The study resulted in four major themes of participant's experiences in the fluid management. They were the challenge of thirst control, fluid/diet restriction management, inadequate information, and the support system.

4.1 The challenge of thirst control

The result of the research showed that majority participants stated that they feel tortured of thirsty suffered from fluid restriction. Thirst or dry mouth is one of the most frequently occurring symptoms in hemodialysis (HD) patients. A study reports that patients CKD reported a widely varying range of thirst intensity, with the majority of subjects having a moderate intensity of thirst. A half of the participants (52.4%) reported that their felt thirsty all the time. Most of the subjects (82.1%) used drinking to reduce their feeling of thirst, 14.3% subjects used other methods to reduce thirst symptoms, such as chewing gum, and 3.6% ignored the feeling of thirst (Yang et al., 2010). The unavoidable thirst due to many activities, weather conditions, and the desire from within to meet fluid needs, encourages participants wanting to drink. The challenges faced by participants are different, depending on the activities that the participants are doing. Therefore, patients tend to feel more suffering and possibly lose control (Stevenson et al., 2018). Thirst control is the most challenging aspect for patients compared to restrictions in terms of diet and other micro-nutrients (Nerbass et al., 2017). A previous study also reported that the contexts of physical discomfort in CKD patients are immobility, hypotension, pain, hunger, cramp, tiredness, polyuria, itching, edema, thirst (Freire et al., 2020). The adherence to fluid intake limitations is a priority in the nursing intervention (Lucena et al., 2018), and non-compliance from patients is influenced by several factors. These include dry mouth conditions, the need to drink while taking medications, the numerous activities performed outside the room, and the hot weather implicated in extreme thirst (Sarkar et al., 2006).

4.2 Fluid/diet restriction management

The results of this study confirm that proper management of fluid is essential for patients with chronic kidney disease. Patients who are committed to fluid restriction have been shown to have fewer hospitalizations, lower morbidity, improved survival and better clinical outcomes (Carman et al., 2013). However, restriction fluid is the main difficulties reported by patients (Carman et al., 2013; Nazly et al., 2013). Food and fluid intake restrictions have been identified as the most frequent stressor expressed by chronic kidney disease patients with hemodialysis (Hong et al., 2017). Moreover, dialysis is an intervention designed to regulate salt, to remove fluid (ultrafiltration, sodium dialysate), and to limit the intake between each session. Also, proper hemodynamic management is a significant component of an adequate patient dialysis program (Canaud et al., 2019). The study results are congruent with a study by Chiaranai (2016) regarding patients' experiences of obtaining treatment and expecting to live with certain limitations and dependence on medical technology. Therefore, survival in this stressful situation is likely to the severity of end-stage cancer (Cho & Shin, 2016).

The hemodialysis patients are also encouraged to reduce fluid intake to control potential interdialytic weight gain (Birute et al., 2017). This manifestation is associated with higher mortality risk (Rhee et al., 2018). Dialysis prescription has a direct impact on IDWG. This includes adequate UF, sodium profiling, and dialysis time. The use of oral diuretics can be of value in patients on regular HD with residual urine output (Maimani et al., 2021). This concept is not widely understood by patients, as inadequate information regarding the fluid prescriptions and patient ignorance towards the agreed policies have led to the practice of individual determinations at will (Dasgupta et al., 2016).

The patients usually can drink 500 ml of fluids plus the diuresis volume, meaning that anuric patients have more difficulty to manage their thirst. Poor management of fluid restriction can cause high interdialytic weight gain (IWG), resulting in increased cardiovascular mortality and morbidity (Theofilou, 2013). The National Kidney Foundation has stipulated five methods to promote compliance with fluid limitations, including engaging in fluid intake calculations, providing specific education / individual fluid prescriptions, managing thirst, limiting excessive sodium intake, and administering dialysis regimens (Bs et al., 2017). Bossola et al. (2020) stated that strategies to reduce thirst on patient with chronic hemodialysis, consist of reduction of dietary salt intake, improvement of xerostomia, use of low dialysate sodium concentration, drugs that target angiotensin II, and other treatments (drinking cold water or dissolving ice chips in mouth may alleviate thirst). The challenges with hemodialysis diet management are usually observed in low self-efficacy in sodium restrictions (Clark-Cutaia et al., 2014).

Therefore, patients in this current study made several arrangements to manage fluid intake and ensured a healthy diet. These include some activities to reduce thirst, control diet and play an essential role in facilitating survival. Also, the possible complication of excess fluid, such as edema is reduced. All participants set a drinking schedule (after eating and while taking tablets) and apply temperature modification to drinks/food (warm or cold water, ice, eating frozen fruit). The participants also prepared individual diets according to the kidney demands by avoiding foods rich in potassium, high salt content and encouraging multivitamin consumption. These dietary plans instruct patients to regulate fruits, vegetables, legumes, dairy products, and whole grains due to the possibility of developing phosphorus and potassium-related problems (Birute et al., 2017). Furthermore, some participants adopted distraction techniques, including the act of fasting between days of dialysis. As observed during the fasting month (Ramadan), dietary patterns and content changes are safe in electrolyte balance, and blood pressure changes for hemodialysis patients (Imtiaz et al., 2016).

4.3 Inadequate information

Some participants reported doctor's or nurse's inability to provide clear information on the fluid prescription or the exact consumable amount per day. Previous research has also shown the unmet communication needs between service providers and patients and interprofessional (Hall et al., 2020). Also, there have been arguments on some seemingly contradictory information provided by the nutritionists and nurses. There have also been complaints about low consistency in the nutritional information delivered by various nutritionists in health facilities. This leaves most respondents confused and ultimately decides to ignore or triangulate the advice with knowledge obtained from fellow patients to identify the best foods (Okoyo Opiyo

et al., 2020). Kelly (2018) also highlighted some of the factors implicated in the diet failure of chronic kidney disease patients, including stagnated diet management due to excessive advice, the unpreparedness of patients towards these changes, and barriers to access diet-related services. It is also essential for nurses and other health care workers to identify strategies required to improve communication by strengthening fluid/dietary counseling activities for patients and family members. This helps in facilitating adherence to medication regimens and fluid/nutritional guidelines (Beerendrakumar et al., 2018).

4.4 The support system

The majority participants said that they got support from family, peer, and professional advice. Some of them said that their source of strength from family, includes support and caring from husband/wife, and their children. The support obtained from family, friends, and dialysis staff is a significant factor in promoting acceptance and adherence (Stevenson et al., 2018). These are the core backings estimated to promote adaptation behaviors (Cho & Shin, 2016) due to emotional and physical encouragement. The support is provided by ensuring the appropriate food is available, consistently reminding the patient to limit fluid intake, and verifying the adherence to the recommended diet. The previous study showed that peer support programs improved self-management in patients with CKD undergoing hemodialysis. Peer support programs should be offered early to individuals undergoing hemodialysis so that they can learn about self-management from other patients (Husain et al., 2020). The dialysis staff also plays an essential role by emphasizing the need for fluid limitation at each hemodialysis session. Several other strategies have been adopted to provide mental support and sustain positive attitudes towards the diet and fluid restrictions and modifications. The phenomenological research by Shahgholian & Yousei (2018) recognized patient's dislike for others' pity. They hoped for a change in the attitude of people through the provision of support and assistance.

All participants in this study came from the Minangkabau ethnicity. In the Minangkabau population, animal protein sources as well as saturated fat, and palm oil due to the traditional heritage of food processing, are quite high (Lipoeto et al., 2004). According to the Indonesia's total dietary survey data, the Minangkabau population consumes an average of 50.4 g of fat daily in oil, fried foods, coconut and coconut oil, and less than 100 g of vegetables and fruits per day (Indonesia National Institute of Health Research and Development, 2014). The results of a study showed that consuming a poor quality diet was consistently associated with increased risk factors associated with chronic disease (Estruch et al., 2018). Renal dietary prescription can vary substantially among patients depending on age, comorbidities, and treatment goals (Kalantar-zadeh et al., 2016). Changing eating patterns and restricting diet and fluids is not easy for CKD patients. However, the diet is considered more burdensome and challenging for patients who need to change some diet components (e.g., sodium, fluids, potassium, and phosphate) and those who come from culturally and linguistically diverse backgrounds (Stevenson et al., 2018). Patients expressed some frustration that the nutritional information and resources they received were not culturally relevant, and they did not know how to integrate dietary recommendations into their diet. Strong influence from family and friends on patients' dietary beliefs and habits is well known. Patients describe the emotional and physical support that they receive from family and friends who assist with food preparation, meal preparation and act as reminders and reinforcement for patients to adhere to their dietary and fluid restrictions (Walker et al., 2012).

5. Implications and limitations

The results of this research have important implications for health professionals working in the hemodialysis units to serve as an input for further research about strategies how to reduce thirst. The findings are applicable as inputs for dialysis staffs to evaluate and improve the hemodialysis units' information dissemination system. Furthermore, individual approaches and structured education implementation are very crucial.

The study has some limitations. First, the choice of interview time and place was during the hemodialysis process or while in the hospital waiting room. Participants selected during the treatment time, approximately 30 minutes after the commencement of the hemodialysis, may have affected how the participants answered the questions since the room was too wide and participants did not have privacy. During the interview process, the interviews were sometimes

interrupted by the arrival of a doctor or nurse to carry out an examination. Second, the principal researcher, who is novice, may impact how deep the interview was conducted and how to analyze the data forming the themes. However, to ensure the data quality, all participants were subjected to member checks and peer debriefings with more experienced researchers in data processing.

6. Conclusion

The research results showed the severe suffering and sadness experienced by chronic kidney disease patients in hemodialysis who conform to fluid restrictions. In addition, adequate compliance is required for survival and also to improve the quality of life. Moreover, some of the challenges implicated in poor adherence include unspecific and inaccurate education and information delivery. This instills confusion and further prompts the individuals to make personal decisions regarding the amount of diet consumed. Therefore, this study recommends nurses to provide clear information on the fluid prescription or the exact consumable amount per day. Also, the respondents' engagement in numerous unique activities to overcoming thirst, and further research are needed with an emphasis on individual experiences. The support obtained from family, friends, and dialysis staff is a significant factor in promoting acceptance and adherence. So, it is essential for nurses and other health care workers to identify strategies required to improve communication by strengthening fluid/dietary counseling activities for patients and family members. This helps in facilitating adherence to medication regimens and fluid/ nutritional guidelines. Furthermore, it is essential to modify structured education with a personal approach to ensure detailed information regarding "fluid prescribing".

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Author contribution

All authors contributed to the study conception and design (FM, RM, YH), data collection (FM, RM), data analysis (FM, RM, YH), and manuscript preparation and revision (FM, EH, CMC, KLA).

Conflict of interest

The authors declare no potential conflict of interest concerning this research, authorship, and/or publications of this article.

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