

Exploring the Challenges in Following Nutrition Recommendations Among Malaysians with Early Stages of Chronic Kidney Disease (CKD)

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Abstract

Chronic kidney disease (CKD) is a significant global public health problem. Despite the growing burden of CKD and its accompanying co-morbidities, the difficulties faced by the CKD population in Malaysia, particularly those who are in the early stages of the disease, have not yet been identified. Hence, a qualitative study was undertaken to identify the challenges faced by CKD patients in following nutrition recommendations. Eight patients diagnosed with early stages of CKD (stages 2 and 3) were recruited to undergo in-depth semi-structured interview sessions consisting of open-ended questions were conducted. Responses given in Malay were recorded verbatim and were translated into English. The data was analysed thematically with NVivo version 12 software. Five themes emerged from the interviews: 1) CKD health literacy, 2) changes in lifestyle and eating behaviours, 3) challenges in following CKD recommendations, 4) nutrition education perceptions and preferences, and 5) quality of life. The major challenges encountered by CKD patients in following nutrition recommendations were a lack of knowledge of CKD, insufficient communication between patient and healthcare professional (dietitian), inadequate healthy food choices, and a lack of time to prepare healthy food. The majority of the patients had never heard of nutrition education, yet they all agreed that nutrition and health education were essential for CKD patients. In addition, positive support from family and friends was considered a key component in improving their personal needs and quality of life. From the findings, it is concluded that effective nutrition education should be developed and explained clearly to the patients in order to improve patients' self-management and empower them to make appropriate food choices. This study can be useful for healthcare professionals and policymakers intending to implement nutrition education-related interventions in order to improve CKD patients' knowledge and their quality of life.

Keywords: barriers, challenges, chronic kidney disease, early stages, Malaysian, nutrition education

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INTRODUCTION

Chronic kidney disease (CKD) is a significant global public health problem, affecting millions of people worldwide. CKD is characterised as a reduction in kidney functions, due to structural changes to the kidney. It results in either loss of nephron tissue or reduction of functional renal mass with glomerular filtration rate less than 60 ml/min/1.73 m² for more than three months (Palmer et al., 2017). The prevalence of CKD in Malaysia is alarming, as it has steadily increased over the years. A study undertaken in Malaysia found that more than 90% of the CKD population were treated in primary healthcare only after being diagnosed with stage 2, and stage 3 based on their glomerular filtration rate (GFR). A major concern is that the uncontrolled and improper management of CKD risk factors in patients such as diabetes, hypertension, and obesity precedes end-stage renal disease (ESRD) (Bujang et al., 2017).

Haemodialysis is the most well-known kidney replacement therapy among CKD patients. The expected expenses per patient receiving dialysis at the Ministry of Health Malaysia ranged from RM29,092 to RM 33,642. Due to

the growth of kidney failure cases in Malaysia, the expected cost to treat all dialysis patients in 2040 will be 10 times greater than in 2000, based on an average cost of RM30,000 (Bujang et al., 2017). About 67.1% of the haemodialysis (HD) treatment expenditures are supported by the public sector, the Ministry of Health, and other organizations owned by the federal and state governments (Ismail et al., 2019). This health resources expenditure needs to be reduced as it is neither economical nor sustainable for the government. Therefore, it is argued here that there is a need to shift the focus to primary prevention strategies.

Primary prevention interventions such as improving CKD knowledge and nutrition education can potentially prevent or improve the management of CKD (Anderson & Nguyen, 2018). Nutrition education is a combination of educational strategies developed to facilitate voluntary practices of food choices and other nutrition-related behaviour beneficial to health and well-being (Jones et al., 2007). The burden of CKD correlates not only to the healthcare needs of patients but also to a broader public health issue. Besides, CKD is considered an independent risk factor for cardiovascular disease among CKD patients. As a result, preventing CKD not only reduces the burden of ESRD but also the associated complications such as cardiovascular morbidities and mortality.

Nutrition education and diet counselling are advocated in the prevention and management of CKD. According to the latest National Health and Morbidity Survey (NHMS) 2019, it was reported that a rising prevalence of obesity, hypertension, and type 2 diabetes are the leading causes of CKD (Saminathan et al., 2020). Thus, the importance of addressing nutrition among CKD patients should be given greater attention. However, the dietary guidelines for those with CKD patients can be complicated. A successful dietary management necessitates detailed menu planning, frequent nutritional status assessment, and the monitoring of dietary adherence.

Despite the known adverse effects of CKD, the majority of people with CKD remain unaware of their condition. It was reported by Saminathan et al. (2020) that the awareness of CKD diagnosis in Malaysia was unacceptably low at 5%, which is much lower as compared to other countries. Comparatively, within a 10-year period the awareness of CKD was found to be 12.5% in China (Zhang et al., 2012), 7.9% in India (Singh et al., 2013), 5.3% in Canada (Arora et al., 2013), and 1.9% in Thailand (Ingsathit et al., 2010). This, in turn, leads to late detection of illness and results in serious complications including kidney failure and cardiovascular disease (CVD).

CKD is linked to low quality of life, early mortality, substantial family burden and increased medical costs (Saminathan et al., 2020). As a result, strategies to prevent the progression of CKD, reduce complications and enhance quality of life are crucial. One of the cornerstones to enhancing CKD outcomes and quality of life is self-management of CKD. It is the active management of one's CKD condition, which includes adhering to treatment (for example taking medications or changing lifestyle behaviour), coordinating care, and using resources (Peng et al., 2019). An in-depth understanding of the experiences, challenges, and needs of patients with CKD is vital to improve the self-management of CKD. However as noted by Baumgart et al (2021), in clinical settings, this might not always be communicated by the patients, or their views frequently not being recorded. The self-management of CKD is encompassed by a variety of challenges, including dietary restriction, physical activity and lifestyle changes. According to a study undertaken by Meremo et al (2017) of patients in Tanzania, diet management was one of the most challenging self-management tasks reported by CKD patients. However, the challenges in meeting the nutrition recommendations in the early stages of CKD were not identified. Hence, this qualitative study aims to identify the challenges and gain deeper insights into the problems related to meeting the nutrition recommendations among CKD patients.

METHOD

This qualitative research was conducted using in-depth semi-structured interviews consisting of open-ended questions to gain insight into the challenges faced by CKD patients in Malaysia. Recruitment and interview sessions were conducted from October 2021 to March 2022. Under the movement control order (MCO) due to COVID-19, virtual interviews were used in this study. The research ethical approval was obtained from the Science and Engineering Research Ethics Committee of the University of Nottingham Malaysia (Ethics approval ID: MHMH011021).

Various sources suggest five to fifty people are an adequate number of participants in a qualitative study (Showkat & Parveen, 2017). The patients were recruited from several Malaysian CKD patient support on social media such as Facebook, WhatsApp, and Telegram. The inclusion criteria were: patients diagnosed with stage 2 or stage 3 CKD, aged 18 to 60 years old, and able to write and speak in Malay or English. Meanwhile, patients diagnosed with stages 4 and 5 and those who had kidney transplantation or had a psychiatric or mental illness were excluded. In this study, eight patients were finally recruited, four males and four females. All patients were Malay with a mean age of 44.75 ± 9.6 years old. Of the eight patients interviewed, seven were married while one was unmarried. They were located in Kuala Lumpur city and the central region Selangor of Malaysia. Their mean body mass

index (BMI) was $25.8 \pm 4.3 \text{ kg/m}^2$, which was considered as being overweight. Five of the CKD patients were diagnosed with stage 3 CKD while three were in stage 2. Four patients were diagnosed with CKD between 1 to 5 years later. In terms of comorbidities, about six patients had hypertension and four had hypercholesterolemia before being diagnosed with CKD. A brief introduction about the interview session was explained.

Data Collection and Analysis

A set of questionnaires was developed (see Appendix 1) based on a previous research study undertaken by Van Dipten et al., (2018). The questionnaire was pilot-tested on two CKD patients. All patients received a Google form link before the interview session to collect their demographic information and obtain their consent. Patients were requested to self-report their height in metres (m) and their weight in kilograms (kg). Each participant's Body Mass Index (BMI) was determined by dividing body weight by squared height (kg/m^2). The BMI was categorised according to World Health Organization (WHO) criteria for the Asia-Pacific classification of BMI (Nishida et al., 2004). The interview sessions took place using phone calls, Facebook calls, or WhatsApp calls in the Malay language. The interviewer first explained the purpose of the interview, followed by the interview guide. It took an average of 40 minutes for an interview session. Patients were encouraged to express their opinions, and appropriate probes were used to gather in-depth insights and comprehensive findings. All the interviews were conducted by a researcher and the responses given in Malay were audiotaped, recorded and transcribed verbatim. The transcribed responses were translated into English before being coded using NVivo version 12 software and analysed thematically. Each transcript was reviewed line-by-line and the identified codes were categorised under the emerging themes.

RESULTS

In this study, five themes emerged from the interviews: CKD literacy, changes in lifestyle and eating behaviours, challenges in following CKD recommendations, nutrition education perceptions and preferences, and quality of life.

CKD Literacy

When the patients were asked to define CKD, most of the patients provided indefinite and incomplete answers. For example: the kidneys are leaking, the kidneys fail to filter toxins or other substances, or kidney function decreases. Some of them even refer to unreliable sources for CKD definition.

"... according to some people, the kidneys fail to filter out toxin as well as the important substances that are stored in the body". (Patient 1)

"... according to the villagers, kidney disease happens when our kidneys are damaged and no longer functional. It is unable to filter anything that enters into the ". (Patient 2)

The majority of the patients can list the main symptoms and causes of CKD. However, it was based on their own experiences and self-diagnosis. The patients experienced familiar and repeated CKD symptoms such as urinary symptoms or bad urination, back pain, swollen leg (oedema), bad breath, and itchy skin.

"When I was in stage 3a, my urination was always bad (urinary symptoms) and my legs were swollen". (Patient 2)

"Before this, I was always suffering from back pain. It was as if someone was attempting to break someone else's waist. It feels like the backache worsens, especially when my period comes. I had no idea I had a kidney problem at that time. After that, I noticed that my ankles were a little swollen. I was feeling uneasy at that time, so I looked up the symptoms I was experiencing on the internet. I was a bit disappointed that no one ever told me for so many years as I always go to the health clinic for medical check-up. In addition, I also had trouble breathing." (Patient 4)

The causes of decreasing kidney function among the patients also include prolonged medications or painkillers, and a majority of them suffer from hypertension. Excessive uptake of non-clinically proven supplements, for instance, Malaysian herbs (Jamu) is also one of the causes of CKD in this study.

"I knew from the doctor that the reason for my CKD was taking medications for an extended period (for twenty to thirty years). For example, I took medication for high blood pressure and nerve constantly". (Patient 2)

“Back then, when I was sick, I used to take medicine like painkillers. Then, take the herbs (jamu). When my body felt a little pain, or had a headache, I need to take medicine (painkiller)”. (Patient 3)

Lastly, patients were asked about CKD treatment or kidney replacement therapy. Dialysis and kidney transplant was the most cited by patients.

“As far as I am aware, there are only two treatments. If a kidney donor is available, transplants can be performed. The second option is living with a dialysis machine for three sessions per week”. (Patient 1)

“Level 5 is normally reserved for dialysis. However, if someone can adhere to a strict diet, he/she may able to maintain at stage 4”. (Patient 5)

Changes in Lifestyle and Eating Behaviour

All patients stated that their lifestyle and eating behaviour altered drastically after being diagnosed with CKD by their doctors. Patients were motivated to change because they believed that CKD progression could be delayed or reversed, and they wanted to live a healthy life. Some patients narrated that their responsibility to their family members motivates them to adopt a healthier lifestyle.

“The reason I have to go on with my life is because my kids and family still need me.” (Patient 2)

“I really want to be healthy, so I have to eat healthily. In addition, I have to be optimistic. When I joined the CKD group, I met many CKD friends, and they gave me so many words of encouragement. When we are in the same condition, we can motivate each other to be healthy. Previously, I used to feel demotivated when I was lonely. Now, with the help of my friends from the support group, I can learn and practice healthy tips about CKD”. (Patient 3)

However, there are opinions about the reasons for not eating a healthy diet among CKD patients. Some CKD patients mentioned they felt hopelessness, demotivation, lack of awareness, lack of self-management, and uncontrolled desire.

“I think sometimes we do not follow the healthy diet because we have lost hope or we only found negative sides of CKD”. (Patient 1)

“Probably the factors for not adhering to the healthy diet are uncontrolled desire, big appetite, and lack of knowledge about CKD. Some might have a lack of awareness about CKD”. (Patient 4)

Challenges in following CKD recommendations

The patients expressed some of the challenges in adhering to CKD recommendations. The first challenge they encountered was insufficient communication between patients and healthcare professionals. Patients were looking forward to having a consultation with a dietitian to seek nutrition guidance and CKD diet recommendations.

“Even the nurse or doctor did not say anything about healthy eating or any nutrition advice. So I googled everything”. (Patient 1)

“It's scary, because when the patient leaves the hospital, they were not referred to see a dietitian. Nutrition is not shared directly. So, as a patient I will think, okay what am I going to do next?” (Patient 6)

“Actually, I had never experienced meeting with any dietitian for 30 years as a CKD patient. It's true”. (Patient 8)

The patients also mentioned that their daily lifestyle, which includes job, travel, and living environment, has a negative impact on the selection and preparation of healthy food. Patients also did not have sufficient time to prepare healthy food due to the demand for daily activities.

“The main reason might be our lifestyle. Our life is hectic and sometimes we don't have time.”

Sometimes we just want something to be easy and fast. Especially now with our children, our jobs, and different living environment can also influence our eating habits. Some of the restaurants do not sell a variety of vegetable (healthy) dishes. Every time I go, the dishes are always sold out and most of the dishes are not suitable for me". (Patient 5)

Nutrition Education

The majority of the patients had never heard of nutrition education, yet they all agreed that nutrition and health education were essential for CKD patients.

"I never heard about it". (Patient 1)

"If I did my own research on nutrition education I can possibly know about it. Right now, even my family does not know about this". (Patient 6)

The internet was the main source of CKD knowledge that patients used to refer to, besides nurses or doctors. Other than that, patients mentioned that they get CKD information and health advice from social media platforms such as the posts on the support group page. Some of them also referred to the content of some influencers on social media.

"For me, I refer to Doctor Nordin (a doctor and content creator), as if you ever heard of it. Besides, I personally consulted with that doctor". (Patient 3)

"I am comfortable with the doctor, as he seems to be telling me the truth. He wanted me to look healthy. He also gave guidance on how to eat healthy, even though he is not a dietitian". (Patient 4)

According to the patients, the important information that has to be taught in nutrition education is the CKD concept, healthy food choices, healthy activities, and healthy mental well-being.

"First, you need to explain some categories of such diets. For example the low carb diet and the keto diet. For CKD, what diet should be chosen? This is number one. Next number 2, a list of foods that must be avoided, for example, bananas because they are high in potassium. Then can be specific based on the disease stages, for example, what to eat at stage 1 up to stage 5". (Patient 1)

The patient also suggested developing a healthy menu or menu planning, specifically for CKD patients.

"If possible, make a food checklist for CKD, and list all the food. For those with diabetes a healthy menu for them as well. Other than that, you can list the menu or recipes that are suitable for patients according to their disease". (Patient 6)

Quality of Life

In order to improve their quality of life, the majority of patients responded that they need to maintain an active lifestyle and exercise regularly. In addition, getting enough rest and sleep quality allowed them to have a better quality of life.

"For me, I do exercise. Get enough sleep and sleep on time. (Patient 4)

"Physical health is the first thing the people here need to maintain. At least make some moves (be active). Do not sit still. If you sit still, your body will be weaker. Another thing, I maintain my jogging. Some people say running like a child (brisk walk). We are sick and we can't do much work, but we try to do something. Practice a light exercise.. (Patient 1)

In terms of psychological support, the majority of married patients reported receiving positive support from their spouse rather than family members. Social interaction with friends was cited as a key component in addressing their personal needs and improving their quality of life.

"So far, I am grateful to the Lord. I told my mother about it and now she cooks a lot of vegetables, along with other healthy food, using olive oil. I'm also thankful for being able to find the Facebook group that is the kidney group. At first, I thought that I'm the only

person in the world that has CKD. When I met that group, apparently many others have the same problems as me". (Patient 1)

"We have to be strong. Mentally strong especially. We must take care of our own physical health and family support is also important. Following that, we have to make friends with positive people rather than with negative people". (Patient 3)

DISCUSSION

CKD is a chronic disease, which affects physical well-being, emotion, family, lifestyle and relationships. This study has shed light on the challenges faced among early-stage CKD patients in following the nutrition guidelines. The online platform that was used in this study provided a convenient and flexible timeframe for CKD patients to share their experiences and challenges of living with CKD, their perception of nutrition education and ways to improve the quality of life among CKD patients. The mean age of our CKD patients was around 45 years old and the majority of them (75%) were more than 40 years old. This finding is in agreement with a population-based study that examined the prevalence of CKD among 890 Malaysian adults. The study reported the mean age was 48.8 ± 15.6 years old and that CKD was significantly associated with increasing age (Saminathan et al., 2020).

Our findings showed that the majority of the CKD patients were in the overweight (37.5%) or obese category (37.5%). Our study is in line with the previous study that revealed that there is a strong relationship between BMI and the risk of CKD (Prasad et al., 2022). Obesity can lead to several conditions such as insulin resistance, dyslipidaemia, atherosclerosis and hypertension which increase the risk of CKD. According to our findings, patients with CKD frequently have one or more comorbidities, which are potential risk factors for CKD disease progression and increase the self-management burden on CKD patients. Previous research has reported on this similar phenomenon (Saminathan et al., 2020). The most prevalent comorbidities of CKD are diabetes and blood pressure. Clinical practice guidelines (CPG) on the management of CKD have been released by the Ministry of Health Malaysia to help with the management. Despite the guidelines being available, CKD patients highlighted the challenges they faced related to lifestyle management or managing CDK when it coexists with diabetes, high blood pressure, or both. This was also noted in a study conducted by Cheo et al (2022). Therefore, it is important to understand each CKD patient's medical history as well as the challenges they face in order to develop personalized and effective care management.

Our findings highlighted that the patients from this study received insufficient CKD information. Patients reported having limited knowledge regarding the CKD symptoms, causes and kidney replacement treatments. This could be due to a lack of exposure and also a lack of involvement from clinicians. Clinicians, particularly those working in clinics and hospitals, frequently have very little time to address patients' various concerns. Greer et al (2012) found that the most frequently mentioned barrier to CKD education was the lack of time available during routine clinic appointments (Greer et al., 2012). In our study, patients also reported that there was a lack of communication between the healthcare professional and the patients. There are also misconceptions, ambiguities and misinterpretations reported among patients about CKD health literacy due to the different types of sources, unclear information, and unreliable references (Van Dipten et al., 2018). Lack of standardised and early-stage CKD data is another possible factor that can contribute to the patient's knowledge gaps and low CKD health literacy. It was also stated in the Kidney Disease Outcomes Quality Initiatives (KDOQI) that no guidelines were provided for CKD stages 1 and 2 due to a lack of clinical relevance and data (Ikizler et al., 2020).

Patients with CKD may encounter a range of symptoms. The burden of bearing the symptoms will negatively impact on quality of life among CKD patients. Therefore, monitoring patients' symptoms and quality of life is an important step to optimise the management of CKD. Our study indicates that the majority of the patients experienced early symptoms before being diagnosed with CKD. The typical symptoms are urinary symptoms, back pain, swollen legs, bad breath, itchy skin, and difficulty to breath, as was noted by Almutary et al., (2013). Other symptoms including anxiety and depression were also reported. CDD patients are at a higher risk of experiencing depression, anxiety and lower levels of quality of life.

One of the most challenging self-management tasks identified by the patients was managing their own diet. Those who are diagnosed with CKD have to undertake significant dietary and lifestyle adjustments. All patients acknowledged their lifestyle and eating habits had completely changed. This is in accordance with another study that revealed CKD diet plans are different depending on the stage of CKD (Ko et al., 2017). The patients repeatedly mentioned their struggle to follow the CKD dietary recommendations. For instance, certain food that is high in potassium or salt might be restricted depending on the individual's lab findings. It is recommended that patients with CKD be referred to a dietitian for an individualized diet plan, particularly for patients with comorbidities, as the diet plan is further complicated by having CKD and comorbidities. However, surprisingly, half of the patients

reported that they had never met any dietitian after being diagnosed with CKD. This showed that the patients with early stages of CKD were not being educated in a timely manner. The lack of guidance will lead to unhealthy dietary and lifestyle behaviour and ultimately lead to the progression of CKD disease.

Our study has found that the majority of the patients used the internet as their main source of information to look for CKD knowledge and guidelines. The National Kidney Foundation online community has also reported that CKD patients used the online forum not only to look for information but also for emotional support for managing their CKD conditions (Du et al., 2022). Due to the advancement of technology today, many initiatives have been developed online to help CKD patients that are aimed at improving their knowledge and quality of care. As a result, the Internet has emerged as the most effective way for educating patients in managing CKD (Schiffer et al., 2021). However, it is noteworthy that not all patients will have access to technology and the internet, due to their social determinants and low socioeconomic status (Bonner et al., 2018).

Patients' busy schedules in their daily activities presented another obstacle to living a healthy lifestyle. Most CKD patients fail to follow dietary recommendations for CKD due to daily activities including working, traveling, and living environments. The majority of the patients are currently employed and some need to travel to work having limited time to comply with the dietary guidelines. It has been reported that long working hours have been associated with higher energy, sugar, and fat consumption as well as increased usage of convenience foods and dining out (Jones et al., 2007; Devine et al., 2009). For CKD patients who work for long hours, it reduces the amount of time that can be spent cooking, preparing, and eating a healthy meal or even shopping for nutritious food. Furthermore, the dearth of healthy food available in the restaurant also had an impact on the patients' food choices. Patients stated that most restaurants do not sell healthy food such as a variety of vegetable dishes.

As most of the restaurants were not CKD-friendly restaurants, this for sure affected patient's food choices. It is also noted by Bello et al. (2008) that patients with lower socioeconomic status are found to have a higher association with the severity of CKD progression. In our study, some of the patients also mentioned that healthy and nutritious foods are too expensive and limited. Thus, patients would opt for fast food, and other dishes that are typically high in calories and are low in nutritional content when healthy food is not accessible and affordable. Therefore, fostering a health-supportive food environment is a critical component both at home and in restaurants in order to improve self-management of CKD.

Patients' adherence to dietary advice was also influenced by their living environment, especially those who stay together with their family members and friends. CKD patients' diet differs from healthy individuals' diet, particularly in the amount of sugar, salt, fat, and protein intake. CKD patients are advised to follow the recommendations as stated in the Second Edition of CPG: Management of Chronic Kidney Disease (Hooi et al., 2021). Numerous diet components, including calories, protein, salt, potassium, calcium and phosphorus need to be carefully monitored (Beto et al., 2016). However, we found that most patients are likely to consume food prepared by their family members, or similar food that does not follow the CKD dietary recommendations when eating out with friends. Patients are in a difficult position when trying to adopt a healthy diet due to a lack of support from their immediate family and friends. Therefore, we should empower the patients and their care partners, especially regarding the menu modifications, to enable patients to meet the nutritional recommendations.

Patients with CKD are recommended to have dietary counselling and nutrition education to prevent the progression and better management of the disease (Anderson & Nguyen, 2018). However, in this study, patients were found to be unfamiliar with and not well-informed about nutrition education. It was also reported in a previous study that CKD patients were not informed about nutrition counselling in the early stages of CKD (Anderson & Nguyen, 2018). Healthcare professionals are commonly expected to perform renal nutrition counselling, but it is noted by Kahan & Manson (2017) that the professionals may, however, lack formal nutritional education training. As the majority of the patients with CKD often experience other co-morbidities (such as diabetes and hypertension), more tailored individualised nutrition education plans are needed to improve dietary adherence in order to ensure better clinical outcomes as recommended also by Van Dipten et al. (2018). Therefore, given the findings in our study, dietary counselling and nutrition education for CKD patients remain an important point that demands attention.

Quality of life is an indefinable concept to understand, it relates to the overall well-being of individuals or groups, encompassing both positive and negative experiences, and their impacts on someone's evaluation and later reactions (Felce & Perry., 1995). The patients with early-stage CKD experienced significant changes in quality of life compared to those with later-stage CKD. In our study, patients believed that exercising, getting enough rest, and sleeping well would enhance their quality of life. As noted by Mujais et al. (2009), the psychological component in the quality of life was found to be the most crucial element among CKD patients. This may be due

to the chronic nature of the CKD disease. Patients need to adjust psychologically to their new and changed lifestyle as well as to the disease treatment, which significantly affects patients' quality of life over time (Kefale et al., 2019). Meanwhile, the support from the patient's family, friends, and peer support group is of utmost importance to the patients. Furthermore, joining a support group on social media is beneficial to patients as it encourages a positive and supportive environment among the group members. Therefore, the interventions should focus on improving online settings regarding patient care as well as social support from family and friends to improve their quality of life.

Limitation of Study

The CKD patients who participated in this study who were selected from CKD support groups were coincidentally from only one section of the Malaysian racial composition, as all of them were Malays. The reason may be due to the fact that Malay patients make up the majority of the support group members. Thus, the research findings do not necessarily reflect the broader spectrum of Malaysian CKD patients. However, patients were recruited from different parts of Malaysia and the majority of the patients had different years of having endured CKD. Another limitation of our study is the small sample size. This is due to fewer patients participating in CKD support groups and having social media accounts. Nevertheless, data saturation was achieved despite the small sample size in this study.

CONCLUSION AND RECOMMENDATION

In conclusion, our study found that the majority of CKD patients aged above 40 years tend to be overweight as well as obese and diagnosed with other comorbidities. Thus, more tailored individualised dietary recommendations should be developed and promoted to ensure better self-management of the disease. Our study also found that there is a necessity to focus on and promote CKD knowledge, particularly in early-stage CKD patients as there is a significant lack of knowledge on dietary recommendations. In addition, patients faced a number of challenges such as insufficient communication with healthcare professionals, inadequate healthy food choices, and lack of time to prepare healthy food. Despite the patients' motivation to alter their lifestyle, crucial guidance from reliable sources or healthcare professionals was found to be lacking. Even in the early stages of CKD, enhancing the communication between the patient, doctor and dietitian is beneficial in delaying the progression of the disease. Furthermore, counselling sessions and nutrition education aimed at increasing patients' knowledge that can eventually improve their self-management of the disease and their quality of life are important. Therefore, effective nutrition education should be developed and explained clearly to the patients to improve patients self-management and empower them to make appropriate food choices. A major recommendation is that policymakers and healthcare professionals, especially dietitians and nutritionists, should collaborate to establish nutrition education-related interventions to improve patients' knowledge and self-management to practice a healthy lifestyle.

DECLARATION OF STATEMENT

The lead author confirms the manuscript's integrity, stating that it provides an honest, accurate, and transparent account of the reported study. No crucial aspects of the study have been omitted, and any discrepancies from the planned (and, if applicable, registered) study have been appropriately explained.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest. All co-authors have reviewed and approved the manuscript, and there are no financial interests to disclose.

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Appendix 1: Semi-structured interview guide

Questions

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1. Can you please describe to us what CKD is? (causes, symptoms, treatment)
 2. Did your eating behaviours and your lifestyle change after diagnosed with CKD?
 3. What factors have caused these changes? /or what factors influence your current eating behaviour?
 4. Please tell me, a few reasons why you need to eat healthily or what motivates you to eat healthily.
 5. Please tell me a few reasons why CKD patients might not eat healthily.
 6. Are there any barriers that keep you from following nutrition recommendations?
 7. Which of the previously mentioned factors have had the greatest influence? How and why?
 8. Thinking of nutrition education in CKD, what comes to your mind?
 9. What kind of information do you think is important to people with CKD? Where do you get the information?
 10. In what format did you receive the nutrition education? Is it face-to-face counselling, pamphlet, or online?
 11. How to improve the quality of life among CKD patients in terms of physical health, psychological, social relationships and living environment?
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