

## ORIGINAL ARTICLE

# The Experiences of Patients with Chronic Kidney Disease Undergoing Dialysis in Managing the Symptoms

Fitri Mailani<sup>1</sup>, Yelly Herien<sup>2</sup>, Rahmi Muthia<sup>1</sup>, Roxsana Devi Tumanggor<sup>3</sup>, Emil Huriani<sup>1</sup><sup>1</sup> Medical-Surgical Department, Faculty of Nursing, Universitas Andalas. Limau Manis Campus, Padang, West Sumatera Indonesia. 25163<sup>2</sup> Child-Maternity Department, Faculty of Nursing, Universitas Andalas. Limau Manis Campuss, Padang, West Sumatera Indonesia. 25163<sup>3</sup> Faculty of Nursing, Universitas Sumatera Utara, Medan, Jl. Prof. Maas no. 3 campuss USU-Medan, North Sumatera, Indonesia.**ABSTRACT**

**Introduction:** Patients with chronic kidney disease undergoing hemodialysis experience various physical and psychological symptoms. Severe symptoms can be disabling and have a severe impact on daily activities. Some strategies should be managed to improve the quality of life, such as fluid/diet restriction and coping management. The purpose of this study was to explore the experiences and coping strategies of patients on dialysis in managing their symptoms of Chronic Kidney Disease in a general hospital in Indonesia. **Methods:** This research was a qualitative study with semi-structured interviews. The data collection with was carried out with 14 patients diagnosed with chronic kidney disease undergoing hemodialysis, July to September 2020 involved a purposive sampling technique. They are experiencing physical and psychological symptoms. All interviews were audiotape recorded with permission from participant and were verbatim transcribed. Data were analyzed using the content analysis by Colaizzi approach. **Results:** : Two themes were developed that are symptoms experience and self-management strategy. Each theme consists of two sub-themes. **Conclusion:** This research provided a better understanding of the physical and psychological symptoms experiencing by the patient undergoing hemodialysis and how to cope with the condition. The findings accommodate nurses and other healthcare professionals in facilitating interventions to minimize physical and psychological symptoms during the dialysis process.

**Keywords:** Chronic kidney disease; Symptoms; Hemodialysis; Qualitative study**Corresponding Author:**

Fitri Mailani, MN

Email: fitrimailani22@nrs.unand.ac.id

Tel: +62 852 61699699

**INTRODUCTION**

Indonesia is one of the countries with a high incidence of chronic kidney disease, this also causes the number of patients undergoing hemodialysis to continue to increase every year. The Indonesian Renal Registry (IRR) in 2018 reported that the number of patients undergoing hemodialysis risen significantly from 2016 to 2018. In 2016, there were as many as 52,835 patients, an increase of 77,892 patients in 2017, and an increase dramatically to 132,142 in 2018. Besides, West Sumatra is amongst the top five Provinces with the highest number of patients in 2018, with 1,334 actively participating in hemodialysis therapy (1).

Chronic kidney disease (CKD) patients will undergo

dialysis therapy as renal replacement therapy due to irreversible kidney damage (2). Hemodialysis (HD) is a renal replacement therapy for patients with chronic kidney disease (3). HD can replace kidney function and prolong life, but patients will still experience disturbing such as cramping, fatigue, depression, and itching (4). These physical and emotional symptoms affect the quality of life (QOL) (5) since it's recurring with unique patterns of relationships and contributes a significant problem for patients (6). Symptom burden has been illustrated as a substantial giver to increasing the patients' morbidity and mortality and decreased health-related quality of life (HRQOL) in HD patients (7).

A previous study stated that symptoms experienced by patients undergoing HD in Canada were fatigue, lack of well-being, lethargy, lack of craving, and skin pruritus (4). While Murtagh et al. (2007) reported that fatigue/tiredness, lack of appetite, skin itching, constipation, and pain were the most common symptoms revealed among HD patients (8). Freire et al. (2020) reported that

chronic kidney disease patients experience physical discomforts such as immobility, pain, cramps, fatigue, itching, edema, thirst, and psycho-spiritual discomforts such as hopelessness, sensitivity, and social isolation (9). Previous research showed that symptom experience in non-dialysis dependent CKD patients reported a wide range of symptoms with over 50 different categories and sub-categories emerging from the interview data, 100% patient-reported fatigue, 94.4% said impairing sleep quality, 88.8% pruritus, lower extremity problem and musculoskeletal disorders (11). A research by Davison et al (2015) on supportive care in chronic kidney disease: developing a roadmap to improve quality of care suggests that several validated tools are needed to assess dialysis-related symptoms and components of quality of life in CKD (5) because effective treatment strategies remain limited (10).

Symptom management was identified as a priority for clinical nursing research in patients undergoing HD (4). The critical point of this symptom management is focused on the patients' reports related to the symptoms that occur as the observable manifestations of the disease. Since symptoms are constituted as the subjective illustrations of illness experienced by individuals (11). Understanding symptom burden in the context of a patient's experience may reveal unique and latent aspects of this burden (12)

Patients with chronic kidney disease said that their symptoms are significant to manage, but medical workers often underestimate the symptoms (14). In addition, the study reported that patients wanted more interactions with health care workers regarding their symptoms (6). Recent randomized clinical trials have shown among cancer patients that a standardized set of patient-reported symptoms increases the quality of life and other health outcomes (15).

In Indonesia, data on symptoms of CKD patients undergoing HD are evaluated once a year, the symptoms that are evaluated are more focused on complicating symptoms during dialysis. However, some patients question how these data are used to improve their experiences. Informal symptom evaluations during routine clinical assessments occur more frequently, but data collection and reporting is not standardized. Furthermore, symptom features, patient views, and past experiences may all have an impact on spontaneous symptom reporting. Understanding patient perspectives on dialysis treatment-related symptoms and symptom reporting should help dialysis clinics improve their symptom data collecting. We conducted this study to better understand patient perceptions of hemodialysis-related symptoms and symptom reporting in exploratory studies. Therefore, this study aims to explore the symptoms experienced by patients chronic kidney disease and how their managing the symptoms.

## MATERIALS AND METHODS

### Study Design

This was inductive research, where descriptive qualitative methods were used to obtain the first-hand experience on symptoms from chronic kidney disease patients participating in hemodialysis therapy. This holistic 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 express feelings about their fluid management experiences (15).

### Participants

This study was conducted between July and September 2020. The participants include chronic kidney disease patients in hemodialysis at the Hemodialysis Unit in general Hospital in Padang, West Sumatra, Indonesia. The selection process involved a purposive sampling technique for an individual with the following inclusion criteria: (1) patient age  $\geq 18$  years, (2) chronic kidney disease patients undergoing hemodialysis regularly for over six months, (3) willing to participate in the study and share their experiences, and (4) capable of speaking Indonesian or Minangkabau language. Participants' recruitment methods with study fliers posted in dialysis clinics and in-person recruitment. The researcher screened interested patients for eligibility and obtained informed consent. The participants received transportation reimbursement. This study had 14 interviewed patients, but no new information or ideas were discovered after reviewing the thirteen interviews. To guarantee data saturation, however, one additional interview was done due to the thoroughness of the material collected from the participants.

### Data Collection

Individual in-depth interviews were conducted. The interview venues were selected to suit the participants' preferences, whether during the hemodialysis or in the hospital waiting room. All the patients were selected during the hemodialysis, approximately 30 minutes after the hemodialysis commencement. An in-depth interview lasted 45 to 60 minutes for each participant. The interview guide was developed from three open-ended questions, "People with chronic kidney disease often have a variety of symptoms. Can you tell me which of your symptoms troubles you the most?". "Tell me about your experience with the most troublesome symptom?" and other probe questions such as "When did you start experiencing it?", "How does it affect your day-to-day life?", "How you manage the symptom?". However, the interview was recorded with an audio recorder and directly transcribed verbatim by the first researcher. Data saturation was confirmed when there were no new codes found to culminate into properties of another theme for symptom management experience in the subsequent in-depth interview sessions after 14

participants (17).

### Data Analysis

The audio-recorded interview was transcribed and analyzed 24 hours to avoid recall biases with the Colaizzi approach (1978). 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), (6) Identifying the structural basis of the phenomenon and (7) Return to the participants for validation (15).

### Trustworthiness/Rigor

To confirm the trustworthiness of this study, we had discussions among researchers and experts to make sure that there was no preconception in analyzing and developing themes. All researchers were agreed with all findings. The researchers also conducted interviews with three nursing staff in unit hemodialysis and four family caregivers as part of the triangulation method to compare and confirm the validity of the study results. We had done member checking to validate the finding, as it is the most critical technique to establish credibility (18).

### Ethical Considerations

The data collection process commenced after ethical clearances were obtained from the Health Research Ethics Commission of Dr. M. Djamil Hospital Padang with reference number 209/KEPK/2020. This research was in line with the principles stipulated in Helsinki's Declaration (19).

## RESULT

The participants were fourteen, with seven males and seven females, the range ages 31 to 63 years old with senior high school and bachelor degree education background in the majority. Eleven participants are married, seven participants are working full time, duration of hemodialysis therapy in the range seven months – 8 years, and various primary causes of CKD (Hypertensive Nephropathy, Nephrolitiasis, Diabetic Nephropathy, Glomerulonephritis, Miscellaneous and unknown).

Agreement on themes identified through analysis was achieved through a process of discussion and consensus. A codebook was developed to ensure consistency of theme and subtheme development over time. Moreover, the research themes analysis showed two themes,

including the symptom experience and self-management strategies. Subthemes for symptoms experienced are the physical symptom and physiological symptom. Subthemes for self-management are fluid/diet restriction management and coping management. Verbatim from interview were extracted into several code, compiled, and filtered into 22 symptom categories. These symptoms can be broadly classified into physical (17 symptoms) and psychological (5 symptoms).

### The Symptom Experience

The experience of these symptoms is arranged in category physiological and psychological symptoms, respectively, as illustrated in table 1. It is showed that the participants in this study reported various symptoms. For instance, fatigue, dizziness/ headache, pain, and urinary system disorder are the most commonly occurring categories across the 14 participants. The result supports the conceptualization of Chronic Kidney Disease as a multisystem disease, affecting kidney function and the individual. All symptoms detected contains 22 symptoms, as presented in table I.

**Table II. The Developed Thematic Map of Symptom Experience Patients with Chronic Kidney Disease**

Theme	Sub-theme	Category
Symptom experience	Physical symptom	Fatigue
		Dizzy/ headache
		Pain
		Urinary system disorder
		Edema
		Intolerance activity
		Change in the condition of the skin, hair, and nails
		Pruritus
		Nausea
		Breathing difficulties
		Loss of appetite
		Thirsty
		Impaired sleep quality/ insomnia
		Cramp
		Sexual dysfunction
		Temperature sensitivity
		Infection
Self-management strategies	Physiological symptom	Anxiety/fear
		Stress
		Irritability
		Cognitive impairment
		Denial
Self-management strategies	Fluid/diet restriction management	Set drinking schedule
		Modified the drinking temperature
		Distraction technique
		Healthy eating for CKD
Self-management strategies	Management stress	Management of edema
		Spiritual and pray
		Family source of strength

### *Physical Symptom*

All patients reported feeling tired or fatigue. It is expressed in the terms 'tiredness', 'weakness' and 'physical exhaustion.' The defined CKD fatigue is dissimilar from previous experiences, as expressed by this quotation:

*"My body often feels weak, gets tired quickly, unlike anything that I've had before. Sometimes I have shortness of breath, so I have to rest a lot. When I wake up in the morning, I can't get up right away; I have to sit down for a while because my body is frail and my body is very painful. The doctor said dialysis would remove fluids in our bodies; it reduces our nutrition, so we quickly tired"*(P.5).

Almost all the participants were experienced dizziness/headache. The participants felt dizziness after they finished hemodialysis, but the dizziness was still manageable by the patient, as the following statement:

*"After every hemodialysis, my head hurts. But the pain was still at a manageable level, like dizzy"*(P1).

*"I have frequent headaches, but I am still able to work. I am still working as a driver now"* (P6).

Pain is reported among most participants in some parts of the body, such as the bones, waist, and the whole body that the participant could not describe in detail, such as the statement below:

*"After every hemodialysis, I feel pain in my bones, back pain, especially when the hemodialysis session will end soon, all part of my body feels pain"* (P3).

*"I feel pain all over my body, and I can't sleep"* (P7).

Urinary system disorder was also reported for almost all participants; this symptom was felt from the beginning of chronic kidney disease diagnosis. This urinary system disorder includes frequency disturbances, such as less or no urination. And changes inconsistency such as the urine color change and decrease the amount of urine produced.

*"Now I don't pee at all"* (P3)

*"I only have a little urination, sometimes it's very tight, but what comes out is only a drop or two. At best, if you urinate in the morning, it's just a lot"* (P12).

Most participants reported experience with edema due to violation of fluid intake restrictions. This is also related to the symptoms reported by CKD patients as many as 9 participants that felt thirsty frequently.

*"My cheeks look swollen when I wake up, and the body is getting swollen over time, this condition happens because I drink water a lot, sometimes when the hot weather I can't control it"* (P1).

*"However, it is challenging to avoid water. It's tormented. This thirst is excruciating"* (P14).

Skin problems were found among the participants. For example, 'dry, flaky skin,' 'skin that bruises easily' and 'skin that heals poorly.' The participants described the skin scaliness and exacerbated by pruritus.

*"My skin has become darker and dry. I also have scars because I scratched it until it was blistered"* (P4).

In addition, the participants also acknowledged that there are some changes in hair and nails.

*"because I also have diabetes, so my skin is prone to sores, I scratch the itching and keep my nails looking a little gray, my hair often falls out"* (P11).

Nausea was also reported as a symptom experienced by patients when undergoing hemodialysis and impact the participants' appetite.

*"My hemodialysis schedule is every Thursday, so on Wednesday am getting nauseous. Especially at mealtime. I used to eat three times a day. But now I sometimes eat once a day, sometimes two times, because I lost my appetite"* (P1).

*"So if I follow dietary restrictions, then what else do I want to eat? It will be difficult to restore my appetite"* (P11).

Five participants reported intolerant to cold temperatures and feel sensitive about it.

*"I fill it with a bottle if I urinate at night. The problem is that if my foot hits the water, I immediately shiver and get cold. Currently, when I hit the AC (Air Conditioner), I'm already cold. I can't stand the cold temperature right now"*(P1)

*"I get cold easily, can't hit the wind fan especially at night, I feel chills"*(P9)

Apart from the above symptoms, participants also reported other symptoms such as intolerance activity, breathing difficulties, thirst, impaired sleep quality/insomnia, cramps, sexual dysfunction, temperature sensitivity, and infection. Overall the quotation can be seen in table 4, and the symptom categories of the 14 participant interviews can be seen in table II.

### *Psychological Symptom*

Physical changes also contribute to psychological symptoms that appear in CKD patients, such as anxiety, fear, stress, irritability, cognitive impairment, and denial. Twelve participants reported anxiety in the initial diagnosis and feelings of sadness because of the damage of normal renal function and further health status. It increases bondage on family members and healthcare worker. One participant said fear of death since her mother died after two years on hemodialysis.

*"I often feel anxious and afraid, if I die, what about my family? My children are still very young"* (P1)

*"My mother used to die of kidney failure as well. I am worried about my future, and especially I am not married, my mother was two years on hemodialysis and finally died, I am afraid that it will be like my mother"* (P11).

Some participants reported overthinking the family due to work limitations. One participant said that CKD and

hemodialysis interfere the daily work regularly and cause stress.

*"My work is also disturbed because of this disease. I can say that I am not suitable for this work in the office, I want to recover, but I can't; this is what makes me stressed" (P1)*

Some participants feel irritable, sensitive, and useless in this condition. *"I feel more sensitive and get angry easily, just annoyed with this condition, I think my family didn't need me anymore, and I felt useless" (P8).*

While others reported cognitive impairment, it is an alarming situation for patients who are still productively working. This is related to fatigue and impaired sleep quality so that concentration is disturbed.

*"It's not the same as before. When I work, I often don't concentrate, and it's hard to focus" (P11).*

*"I forget easily and get tired easily. At the office, my friends already understood this condition, so I don't do heavy work" (P13).*

Two participants reported that they had denial with CKD diagnosis for the first time. So, one participant sought a second opinion from other hospitals, while some participants were struggling to believe the diagnosis. It was difficult to accept the condition because family members were diagnosed with CKD and died after two years of undergoing HD.

*"I rarely got sick before, and suddenly diagnosed with kidney failure, I couldn't accept it, I tried to go to another hospital, I even went to Jakarta and Australia for treatment" (P3)*

*"It took me a long time to accept this condition, I do not accept that I also suffer from kidney failure, I still remember clearly how my mother struggled with kidney failure, and after struggling for two years, she finally died, and now I am the one receiving the doctor's diagnosis of suffering from the same disease. I don't feel like it" (P11).*

### **Self-Management Strategies**

Even though some of the most severe symptoms could be handle by working directly with the professional health workers in unit hemodialysis, many participants established that they had to control symptom management to increase the quality of life.

Fluid/diet restriction management

According to some participants, episodes of severe cramping, edema, and breathing difficulties can be prevented by adhering to fluid and dietary restrictions. All participants attempt to set drinking time/schedule to limit the daily fluid intake, based on the following statement:

*"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).*

*"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).*

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 statement:

*"Warm water effectively eases my thirst and makes the stomach feel good" (P1).*

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).*

Some participants adopt the distraction technique to reduce thirst. Two moslem participants actively participate with the fasting on Monday and Thursday, based on the following statement:

*"Therefore, I participate in blood dialysis on Tuesday and Friday. Most times, I fast the Sunnah after the three days of HD from Friday 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).*

Moreover, some respondents take a shower or have a rest in an air conditioner room as a form of distraction:

*"... 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).*

Some participants reported that avoiding fruits that have high potassium or fast food which have high sodium.

*"...I avoid eating fruits with high water and potassium content; hence I only consume papaya consistently every day I eat at home; I always prepare a meal and avoid fast food like instant noodles, salty food" (P12).*

Some participants also consume superfoods/multivitamins and prescribed vitamins to improve body immunity. The statement is shown below:

*"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 in water to achieve a black color before adding sugar and drinking. Also, I eat Habatusaudah, a lot of fish oil, including those from Kling, aqua fish or fishqua," (P3, Male, 58 years).*

Body edema was one of the significant challenges participants experienced after consuming excess fluid. 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).

Edema management required certain activities, including the regulation of daily fluid intake, performing sweat emission-related activities, such as walking and sunbathing, as stated in the following:

*"...I also like to sunbathe in the morning, and possibly take a walk to sweat out the fluid"* (P3).

Also, the participants reported managing fluid by regulating the intake, as stated below:

*"... 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).

### Management Stress

Patients with CKD spent 4 hours on a dialysis machine two days per week profoundly affected participants' mental and emotional health. Some said they struggled with stress and depression and to make sense of the life they were leading. Several participants complained that the uncertainty of symptoms and their health, in general, contributed to stress. They would feel suitable for a while, but they would quickly plummet into anxiety and depression when managing symptoms seemed impossible. All participants have adaptive coping strategies to reduce stress, including optimistic outlooks, self-advocacy, and good spirituality. Many noted that positive attitudes support coping with the HD process and machine dependence. The participants try to accept the condition and a feeling of strength to recover from the disease spiritually. Support from family and belief in prayer to God is a power source for patients to solve psychological symptoms.

*"I pray that I can live for a long time, and my body is healthy. I want to see my children succeed. I believe God will always give strength to his patient servants"* (P8).

*"I want to recover; the important thing is we ask God because he is the one who gives the disease, and he is the one who heals"* (P6).

*"I have visited many places and have eaten many alternative medicines, but there is no chance that I feel. Then I consulted many other patients who had the same disease as mine. They say, now this hospital is my office. I have to take time off every two times a week. Some even have been undergoing treatment for 11 years. If he is able, why can't I? I no longer seek alternative medicine. I have accepted this condition, and this is the destiny of my life"* (P5).

The support from family members, including spouses and children, significantly impacted participants during

hemodialysis. Some participants said that family is the source of strength, as stated below:

*"... My child always reminded me not to drink excess water and to adherence to prescribing for a healthy kidney. They take care almost all my daily activities, I feel so lucky"* (P14).

*"... 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, she is amazing and always be my strength..."* (P5).

### DISCUSSION

This study results that patients with CKD undergoing HD experience various symptoms, which may be involved and manifest both physically and psychologically. Almutary et al. (2016) reported that signs were found to occur in clusters rather than existing in isolation (20). The multitude of symptoms reported by participants highlighted the systemic nature of the kidney disease matter that CKD is an all-encompassing disease process (3).

This research found fatigue, dizziness, pain, urinary system disorder, and edema were the most reported symptoms. Previous studies have suggested that fatigue and pain are common and are the symptoms most frequently reported by patients (19). Another research showed one hundred percent of patients with non-dialysis dependent CKD expressed fatigue, ninety-four percent indicated poor sleep quality, eighty-eight percent reported pruritus, lower extremities problems, and musculoskeletal diseases (11). Physical symptoms associated with impaired integument system, sleep disturbance, functional impairment, and gastrointestinal disorders are many found in patients with CKD (6, 19, 20). Lack of energy may result from anemia in HD patients associated with inadequate erythropoietin, erythropoiesis inhibition, erythrocyte life reduction, or loss of blood during HD. Patients undergoing HD with anemia suffer from tiredness, muscle weakness, lack of vitality, and activity intolerance (3). Pakpour et al. (2010) found that physical activity limitation had the worst score because it shortened the patients' daily and operational activities (21). It also limits physical activity possibilities. Other symptoms such as sleep disorders, fatigue, pruritus, and weakness in the lower extremities eventually disrupted the patient's ability to conduct daily activities (22). Freire et al. (2020) reported that physical discomfort in patients with chronic kidney disease are immobility, hypotension, pain, hunger, cramp, tiredness, polyuria, itching, edema, thirst, and psycho-spiritual discomfort are, despair, sensitivity, social isolation (9).

In this study, six patients reported sexual dysfunction; similar to research by Pugh-Clarke et al. (2017), six patients with chronic kidney disease non-dialysis dependent reported experiencing sexual dysfunction

(11). The prevalence of sexual dysfunction in female patients undergoing hemodialysis is very high, reaching almost 80%. A study by Stefanovic (2012) showed that 79.3% of female patients undergoing hemodialysis experience sexual dysfunction. Female patients and male patients also experience sexual or erectile dysfunction (23).

Five participants stated they experienced temperature sensitivity; they reported intolerance to cold environmental temperatures. However, temperature sensitivity symptoms are not seen in the literature and maybe a new finding. This result showed the reverse of Pugh-Clarke et al. (2017) that heat intolerance symptoms were found in patients with CKD stages 4 and 5 (11). This study's temperature sensitivity means that cold intolerance was described as incapable of tolerating cold environmental temperatures. Although the exact cause of cold intolerance in CKD patients is still unclear, it is known that this disease causes many endocrine disorders (24), which can affect thermoregulation.

The findings of this study show that CKD patients who are undergoing HD have a wide range of symptoms. The most common signs are not always the most serious. Symptom assessment in clinical settings typically focuses on determining the severity of the most common symptoms, such as pain (25). As a result of the inadequate information provided by a one-dimensional symptom assessment, repeated symptoms can go unnoticed and unaddressed, leading to an increase in the overall symptom burden. The significance of assessing the multidimensional aspects of symptoms is stressed to understand symptom burden better and provide more efficient treatment. Participants more commonly reported physical rather than psychological symptoms. Physical symptoms can be so debilitating that they overpower the symptom experience.

To overcome physical and psychological symptoms, participants described their self-management strategies, such as fluid/diet management, setting a drinking schedule, modifying the drink's temperature, distraction technique, healthy eating for CKD, and edema management. Spiritual activities and family support were adaptive coping for stress management patients. Fluid management is essential for patients with chronic kidney disease. Also, proper hemodynamic management is a significant component of an adequate patient dialysis program (26). Therefore, the patient in this current investigation made several arrangements to manage fluid intake and ensure a healthy diet. Also, the possible complications of excess fluid, comprising shortness of breath and edema, are 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, frozen fruit). The participants also prepared individual diets according to the kidney demands by avoiding foods rich in potassium and high

salt content and encouraging multivitamin consumption. Furthermore, some participants adopted distraction techniques, including the act of fasting between days of dialysis. During the fasting month (Ramadan), dietary patterns and content changes effectively affect electrolyte balance and blood pressure changes for hemodialysis patients (27).

The participants in this research reported that support from family and belief in prayer to God is a source of strength for patients to solve psychological symptoms. The relationship between spirituality, religion, and health should have a clear healthcare delivery paradigm. It is revealed that the spiritual phenomena as a source of support in different disease conditions have represented a challenge for science. Religious and spiritual coping methods may be associated with QOL and depression among HD patients (22). Spiritual care has been recognized as an essential domain of quality care for patients with CKD, particularly near the end of life. Studies have shown that these patients have a strong desire for spirituality during their care. The family, friends, and dialysis staff encouragement is essential in fostering acceptance and adherence (28). Since perceived social support can promote positive self-concept and increase handling threats, it is a significant predictor of depression. As a result, the benefits of social relationships for CKD patients have an independent protective impact against depression (29). Faridah et al. (2021) reported that family-supportive therapy has a significant correlation with the quality of life; it can be concluded that after being given supportive family therapy, the quality of life was high. Similar to Isnaini et al (2020) research, there is a strong relationship between family supports for self-efficacy patients with chronic kidney disease (31).

## CONCLUSION

Physical and psychological symptoms are a significant part of the hemodialysis experience for persons with CKD. Patients have reported physical symptoms such as fatigue, dizziness, edema, anorexia, and other symptoms and psychological symptoms such as anxiety/fear, stress, irritability, cognitive impairment, and denial. This study shows that patients with hemodialysis experience various physical and psychological symptoms. This study also emphasizes the importance of conducting an individual symptom evaluation and determining the likely reasons, as well as knowing the individual's coping strategies. The patients' experiences were found to be debilitating and persistent. As a result, it is critical for services, doctors, families, and caregivers.

## ACKNOWLEDGEMENTS

The author acknowledges Universitas Andalas for financial supports (contract number: T/31/UN.16.17/PT.01.03/KO-RD/2020).

## REFERENCES

1. Indonesian Renal Registry. 11th Report of Indonesian renal registry 2018. In: Retrieved from <https://www.indonesianrenalregistry.org/data/IRR2018.pdf>. 2018.
2. Webster, A. C., Nagler, E. V., Morton, R. L., & Masson P. Chronic kidney disease. *Lancet* [Internet]. 2017;389:238–1252. Available from: [10.1016/S0140-6736\(16\)32064-5](https://doi.org/10.1016/S0140-6736(16)32064-5).
3. Thomas N (Ed. . Renal Nursing: Care and Management of People with Kidney Disease. John Wiley & Sons.; 2019.
4. Davison SN, Jhangri GS. Impact of Pain and Symptom Burden on the Health-Related Quality of Life of Hemodialysis Patients. *J Pain Symptom Manage* [Internet]. Elsevier Inc; 2010;39(3):477–85. Available from: <http://dx.doi.org/10.1016/j.jpainsymman.2009.08.008>
5. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *Kidney Int* [Internet]. Elsevier Masson SAS; 2015;88(3):447–59. Available from: <http://dx.doi.org/10.1038/ki.2015.110>
6. Cox KJ, Parshall MB, Hernandez SHA, Parvez SZ, Unruh ML. Symptoms among patients receiving in-center hemodialysis: A qualitative study. *Hemodial Int*. 2017;21(4):524–33.
7. Ng, M. S. N., So, W. K.W., Wong, C. L., Hui, Y.H., Ho, E.H. S. C, B. A., & Miaskowski C. Stability and impact of symptom clusters in end-stage renal disease patients undergoing dialysis. *J Pain Symptom Manage*. 2020;59:67–76.
8. Murtagh FEM, Addington-Hall J, Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Adv Chronic Kidney Dis*. 2007;14(1):82–99.
9. Freire S de M, Melo GA, Lima MM de, Silva RA, Caetano JB, Santiago JC. Contexts of Experience of Being (Un) Comfortable in Patients with Chronic Kidney Disease. *Esc Anna Nery*. 2020;24(4):1–8.
10. Manns B, Hemmelgarn B, Lillie E, Dip SCPG, Cyr A, Gladish M, et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol*. 2014;9(10):1813–21.
11. Pugh-Clarke, K., Read, S. C., & Sim J. Symptom experience in non-dialysis-dependent chronic kidney disease: A qualitative descriptive study. *J Ren Care*. 2017;43(4):197–208.
12. Cleeland C.S FMJ& DA. Introduction to cancer Measurement, symptom science. In *Cancer Symptom Science: Mechanisms, and Management*. Cleeland C. New York: Cambridge University Press; 2011. 1-3 p.
13. Bennion, A. E., Molassiotis A. A Qualitative research into the symptom experiences of adult cancer patients after treatments: a systematic review and meta-synthesis. *Support Care Cancer*. 2013;21(1):9–25.
14. Claxton RN, Blackhall L, Weisbord SD, Holley JL. Undertreatment of Symptoms in Patients on Maintenance Hemodialysis. *J Pain Symptom Manage* [Internet]. Elsevier Inc; 2010;39(2):211–8. Available from: <http://dx.doi.org/10.1016/j.jpainsymman.2009.07.003>
15. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *J Clin Oncol*. 2016;34(6):557–65.
16. Creswell, J. W., & Poth CN. *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.; 2016.
17. Mason M. Sample size and saturation in PhD studies using qualitative interviews. [Internet]. 2010. Available from: [Forum qualitative Sozialforschung/ Forum: qualitative social research, 2010](https://www.qualitative-research.net/forum/qualitative-social-research/2010)
18. Gunawan J. Ensuring Trustworthiness in Qualitative Research. *Belitung Nurs J*. 2015;1(1):10–1.
19. World Medical Association. Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. [Internet]. 2018. Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
20. Almutary, H., Douglas, C., & Bonner A. Which Patients With Chronic Kidney Disease Have the Greatest Symptom Burden? a Comparative Study of Advanced Ckd Stage and Dialysis Modality. *J Ren Care*. 2016;42(2):73–82.
21. Amir H Pakpour, Mohsen Saffari MSY, Davood Panahi, Adrian P Harrison SM. Health-related quality of life in a sample of Iranian patients on hemodialysis. *Iran J Kidney Dis*. 2010;11(1):51–9.
22. Santos PR, Capote JRFG, Cavalcante Filho JRM, Ferreira TP, Dos Santos Filho JNG, Da Silva Oliveira S. Religious coping methods predict depression and quality of life among end-stage renal disease patients undergoing hemodialysis: A cross-sectional study. *BMC Nephrol. BMC Nephrology*; 2017;18(1):1–8.
23. Stefanovic AM. Health related quality of life in different stage of renal failure. . 2012;36(7):581–9. *Artif Organs*. 2012;36(7):581–9.
24. Singh A.K. RA& KJ. Endocrine complications of chronic kidney disease. In: *In Chronic Renal Disease*, (eds Kimmel PL & Rosenberg ME). Amsterdam: Academic Press; 2015. p. 310–9.
25. Jabsonsky A. The multidimensional characteristics of symptoms reported by patients on hemodialysis. *Nephrol Nurs J*. 2007;34:29–32.
26. Canaud B, Chazot C, Koomans J, Collins A. Fluid and hemodynamic management in hemodialysis patients: challenges and opportunities. *J Bras*



- Nefrol. 2019;41(4):550–9.
27. Imtiaz S, Salman B, Dhrolia MF, Nasir K, Abbas HN AA. Clinical and Biochemical Parameters of Hemodialysis Patients Before and During Islamic Month of Ramadan. *Iran J Kidney Dis.* 2016;10(2):75–8.
  28. Stevenson J, Tong A, Gutman T, Campbell KL, Craig JC, Brown MA, et al. Experiences and Perspectives of Dietary Management Among Patients on Hemodialysis : An Interview Study. *J Ren Nutr* [Internet]. National Kidney Foundation, Inc.; 2018;1–11. Available from: <https://doi.org/10.1053/j.jrn.2018.02.005>
  29. Shukri M, Mustofai MA, Md Yasin MAS, Tuan Hadi TS. Burden, quality of life, anxiety, and depressive symptoms among caregivers of hemodialysis patients: The role of social support. *Int J Psychiatry Med.* 2020;55(6):397–407.
  30. Faridah VN, Nursalam, Aris A, Sholikhah S, Rukmawati FS. Improving the Quality of Life of Patients with Chronic Kidney Disease Undergoing Hemodialysis through Family Supportive Therapy. *Proc 1st Paris Van Java Int Semin Heal Econ Soc Sci Humanit (PVJ-ISHESSH 2020).* 2021;535:624–7.
  31. Isnaini N, Sukma R, Dwi H. The Influence of Family Support on Self Efficacy of Chronic Kidney Disease. In: *Proceedings of the 4th International Conference on Sustainable Innovation 2020–Health Science and Nursing (ICoSIHSN 2020) Science and Nursing (ICoSIHSN 2020).* 2020. p. 484–7.