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Lived Experiences of Chronic Kidney Disease Patients Undergoing Dialysis Treatment: A Preliminary Study

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Abstract:

This study affirms the competence of individuals suffering from chronic kidney disease (CKD) who undergo dialysis treatment in their ongoing acceptance of the illness and adjustment to their everyday routines. This study aimed to investigate the tangible encounters of patients coping with CKD while undergoing dialysis treatment. Diagnosis of CKD frequently necessitates modifications in the lifestyle. The preliminary study explores the personal encounters of patients residing on the eastern coast of Malaysia with CKD. A qualitative descriptive study explores the lived experiences of patients with CKD using a narrative approach. Purposive sampling selected the eight patients receiving dialysis treatment, and semi-structured interviews were conducted in a counseling room for confidentiality reasons. Three primary themes emerged in this research: (i) life before and after dialysis treatment in a flashback, (ii) patients' health impacted their social life, and (iii) treatment and illness caused them to adjust their *ibadah* (worship) or religious practice. The challenges faced by patients undergoing dialysis treatment have provided valuable experience. All these primary themes have revealed the quality of life of dialysis patients through their illness. Individuals suffering from CKD with dialysis treatment face many intricate obstacles, including heightened symptom burden and functional restrictions across various routine activities in life. The originality of this study lies in its overall findings, which highlight the concept of embracing the current situation and accepting that their lives have deviated from the norm.

Keywords: chronic kidney disease, dialysis, lived experience, patients, Malaysia.

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慢性腎臟病患者接受透析治療的生活經驗：初步研究

摘要：

這項研究肯定了接受透析治療的慢性腎臟病患者持續接受疾病並調整日常生活的能力。本研究旨在調查患者在接受透析治療時應對慢性腎臟病的具體經驗。慢性腎臟病的診斷通常需要改變生活方式。初步研究探討了居住在馬來西亞東海岸的慢性腎臟病患者的個人經驗。一項質性描述性研究採用敘述方法探討慢性腎臟病患者的生活經驗。出於保密原因，有目的地抽樣選擇了八名接受透析治療的患者，並在諮詢室進行了半結構化訪談。這項研究出現了三個主要主題：(i) 透析治療前後的生活閃回，(ii) 患者的健康影響他們的社交生活，(iii) 治療和疾病導致他們調整他們的崇拜或宗教習俗。接受透析治療的患者所面臨的挑戰提供了寶貴的經驗。所有這些主要主題都透過疾病揭示了透析患者的生活品質。接受透析治療的慢性腎臟病患者面臨許多複雜的障礙，包括症狀負擔加重和生活中各種日常活動的功能限制。這項研究的獨創性在於它的整體研究結果，它強調了擁抱現狀並接受自己的生活偏離常態的概念。

关键词：慢性腎臟病，透析，生活經歷，患者，馬來西亞。

1. Introduction

Chronic kidney disease (CKD) is a global health concern with a rapid increase in prevalence over the past decade because of the growing diabetic population (Kovesdy, 2022). The number of individuals requiring regular dialysis has been steadily increasing worldwide. Over the past two decades, there has been a steady increase in the number of patients with CKD in Malaysia (Ngo et al., 2011). According to the 24th Report of the Malaysia Dialysis and Transplant Registry 2016, there are currently 39,711 patients undergoing renal replacement therapy, with 35,781 patients receiving dialysis. Among these patients, 19.0% belong to the age group of 65 years and above, and among the newly diagnosed dialysis patients, 26.0% are 65 years and older. Given the rising prevalence of health issues such as obesity, diabetes, and hypertension among the middle-aged population, it is reasonable to expect a further increase in the prevalence of CKD among the elderly population in the future (Bujang et al., 2017). Several recent cross-sectional studies have been conducted on the eastern coast of Malaysia using quantitative methods to investigate various issues. These studies primarily focused on knowledge and awareness (Sowtali et al., 2019), medication management for dialysis patients (Fong et al., 2021), and alternative medicine (Islahudin et al., 2021; Zakaria et al., 2021). However, in this study, researchers shed light on experiences and revealed them to the public, providing a unique perspective on these issues.

CKD patients undergo dialysis, which not only poses an elevated risk of mortality but also significantly impacts daily activities and the overall quality of life (QoL) (Ghimire et al., 2022; van Haalen et al., 2020; Dąbrowska-Bender et al., 2018). Moreover, the financial burden of CKD treatment is substantial (Trish et al., 2021; Hassan et al., 2018). Consequently, kidney

failure severely limits the physical, mental, and social activities of affected patients (Wilund et al., 2020), preventing them from leading comfortable lives and it can be life-threatening. However, dialysis treatment can significantly improve the QoL of patients, allowing them to regain a semblance of normalcy (Hall et al., 2020; Wei & Yao, 2021).

The popularity of the QoL concept has skyrocketed. A mere Google search for the keyword quality of life on any website yields millions of results. Quality of life encompasses five dimensions: physical, material, social, and emotional well-being, and development and activity (Felce & Perry, 1995). When a patient is diagnosed with kidney failure, their quality of life transforms. Similarly, when a new patient begins dialysis, they must adapt to a new way of life (Stavropoulou et al., 2020). Many patients find it challenging to acclimatize to an unfamiliar environment, which significantly impacts their lives. Dialysis patients often make significant adjustments to their daily lives compared with their normal lives. Several major aspects have changed the patient's life and adjusted it, but they also necessitate purposeful changes in their functioning. When adjusting their lives, they must consider various factors, such as treatment options and financial concerns. Their professional lives change (Bujang et al., 2017; Kerklaan et al., 2020), often affecting their ability to financially support themselves and their families (Beaudry et al., 2018; Tang et al., 2020). It is important to remember that individuals under dialysis may experience many emotions and moods (Nair et al., 2021; Tarca et al., 2023; Nawi et al., 2023).

Because of their health condition, patients with CKD often must give up other activities such as leisure activities, personal development sports, hobbies, social engagements, and personal growth (Lucena et al., 2018; Hall et al., 2020). It is essential to remember the importance of maintaining a work-life balance while

receiving dialysis treatment to endure the illness. What makes patients with CKD unique is their ability to continue to work while undergoing dialysis three times a week for a minimum of 5 hours. Dialysis should not be seen as the end of life but rather as the beginning of a new life. Therefore, patients must prioritize self-care in all aspects of their lives to preserve their quality of life. The key to maintaining a sense of normalcy for dialysis patients lies in maintaining a positive mindset and putting in effort. The life expectancy of dialysis patients can vary significantly depending on their overall health and adherence to the treatment plan. It is common for dialysis patients to live several years longer, and there have even been cases of patients living for twenty years or more (Aoun et al., 2020).

The exploration of patients' lived experiences with CKD, specifically those undergoing hemodialysis, remains largely unexplored in the relevant literature, particularly among Asians. Certain cultures regard personal life, illness, and burdens as sensitive matters that should not be disclosed. Their struggles may be delicate for the population, leading to reluctance to share them publicly. Gaining a deeper understanding of the life experiences and perspectives of patients with CKD would contribute to enhance overall patient care, family understanding, and, ultimately, QoL.

2. Research Methodology

Ethical approval was obtained from the University Human Research Ethics Committee and the Head of the Hemodialysis Centre for Universiti Sultan Zainal Abidin (UniSZA) Medical Services.

This study used a descriptive qualitative methodological design to investigate the lived experiences of Malaysian patients diagnosed with CKD and who underwent dialysis treatment. This design is the most suitable approach for exploring human experiences and gaining a deeper understanding of the studied phenomena (Marton, 2002; Van Manen, 2016). Participants in the study were from the UniSZA Hemodialysis Center. This dialysis center was on the east coast, in the university compound area. The recruitment criteria considered the potential significance of the participants in providing substantial information regarding their firsthand experience of CKD with hemodialysis. Individuals had to be adults over 18, diagnosed with CKD, have undergone hemodialysis for at least one year, and possess fluent comprehension and speaking abilities in the Malay language. Nurse managers at the hemodialysis center were responsible for identifying potential participants who met the inclusion criteria. A purposeful sampling strategy explored and involved patients' lived experiences with CKD, which could provide valuable insights into the research topic. Eight patients were interviewed for this preliminary study before the actual research. All participants were Muslims, as the locality has a population of 98.0% Malays who are predominantly Muslims. Those who fulfilled the criteria and were willing to be interviewed became participants.

Before recruitment, a thorough briefing explained the purpose and scope of the study.

The researchers ensured the safety and well-being of the patients and the voluntary aspect of their involvement. The patients were assured of confidentiality, anonymity, and freedom to withdraw from the study whenever they wished. Before conducting interviews, informed consent was obtained informing the patients about recording the conversations for the study's purpose and securely preserving them. All names have been replaced with pseudonyms. The process of gathering and analyzing data included conducting semi-structured interviews in a counseling room at the center to maintain confidentiality. These interviews were facilitated by one of the authors. The conversation with patients began with a question about their experiences living with CKD and dialysis treatment, such as "Describe your experience as a CKD patient with dialysis treatment." To promote greater participation and sharing of personal experiences, participants were prompted with additional open-ended questions regarding the impact of CKD diagnosis on their family and social life. For instance, could you please elaborate on the adjustments you have made after undergoing treatment? This narrative approach encourages patients to openly discuss their experiences with researchers. To ensure that patients have a complete understanding of the questions, it is essential to include follow-up questions during the probing process that not only help vague answers but also encourage patients to provide more detailed explanations. In addition, a small token of appreciation was provided to the patients. Each interview lasted for less than 30 min and was transcribed word for word.

The data were subsequently examined through qualitative thematic analysis, which engaged reading, evaluation, coding, and arrangement of the data (Braun & Clarke, 2020). The analysis procedure encompassed initial coding, classification of codes, and formulation of themes. The analysis components were the words or phrases employed by the patients in their statements. The information was condensed into concepts depicting the real-life (Guetterman, 2015) encounters of patients with CKD, following the techniques by Stavropoulou et al. (2017).

The classification of shared ideas facilitated a particular check and differentiation, leading to the identification of three fundamental patterns that depict the encounters of patients residing on the Malaysian east coast affected by CKD and dialysis treatment. To ensure the dependability of the research findings, the team members were actively involved to eliminate any potential bias and achieve a consensus regarding the emerging concepts and patterns (Braun & Clarke, 2020). Furthermore, the debriefing sessions conducted within the research grant team served as a platform to evaluate and enhance ideas and interpretations while acknowledging individual inclinations (Sweeney et al., 2020).

3. Findings

Table 1 presents the sociodemographic characteristics of the participants. The demographic characteristics chosen for distinction included age, gender, occupation, ability to afford the service, and history of dialysis. These factors provide a tailored and personalized experience for patients. Among the participants, eight were patients who had undergone dialysis for more than a year. Their ages ranged from 48 to 68. In terms of gender, three male and five female patients volunteered for the study. All of them had been married for a significant period, although Aunty Bella

and Uncle Ghaz had recently lost their spouses. Of the eight participants, only two were still employed. Aunty Bella worked as a teacher, and Uncle Chik worked as a technician. The remaining participants had retired or resigned from their respective careers, three of whom were housewives. All of them resided with their families. The family members of the four participants covered the cost of dialysis treatment. Aunty Bella, Uncle Ghaz, and Uncle Hassan utilized the medical benefits provided by their employers. On the other hand, Uncle Chik initially paid for his treatment out of his own pocket but later began receiving financial assistance from a welfare organization.

Table 1. Informant characteristics (The authors)

Patients names	Age	Gender	Patient occupation	Dialysis treatment cost cover	Dialysis history (years)
Aunty Ana	48	Female	Resigned general worker	Son	3
Aunty Bella	49	Female	Teacher	Herself	2
Uncle Chik	53	Male	Technician	Welfare organization	1.5
Aunty Diba	48	Female	Housewife	Spouse	5
Aunty Elin	68	Female	Housewife	Son	3
Aunty Fazira	56	Female	Housewife	Daughter	4
Uncle Ghaz	61	Male	Pensioner	Himself	5
Uncle Hassan	58	Male	Pensioner	Himself	3

Note: All names have been replaced with pseudonyms.

3.1. Theme 1: Life before and after Dialysis Treatment in a Flashback

After being diagnosed with CKD and starting dialysis treatment, all participants withdraw from family, friends, and relatives or show little or no interest in the social interactions, hobbies, and physical activities that they once enjoyed. However, they do recall their lives before becoming ill. It is a psychological phenomenon in which a person feels a powerful feeling that could be joyful, sorrowful, exciting, or anything else that comes to mind. All participants discussed their lives before being diagnosed with dialysis for this theme. They generally highlight both exciting and unpleasant incidents that occurred before and after dialysis treatment in their flashback recollections related to their everyday routine. This is a frequent psychological reaction among those who have experienced a major life change. Most of them continually compare their active daily lives to their current circumstances. They are missing the joy and happiness they experienced previously. Aunty Ana, Aunty Bella, and Uncle Chik like and are pleased with their jobs. Aunty Ana noted that during her employment as a general worker, she enjoyed singing and making jokes with her coworkers to relieve tension. They all remember that if they are in excellent health, they may work hard and participate in sports like badminton or enjoy food hunting, as shown in the extract below:

“Three years ago, I was active. I used to play badminton occasionally, but after being diagnosed with diabetes, my health deteriorated. And I suffered a stroke” (Aunty Ana).

“I used to go to eat with my friends, especially viral cuisine, when I was healthy, but now my situation doesn’t allow me to do so” (Uncle Chik).

Participants who are housewives recall activities such as gardening, cooking, decorating their homes, and running a neighborhood business, which they are unable to do due to dialysis treatment and health conditions.

“Because I don’t like to rest at home, I used to do all the housework. Of course, I enjoy cooking and gardening. However, following dialysis, I will have to cut back on these activities and spend more time at home resting” (Aunty Diba).

“I used to like selling clothes, bags, and accessories in my neighborhood but after starting dialysis, I had to give up my hobby” (Aunty Elin).

The female patients describe praying, or *solah*, which necessitates them sitting in a chair or wheelchair because of their inability to stand normally. Not only that, but because of their inability to move for some of them, family members must help them do ablution before prayer.

“I require assistance with ablution from my family, and I am unable to pray as a regular person. I require a chair on which to sit” (Aunty Ana).

“Dialysis makes you sluggish and exhausted regularly. If I want to pray, I will have to sit, and I cannot stand too long for the prayer” (Aunty Fazira).

Two of the retirement patients stated that their workaholic status has led to diabetes, hypertension, and insomnia. They wished they could go back in time and adjust their daily routine to prevent their health from deteriorating to this point.

“I wish I could go back in time. I should organize my life and pay more attention to my health. My illness makes me retire early” (Uncle Ghaz).

“My shift working schedule makes me forget about the appropriate diet intake. I eat whatever I want,

especially during the night shift, and I love to drink carbonated drinks too. Now I regret all my eating habits. I so felt stressed when I knew that I must get dialysis treatment” (Uncle Hassan).

According to Aunty Bella, another factor contributing to her kidney damage is when she helps and trusts a friend who promotes a powder supplement for enhancing health. She bought it to support her friend and consumed it. For about eight months after taking it regularly, she passed out one day after eating too many sweets and was told by the doctor that she had damaged her kidney and needed dialysis. She regrets taking it.

“I used to assist and trust a supplement that was recommended by a close friend. I used to consume it on a regular basis, and the powder is now contributing to my current situation. I felt so disappointed with myself that I was to blame” (Auntly Bella).

Moreover, all of them are frustrated that dialysis prevents them from enjoying extended trips and holidays with their family. When they are in excellent health, participants in this study said they can embark on extended journeys, but dialysis therapy prevents them from doing so. They admit that they can follow and organize dialysis at a nearby trip location, but that it would require some planning ahead of time, which would be challenging for the family members.

“We used to go on extended vacations every year, but if I undergo this treatment, I won't be able to join my children because I must go to the dialysis center. I don't want to be a burden to them because of my health. So, I decided not to join them, as I used to do,” said Auntly Elin.

The participants strive to contrast their lives before and after dialysis. Most recall the activities they can engage in and those they cannot partake in now. They realize they are missing the present moment and openly convey their emotions to the researcher.

3.2. Theme 2: Patients' Health Impacted Their Social Life

Significant health problems can significantly affect a person's life, whether it is chronic or life-threatening. In such situations, patients may feel that nobody truly comprehends their struggles. Regardless of the specific circumstances faced by a dialysis patient, it is imperative not to withdraw during this period. All participants unanimously expressed that dialysis treatment requires a significant amount of time each week, with each session more than 5 hours. Because of the treatment's adverse effects, patients constantly experience lethargy, fatigue, and exhaustion.

Upon receiving a diagnosis of CKD, the participants realized that their lives would be marked by various limitations. Housewives, in particular, find themselves unable to engage in activities such as gardening and cooking for their families because of their unstable physical conditions. Many of them are forced to retire prematurely from their careers and are unable to socialize with friends and relatives. Their health issues compel them to curtail the activities they once enjoyed

when they were in good health. As a consequence, some of them suffer from fatigue all the time. The participants' responses to these challenges are as follows:

“As a teacher, I have to keep track of my activities; because of my condition, senior management considers my working hours and holds me accountable” (Auntly Bella).

“I can no longer accomplish many domestic tasks at home without the assistance of my children. I'm unhappy because it's part of my responsibility” (Auntly Diba).

“When I receive my dialysis treatment, I cannot work effectively after that, even when I go to the office. I felt so exhausted, and my productivity at work decreased. I decided to retire earlier” (Uncle Hassan).

Among the patients who participated in this study, diagnoses of diabetes, hypertension, gout, insomnia, and low blood pressure were prevalent. It was observed that individuals with diabetes and hypertension often experience kidney failure, which may require dialysis. These participants expressed that their illnesses have deprived them of their primary roles as family breadwinners or mothers. Consequently, they may experience feelings of guilt, believing that their health outcomes have placed a burden on their family and relatives.

“My children and hubby must assist me with my daily routine” (Auntly Ana).

“The majority of the chores fall to my wife. I could assist the last time, but on days when I had dialysis, I needed to relax because of exhaustion” (Uncle Chik).

“My children must make sacrifices for my illness, including cooking meals and caring for me” (Auntly Fazira).

Their daily routine revolves around relying on others for various aspects of their social lives. This includes arranging transportation for dialysis sessions three times a week, as they are no longer able to drive themselves. In addition, they require assistance with ablution before prayer and financial support to cover the costs of their dialysis treatment. Moreover, they bear the responsibility of handling strenuous household tasks such as cleaning, cooking, and managing their younger siblings. Unfortunately, due to their treatment, they have limited time to attend gatherings with other relatives and spend quality time with their own family. One of them said that his wife had difficulty understanding him at the start of the treatment. His wife used to wonder why he would sleep instead of helping her at home after dialysis sessions. The emotional toll of these circumstances was evident as both Auntly Ana and Uncle Chik shed tears while discussing how their social well-being and ability to lead a normal life were profoundly impacted by their experiences.

“I cannot cook just like before because of the fatigue. I just give instructions to my family” (Auntly Ana).

“I am so sad sometimes and let my wife do most of the housework after my dialysis, and I feel so

exhausted” (Uncle Chik).

Because of their dialysis treatment and physical condition, especially fatigue syndrome, they faced difficulties socializing and engaging in activities with their friends. They made a conscious decision to isolate themselves because of their health circumstances. Many of them chose to introspect and embrace their situation as a divine decree. They sought solace in living in a tranquil setting and devoted themselves to religious practices. By focusing on *ibadah* (worship), or religious practice as Muslims, they found comfort and contemplated their past lives within this context. It seemed evident that they had come to terms with their illness and health, accepting their fate, or *redha*.

“After being diagnosed and needing treatment, I *redha*, prefer to be alone focusing on *ibadah*” (Aunty Elin).

“I choose to be on my own at home. I prefer to pray and *zikir* (remembering Allah) to Allah during that time” (Aunty Ana).

“I must accept my fate and *redha*. Preparing that maybe I must prepare myself for another life and do *ibadah* as much as I can” (Uncle Hassan).

The participants in this study were required to select a specific diet based on their medical conditions and adhere to the prescribed restrictions. They firmly believe that by monitoring their dietary habits and engaging in regular exercise, they can prevent illness. The information they have received regarding proper nutrition has been transformative, enabling them to make significant changes in their lives. Aunty Bella, however, finds herself in a particularly challenging situation as she recently underwent toe amputation surgery to remove a portion of her toe. Given her health condition and personal circumstances with her family, she experiences high levels of stress and anxiety. Aunty Bella also expresses remorse to the researcher for having taken supplements, as she was persuaded by both the product agent and her friends. Unfortunately, her health deteriorated because of consuming these supplements. Consequently, she has now resorted to preparing her own meals instead of purchasing them to adhere to her dietary restrictions.

“I must cook for myself. Quite seldom I buy from outside after I must get dialysis treatment” (Aunty Bella).

Because of their circumstances, most of them require support from their family and relatives for their daily tasks. The dialysis facility has become a familiar environment for them, serving as both a treatment center and a meeting place for patients facing similar challenges. The dialysis center has transformed into a hub for socializing and connecting with others who share their life circumstances. This observation was evident during the data collection process.

“I like to see my dialysis friends. Sometimes we communicate and share stories” (Aunty Ana).

“Now the dialysis center is my second home and I am meeting new friends” (Uncle Chik).

“I try to schedule my dialysis time so that I can meet my friend at the center” (Aunty Fazira).

The illness affected the participants in this study, specifically in terms of their daily routines and social activities. The patients must adapt to their new life after undergoing dialysis treatment; this is the aspect they have been discussing during the interviews. They depend on assistance from others, especially their family members, to perform their daily activities. The support and understanding of their families are crucial for the participants to make progress.

3.3. Theme 3: Treatment and Illness Cause Patients to Adjust Their *Ibadah* or Religious Practices

Practices and customs play a significant role in the Islamic faith. Certain rituals, such as daily prayers, are performed regularly, whereas others, such as fasting during *Ramadan* (the ninth month of the Islamic calendar and as a month of fasting), are observed annually. Despite the limited number of religious events and ceremonies in Islam, they hold immense importance. The *unnah* (manner of acting), for example, not only serves as the foundation for major Islamic rituals such as prayer but also influences everyday activities such as engaging in charitable work and showing kindness to those around us.

The participants who were interviewed expressed deep concern regarding their *ibadah* as Muslims. Their tone of voice, choice of words, and emotions during the interview revealed their distress when they could not perform *ibadah* as usual due to their diagnosis. Throughout the session, six participants shed tears while discussing *ibadah*. Some participants, for instance, shared their thoughts by stating the following:

“I require assistance with ablution from my family, and I am unable to pray as a regular I require a chair in which to sit. I feel so sad because I am not normal anymore,” Aunty Ana said, and the researchers saw the tears, and she wiped her eyes.

“Last time, I used to go to the mosque to pray every prayer time, but now, due to fatigue symptoms, I can go to the mosque only once a day” (Uncle Ghaz).

“I felt lost because I did not perform much *ibadah* when I was healthy. I wish I could turn back my time” (Aunty Elin).

Because of their current state of health and ongoing treatment, the individuals recognize the significance of engaging in as much *ibadah* as possible. Each member of the participants’ family adheres to their own set of Muslim customs daily. Let us now examine how participants respond to these practices. Aunty Ana regularly attends Islamic lessons in her local community, which are held twice a month. Through her active involvement in various activities, she has become acquainted with the concept of *jama'*, which entails combining prayers for the well-being of patients. Following her dialysis treatments, she used to perform *solah jama'* (combine prayer). However, she experienced a sense of disappointment because she

could not stand and pray like a typical Muslim. Instead, she had to sit on a chair or lie down on a bed. The researchers observed her expression of discontent when she found herself dissatisfied with the situation. Similarly, Aunty Elin was also familiar with the *jama'* concept. Both participants mentioned this practice as beneficial for patients.

“As a patient for dialysis, we can do *solah jama'*” (Aunty Elin).

“I knew about *solah jama'* because I used to listen to the sermon” (Aunty Ana).

“As patients for dialysis treatment, we can perform *jama'*” (Uncle Hassan).

On the other hand, Uncle Chik and Aunty Diba are utterly unaware of the benefits of the *Jama* prayer for the ill in Islam. Uncle Chik and Aunty Diba keep mentioning what they should have done if they missed the *solah* and the *qada'* prayer (compensation prayer if an individual did not perform it within the prayer time).

“I do not know how many prayers I must *qada'* because of the dialysis session. After dialysis, I felt tired and sleepy, so I did not perform *solah*” (Aunty Diba).

“Dialysis time sometimes makes me neglect Zuhur (noon prayer) or Asar (prayer before the sunset). Because after dialysis, I feel tired and sleep at home. When I woke up, the prayer time was over, and I must *qada'*” (Uncle Chik).

He also expressed his dissatisfaction with the fact that he was unable to attend the mosque daily because of the COVID-19 pandemic. Researchers could monitor and evaluate his emotions as he spoke. As he halted his statement for a few seconds, we could see him wipe his eyes.

“I feel unhappy and sad about my health sometimes. I cannot do *ibadah* as a normal person,” Uncle Chick wipes his eyes.

Aunty Diba also continued to do the *qada'* prayer even though she failed to count the necessary prayers that she omitted. Aunty Bella, on the other hand, made no mention of *jama'*. They all believe that more *sunnah* prayers (additional prayers), such as *tahajjud* (night prayer), *dhuha* (prayer after the sunrise), and *taubah* (repentance prayer), should be performed. They used to remark that they were about to leave this life because their devotion to God was sincere. Because of their health concerns, all participants in this study said that they would be unable to fast for the entire month of *Ramadan*. They mentioned that they try to finish as many days as they can. Because of their dialysis and diabetic concerns, they could not go hungry. Furthermore, Aunty Diba has low blood pressure and is prone to fainting. *Zikr*, reciting the *Quran* (Islamic religious textbook), and *sadaqah* (voluntary offering of charity as a Muslim) are some of the *ibadah* that accompany it. In addition, the study participants emphasized the need for *zikr* (devotional acts in which short phrases repeatedly recounted) and more frequent *Quran* recitals. According to most of them, their sleeping patterns have changed because of their dialysis

treatment.

“I will do more *ibadah*, for example *taubah*, and *tahajjud* prayer, recite the *Quran*, *zikr*” (Aunty Ana).

“For me, because of the dialysis session in the morning, I will wake up early and do as much *ibadah* as I can before leaving my house for dialysis” (Aunty Bella).

They woke up early in the morning to memorize the *Quran*, perform *zikr* and *tahajjud* prayers, and extend their prayers until the *fajr* or Morning Prayer. Many of them prefer to undergo dialysis first thing in the morning. A few participants raised the notion of *sadaqah*. As Muslims, we are encouraged to donate food, money, knowledge, or aid, and God will amply reward us for it, just as the participants have done throughout their lives.

They all believe that the sickness has impacted their lives and prompted them to increase their *ibadah* as Muslims. The participants agree that they have given Allah more of their lives because of their struggle than they had before their illness. In comparison to before the treatment, they perform *sunnah* prayer, *zikr* to Allah, and recite the *Quran* regularly. Their *ibadah* has taken on increased significance in their lives because of their situation.

4. Discussion

Considerable data has been accumulated on the topic, specifically on the health and lived encounters of patients before and following their diagnosis with dialysis treatment, which significantly impacts their overall well-being. This analysis has revealed several significant findings, emphasizing three primary themes that elucidate the journey of patients with CKD and their experience with dialysis treatment, offering valuable insights into their ordeal. From the first theme, the participants reflect on their daily routines before falling ill. Every participant experiences their illness subjectively. Many of them recall the pleasure they found in their work, engaging in activities such as household chores, not performing *ibadah* in normal form, family vacation, and enjoying time with friends for food hunting. They contrast these memories with their current situation, in which they must adapt and cope with their illness. All of them expressed a desire to turn back the time and prioritize their health, leading healthier lifestyles. Now, they must make changes to their lives based on their treatment and health conditions. This study finding agreed with the studies conducted by Stavropoulou et al. (2020), Kerklaan et al. (2020), and Tadesse et al. (2021), where participants described the loss of their freedom to participate in their normal activities, restrictions in diet as well as movement, and decreased ability to perform their jobs. None of them, however, make any mention of the flashback component in their research, which was discussed by the participants in this study as they compared their current circumstances with their previous state of well-being. Nevertheless, there is a scarcity of research that specifically examines the

occurrence of flashbacks and compares the healthy and illness-related aspects of patients' conditions. Numerous scholars have focused their attention on investigating the issue of trauma-induced flashbacks and the corresponding treatment methods upon receiving a diagnosis of the illness (Crouse, 2022; Raut et al., 2022; Rotharmel et al., 2024).

The second theme of discussion among participants revolved around the limitations and restrictions they face in fully participating in their social lives and daily activities due to CKD and dialysis. Activities that were once easily accomplished during healthier times are now out of reach. Fatigue was a common experience mentioned by most participants and was described as diminishing their potential and energy, resulting in a decreased ability to perform daily tasks. These limitations in activities have a significant impact on the participants' social lives and overall quality of life. Many participants expressed feelings of loss due to constant fatigue. Additionally, participants shared how their social roles have been disrupted, with male participants no longer able to fulfill their role as the breadwinner for their families and female participants unable to fully embrace their roles as mothers and wives. As a result, many household responsibilities have been transferred to their children and spouses. Furthermore, participants encounter the obstacle of abiding by complex dietary restrictions while also requiring assistance in their daily activities. Similar findings have been reported in studies conducted by Tedesse et al. (2021) and Hall et al. (2020). The participants emphasized the significance of acceptance, or *redha*, of the disease and the effort to lead a better life within this context. These were identified as critical factors for moving forward and maintaining a positive outlook on life. The current study sheds light on the impact of the disease on patients' emotions and inner psychology, illustrating the transition from despair to acceptance, adaptation, and the endeavor to effectively manage their condition. When individuals embrace this situation, they tend to prioritize religious practices and engage in virtuous deeds in their daily lives. This demonstrates the importance of accepting the disease (Stavropoulou et al., 2020; Hall et al., 2020). The patients, who used to isolate themselves because of their health conditions, have found solace in the dialysis center, where they can socialize and share their stories with one another. It is noteworthy that the fact that the dialysis center has become a social hub for patients has not received much attention from researchers. However, Kerklaan et al. (2020) highlighted the importance of patients forming friendships and socializing with their fellow dialysis patients at the center.

The participants in the final theme expressed a deep sense of sadness regarding their illness, yet they have accepted or embraced their health condition. During the interview sessions, many of them displayed their sadness and regret through their tone of voice and tears due to their illnesses. The prevalence of this scenario is

widely acknowledged, as numerous studies (Mariyama & Betriana, 2021; Estave et al., 2021; Levi & Moss, 2022) have extensively discussed the expression of sadness through vocal tones and tears. Their focus has shifted toward engaging in the good practices of *ibadah* and drawing closer to God. Multiple studies have shown that individuals with chronic illnesses benefit from engaging in spiritual well-being practices according to their faith. These studies include research conducted by Bandeali et al. (2020), Merath et al. (2020), Asadzandi (2020), Kutman et al. (2021), Osman et al. (2021), and Balboni et al. (2022). Furthermore, Kutman et al. (2021) and Merath et al. (2020) specifically emphasized that the ability to adapt to chronic illnesses improves when individuals incorporate spiritual practices. This finding is associated with the third theme of the study. They feel a sense of urgency to engage in righteous deeds in their remaining time, fully aware that their meeting with God is imminent (Fradelos et al., 2021; de Padua Paz et al., 2021). A common regret expressed by patients in this study is that they did not engage in enough good practices as Muslims when they were healthy. This scenario bears resemblance to the findings of a comprehensive study by Osman et al. (2021), which extensively explored the religious practices of Muslim patients. Additionally, Merath et al. (2020) emphasized the significance of faith and spirituality in patients, particularly in terms of their preparedness for the inevitability of death. The patients in this study expressed their dependence on their family's assistance, particularly in terms of physical mobility and fulfilling their daily responsibilities, including religious obligations and household tasks. Numerous studies have highlighted the significance of family social support in the daily routines of chronically ill patients, irrespective of their specific condition (Griva et al., 2020; Tedesse et al., 2020; Ng et al., 2020; Darwish et al., 2020; Riazuelo, 2021). Because of their health issues, especially the lack of physical strength, they must adapt their *ibadah* style according to the guidelines provided by Islam, which accommodate the ease and capabilities of patients known as *rukhsah* (Arif et al., 2014; Yusop, et al., 2023). The research methodology employed enabled us to delve into human experiences and gain a deeper understanding of the actual phenomena that chronic kidney patients undergo throughout dialysis treatment. It is crucial to keep in mind that individuals vary in how they cope with and manage their illness. While the findings of our study align with those of previous research on the lived experiences of CKD patients, our sample consisted of individuals from the east coast of Malaysia, where there is limited available information. Obtaining genuine firsthand experiences from patients is challenging because of the sensitive and confidential nature of their condition, which they may choose not to share with others. However, the information gathered, including reflections on past regrets and the importance of accepting one's illness while incorporating religious

practices as a coping mechanism, can serve as a valuable resource for healthcare providers and stakeholders. These data can guide future patients and their families in supporting individuals dealing with similar situations.

5. Conclusion

Most of the existing literature on this subject has focused on the fact that CKD patients who undergo dialysis tend to have a lower quality of life and experience feelings of sadness because they rely on others for assistance. This study has identified several similar situations mentioned by the patients, which align with the findings in the literature. However, what sets this study apart is its exploration of the concept of true acceptance of the situation among dialysis patients. Unlike other chronic illnesses, such as cancer, not many researchers have written about this concept of CKD patients because CKD, being a chronic illness, allows patients to continue working and receiving treatment to manage their condition. Acceptance is applied to various aspects of life, such as daily mobility and religious practices, to cope with illness. The study of the lived experience of CKD and dialysis treatment about acceptance of the situation covers only the Asian community, including Malaysia's culturally diverse population. Therefore, this study aimed to enhance the understanding of the lived experience of CKD patients undergoing dialysis and how they cope, filling a gap in the health science literature. The study focused on the perspectives of Muslim patients because of the research locality, so the data obtained may not be comparable with other beliefs and practices. Future research should explore the lived experiences of CKD patients with different populations and beliefs. The limitations in daily functioning, including social activities, physical mobility, and religious practices, can be shared and used as a reference point for a broader society. Therefore, the study also recommends that future CKD studies emphasize the Malaysian community to support and better understand CKD patients' situations, especially their families and relatives, referring to the acceptance concept. In conclusion, the findings of this study serve as a valuable source of information to develop strategies to improve the QoL for patients and their families.

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