

Patients' Response to Early Stages Chronic Kidney Disease: Learn To Recognise the Illness

Irsanty Collein^a, Ratna Sitorus^{b*}, Krisna Yetti^c, Sutanto Priyo Hastono^d,

^aDoctoral Nursing student Universitas Indonesia, Depok, West Java, Indonesia, ^bFaculty of Nursing Universitas Indonesia, Depok, West Java, Indonesia, ^cFaculty of Public Health Universitas Indonesia, Depok, West Java, Indonesia, ^dPalu Health Polytechnic of Health Ministry, Palu, Central Sulawesi, Indonesia, Email: ^{b*}ratnasit@hotmail.com

Objectives: Early stages of chronic kidney disease may have no symptoms; therefore, the identification and treatment of these manifestations early possibly help in preventing a transition into kidney failure and subsequently prevent the risks of progression. This study aimed at exploring the experience of self-management conducted by patients with early stages of chronic kidney disease (CKD). A descriptive phenomenological qualitative design was used, which required the recruitment of fifteen participants, using a purposive sampling technique. Furthermore, the data collection instruments employed consisted of in-depth interviews, field notes, and tape recordings. In addition, interview guidelines were prepared based on the objectives of the research which were further translated into a number of questions, to explore the experiences of patients, and the Colaizzi method was applied in data analysis. The results characterised the decisions to perform self-management, dealing with a health condition and social support as important aspects. This study identified several themes in the experiences of patients with decreased kidney function, suggesting that patients distinguish factors that facilitate and inhibit self-management, acknowledging its characteristics and readiness.

Key words: *Learning, self-management, patients with early stages of chronic kidney disease*

Introduction

Early-stage kidney disease is known to be a risk factor for heart disease, and it also promotes the progression of CKD. This leads to an upsurge in the number of patients that choose hemodialysis and transplant, due to the diagnosis of end-stage kidney disease, which

subsequently elevating the cost of health insurance (Coresh et al., 2007; Stevens et al., 2006). In addition, CKD is a major risk factor of cardiovascular disease, and the prevalence patients at the early-stage are thought to have increased due to the rising trend of diabetes and hypertension (Kamar et al., 2017; Costantini et al., 2008; Lin et al., 2013). Nationally based data from basic health research in 2018 regarding the number of patients declining kidney function are not yet available as well as in hospitals (Manjula, 2018).

There has been a sub-optimal administration of treatment by nurses, as observations in August 2018 at the medical ward in Undata Hospital Palu showed the attitude of limited knowledge towards patients with decreased kidney function; thus, there were no specific approaches towards intervention. Meanwhile, at Anutapura General Hospital, nurses tend to not participate in the provision of precise health education to CKD patients, as the treatment plans administered are often spontaneous. This was also the case for patients in inpatient rooms, related with the delivery of knowledge on self-management because being treated in the general care and internal medicine room makes nursing attention to be more of conventional, and less specific towards the clients with reduced kidney function (interview with nurses) (Parameswary, 2018). Moreover, interviews conducted with patient's show that most did not realise they suffered early-stage CKD, and consequently appropriated no action.

In addition, the experience of diagnosed individuals also varied based on the following perceptions: (1) Some take it as a challenge, due to the absence of symptoms, introduction of chronic conditions and uncertainty, alongside the absence of recovery, which is observed as a separate stressor; (2) Others have diverse beliefs about the disease incidence: This is pertaining to the uncertainty of the cause, which include heredity, poor lifestyle, use of drugs, supernatural causes and pre-existing conditions; and (3) There were also concerns based on disease progression, which were often in the form of anxiety, paying more attention to the impact on the family, interests related to the safety of treatment procedures and its effect on daily life (Walker et al., 2013). Meanwhile, research-based on self-management was conducted by patients chronic kidney disease to improve organ function, although their experiences above served as the basis for health workers to make models regarding interventions deemed appropriate. Furthermore, references to the study background instigated the interest in understanding the familiarity with self-management performed by patients with early-stage chronic kidney disease, to establish an appropriate model; therefore, this study aimed to explore their specific experiences (stage 1-3a).

Materials and Methods

Study Design

A qualitative thematic analysis approach was used in this study, which involved the application of semistructured, open-ended interviews.

Participants

A total of 20 high-risk patients were screened, and only 15, aged between 42-68, fulfilled the study criteria, up to the saturation point (Creswell, 2013). In addition, participants were recruited from three hospitals in Palu District, using a purposive sampling technique. Furthermore, they were observed to have a GFR between 47-88 mL/min/1,73m², ACR (albumin creatinine ratio) 3,76-434,56 µg/mg kreatinin, comorbid Diabetes Mellitus and hypertension, as well as compos mentis, verbal communication skills in Bahasa, and the willingness to participate in the investigation. Therefore, ethical approval was received from the Faculty of Nursing, Universitas Indonesia number 281/UN2.F12.D/HKP.02.04/2018.

Instruments

Data collection required in-depth interviews, which was conducted for 45-60 minute, using (1) guidelines, which was specifically prepared based on the research objectives, and subsequently translated into a number of questions, to explore the patients' experience; and (2) Field notes, which were employed in taking record of non-verbal responses during the interviews, and tape recorders record all the information obtained. Furthermore, quantitative research required that the information obtained was in the form of numbers while the qualitative form uses data retrieval tools instead, including tape recorders (Creswell, 2014; Streubert & Carpenter, 2011).

Recruitment

The number of patients with early-stage kidney disease in hospitals is not yet available. Therefore, the researchers screened 20 Diabetes patients and hypertension who visited the clinic. The data were collected during in-depth interviews conducted for one month, which were based on open-ended questions, where the first meeting with the participants involved an appointment requesting for their willingness to take part in the study, and also to obtain the laboratory test from Prodia Palu. Therefore, after the arrival of the results, phone calls were made with patients, to fix appointments towards the interview process, which was dependent on the agreement, all of which were conducted at the patients' home.

Data Collection

Prior to the initiation of a procedure, a tape recorder was prepared to record conversations, and also stationery was employed to document non-verbal languages. Moreover, permissions were also obtained to use tape recorders at a distance of approximately 50-100 cm, between both parties, and the interview guide contained special questions, based on the research objectives (Creswell, 2014). In addition, general descriptions associated with the core study question were provided, outlined in instances where the participants found it difficult understanding, in accordance with the guide. Furthermore, there were also attempts to not pass judgment based on understanding or experience after answers were provided, and the process was terminated after the necessary information was obtained, based on the saturation of data. Field notes containing important details were written not to overlook some helpful natural elements, documenting the atmosphere, facial expressions, behaviour, and non-verbal responses, in an attempt to describe the participant's response, and subsequently coupled with the transcripts. Therefore, the interviews were terminated with the attribution of thanks for participation and cooperation, and the next meeting was scheduled to validate the data provided (Streubert & Carpenter, 2011).

Data Analysis

The characteristics of participants were analysed using a phenomenological approach, where the recordings were transcribed after data collection, involving reading and identifying keywords related to the investigation (Creswell, 2013). Furthermore, a thematic analysis procedure was used to ascertain the level of experience, as well as the meaning of each patients' view. In addition, the meaning of life experience is comprised of the key thematic points of the findings, and the evaluation process followed the steps described by Creswell (2014).

Results

In this investigation, the fifteen participants involved seven males, eight females and two widows, aged between 42 - 68. Furthermore, thirteen patients presented with the comorbidity of diabetes, and two had hypertension, while four had both conditions. In addition, two patients manifested a low-risk progression to chronic kidney disease, five patients manifested a moderate risk, five were high risk, and one patient has a very high risk. Three patient has a stage 1 of CKD; nine patients have a stage 2, and 3 patients have stage 3a. Furthermore, three themes emerged from the data obtained, including the decision to conduct self-management, the act of dealing with a health condition and the importance of social support (see Table 1).

Table 1: Themes identified were related to self-management for patient with early stages kidney disease, including.

Significant statements	Categorised	Sub-themes	Themes
Control of eating ... diet (P8), (P9), (P10), (P11), (P13)	Control eating	Taking on the role of managing self	the decision to conduct self-management
I often control my eating, but sometimes my wife does... although I am dominant (P6)			
I make the food consumed by myself ... and no longer tell my child (P2).			
Yes, I personally control what is eaten, because I cook (P5)			
I control the food I consume (P8), (P14), (P15)			
Yes I have (high blood sugar level); hence, I observe feeding limitations (P6)			
I also control the food I eat, although sometimes I become naughty, but not like before. (P4)			
I have observed a restricted use of salt, and low-calorie sugar drinks (P6)			
This is because I already consume low-calorie sugar (P3)			
I often use low-calorie sugar while drinking tea (P8)			
My son instructed me to drink lots of water because of the numerous medicines ingested (P7)	Following advice from various sources	Learn to recognise the illness	
I usually obtain information from Google and little from doctors, because of their limitation of details (P3)			
I do take herbs ... usually traditional medicines because there is no match prior to eating diabetes medication. Hence, I take a lot of it, based on the suggestion of others (P8), (P12)			
There have been no attempts to ingest herbs or other therapies other than medication from the hospital, and I also did not seek therapy from traditional sources (P5), (P13), (P14).			
I always take the time to control and check (P3) (P15)			
I often consult with the primary family doctor (P6)			
I have learned that eating a little is also the same, which sometimes goes up; thus, my thoughts don't let it become a factor. Therefore, the thoughts that seem too hard allow me to eat, and if I check, there is definitely an upward trend ... thus as long as I suffer, there is the knowledge that the hurts are mostly due to pain, and my guess is sometimes true (P3).	Self-study the disease	Make judgments about yourself	
On instances of headaches, and tension, bad taste is			

experienced, and nausea too. Hence, I usually become tense, and sometimes not immediately, and I subsequently take medication. This is because of the knowledge on night medication (P4)			
Yes I have elevated blood sugar, therefore leading to diet limitation (P6), (P9) I realise and pay attention to my health by studying the symptoms (P13), (P14), (P15).			
what if you don't need to take medicine anymore? (P1)	Curious about prevention	Receive ill conditions	Dealing with the condition
How don't it not get worse? (P8)			
I just want to know the prevention approach towards this disease (P3)			
Do you think the consumption of drugs has taken too long? (P6)			
About this manifestation, I choose to take things easy, and not think too much. Thus, I relinquish stress because most people are stressed after being knowledgeable of the illness presence, which slowly drops (P8)	Not thinking about complaints related to illness		
I often take it easy ... and not really worried, thus, thinking about what to probably do (P3), (P10)			
No complaints (P3), (P9), (P13), (P14), (P15).			
I hope it's healthy, son ... that's already scared of me behind my back, probably the kidneys might (P7)	Given health	Have hope for health and recovery	
In an attempt to be healthy (P8), (P9).			
I'm 100% willing to obtain wellness, and desire to perform anything for that purpose ... thus, my simple demand, centred on the need to obtain information about this disease (P2), (P13), (P15)	Given healing		
If possible, I aspire to recover, or at least not make the disease worse (P3)			
I really hope to obtain wellness soon enough, in order to wear shoes again, because I have been wearing sandals alone (P8)			
Relationships with families and socialisation are good, and only that movement has been reduced (P4)	Establish interactions with others	Live daily life	
There are no problems based on relationships with neighbours, and ordinary standard assists, in the sense that it is normal to help while healthy. Thus, on instances where a lot of legs are hurt, there is no mischief (P7)			
The relationship is fine with family (P2), (P10), (P11)			
Yes, there are no communication obstacles (P3), (P13),			

(P14), (P15).			
God willing, I can maintain my diet as suggested (P6), (P15).	Confidence in yourself		
if possible, I'll do it. Therefore, in cases where you can't, this is bamasak (pointing to his child) (P7).			
I believe in myself ... I can, and, thus, always take the time to control and check (P3), (P12), (P13)			
I personally arrange food and choose daily activities ... Husband Sometimes aids in reminder, but I'm alone most times (P4)			
This man, what is it ... You know what is for him, the best ... (P5)			
For me, a clear control demands that I need guidance; hence I don't ... after obtaining the next ... I become healthy (P8), (P9), (P10).	Information support	form of support	Family support is important in self-management
In need for explanations based on the illness from health worker as well as attention (P3), (P13)	Emotional support		
Delivering control to the hospital and subsequently motivating (P8), (P14)			
While eating, I have a wife that often controls (P3), (P10)	From family	Sources of support that has been obtained	
Associated with social activities, dealing with friends or outsiders must be related (P1)			
I am still being helped by my child or other family members to observe the medicine to be consumed ... All families that stay home tend to pay attention and worry about the situation, especially my child (P2)			
Sometimes husband reminds me too, but I'm more alone (P4), (P12), (P14)			
I personally use to arrange meals, although dominant (P6)			
Cooking ... My daughter is in contro(P7)			
Family, including parents and siblings, husband, if for example I go for check-up (P8), (P14)			
They tell me .. restrict eating ma'am .. up and down, imagine informing the doctor to give Jo the medicine in place of not cooking good, hence, the response from doctor jimmy was ooo so (P7)	From health workers		
Not discussing kidney problems, except with doctors alone that is told about diabetes (P3)			
Yes I do Follow advice from health workers (P5)			
Information is obtained mainly from doctors, based on			

dietary restrictions, while that for the disease is related from a nutritionist, and nurses only tend to provide tension measures (P2)			
Ordinary nurses only input tension, while the nutritionist was only met once (P6)			
I always follow advice from nutritionists, even though there are a lot of dietary restrictions, which is too much (P3), (P9), (P13), (P14), (P15).			
I follow the advice of nurses and nutritionists, encompassing not eating or performing activities that are not recommended (P2)			
I need the help of someone else (P3), (P11), (P13)	Health workers and others	Sources of support expected by the client	
Yes, if this is the best, there is a need for other good people (P5)			
obviously we require others to help stay healthy (P8), (P14), (P15)			
Yes, it is essential to have a doctor, and other health workers (P8), (P13)			
There is a need for everyone, including doctors, nurses and others (P1)			
I cannot choose because I need both family and health workers (P2)			
Yes there is a need for children and older members (P5)	Family		
My daughter assists me (P7)			
I cannot choose because there is a need for both family and health workers (P2), (P11), (P13)			
Actually, it is not possible to conduct self-support; thus, the kids serve as a constant reminder ... If it hurts, the first child tends to assist, because most times my husband is ignorant. Hence, I complain to children more often (P4)			
Of course, my wife is needed (P1)			
I often tend to desire my wife (P6)			
I need my husband to be more considerate (p8)			

Discussion

The decision of conducting self-management was described by the participant as an initiative to take the role of personalised supervision, by controlling what is eaten, learning to recognise the illness by following advice from various sources, and self-evaluation through consistent study. Research conducted Teasdale et al. (2017) on clients diagnosed with CKD that had not undergone dialysis resulted in the theme of "help me to help myself". This was

shown by the expression of being able to manage through circumstances of sufficient knowledge on disease independently; therefore, those at early-stages decide to learn more on the realisation of its long-term nature (Lin et al., 2013; Tong et al., 2015; Schulman-Green et al., 2012). In addition, the learning process, which plays a major role in health, subsequently leads to the practice of health promotion activities through self-management, which focuses on sick needs (Walker et al., 2013).

The ability to deal with a chronic disease condition illustrates the nature of the participants that have accepted the illness and also centred on the hopes of being provided with health and healing. This is accompanied by living a normal daily life by means of interacting with others and having strong beliefs about personal capabilities. Furthermore, it was stated that patients with early-stages CKD demand to education on the disease, through enquiring specific information on diet, signs and symptoms, travel means, as well as the medications to take. Adjustments were also made with regards to personal roles, as they venture more into exploring decreased kidney function, realising its long-term nature, which leads to the feeling of being at peace with the situation. Moreover, dealing with the condition was also interpreted based on the characteristics of hemodialysis preparation at a later time. However, negative emotional response was subsequently expressed, through the adoption of lifestyle changes, seeking social support, and utilising complementary care (Lin et al., 2013). This also involves the attitudes towards living with the chronic illness, adjusting to the condition, activating the ability to integrate the situation into daily life through lifestyle modifications, and finally, the ability to make meaning out of life (Tong et al., 2015; Schulman-Green et al., 2012).

Early-stage CKD patients were reported to have obtained information and emotional support from relatives and health workers. However, it was observed that more was required, especially from the immediate family living within the same house. In addition, patients that have not endured hemodialysis continue to build support, particularly towards compelling the treatment and health workers to readily listen to personal complaints, with the expectation that they believe in decisions regarding therapy, the need for encouragement from peer groups, and consequently building mutually beneficial relationships with health workers. This also involves the willingness to learn during clinical meetings, trusting in the ability to deal with problems within the united kingdom, participation in related decision making, which is often limited while following the doctors' advice, and also by regulating diet, taking medicine, avoiding careless drug ingestion, and adopting a healthy lifestyle (Inker et al., 2014; Stevens et al., 2006). In addition, it is also possible to obtain support from health workers, psychological, spiritual, and social community (Malm et al., 2012).



Conclusions

Patients with early stages of CKD perform self-management from the onset, which is shown through personal management of the condition. In addition, family support is identified to play an important role through the process, which is conducted early enough, specifically when the patient manifests with $GFR > 45 \text{ mL / min/1.73 m}^2$, and preferably in those with the risk of mild progression. However, most participants did not realise the symptoms; therefore, the advice addressed to health workers are expected to encourage patients to often engage in screening exercises early enough, especially for those with high-risk diseases, including Diabetes, hypertension and people over 60 years of age.

Acknowledgement

The authors would like to give thanks to the 2019 Doctoral Universitas Indonesia Grant and acknowledgement to all participants who were willing to participate and to share their experiences in this research.



REFERENCES

- Coresh, J., Selvin, E., Stevens, L. A., Manzi, J., Kusek, J. W., & Eggers, P., et al. (2007). Prevalence of Chronic Kidney Disease in the United States. *Jama* [Internet]. 2007;298(17):2038. Available from: <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.298.17.2038>.
- Creswell, J. W. (2013). *Qualitative inquiry & research design*. Third edit. Sage.
- Creswell, J. W. (2014). *Research design Qualitative, quantitative, and mixed methods approaches*. Fourth edi. Sage.
- Costantini, L., Beanlands, H., McCay, E., Cattran, D., Hladunewich, M., & Francis, D. (2008). The self-management experience of people with mild to moderate chronic kidney disease. *Nephrol Nurs J* [Internet]. 2008, 35(2):147–55. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18472683>.
- Inker, L. A., Astor, B. C, Fox, C. H., Isakova, T., Lash, J. P., & Peralta, C. A., et al. (2014). KDOQI Commentary KDOQI US Commentary on the 2012 KDIGO Clinical Practice Guideline for the Evaluation and Management of CKD. *Am J Kidney Dis* [Internet]. 2014;63(5):713–35. Available from: <http://dx.doi.org/10.1053/j.ajkd.2014.01.416>.
- Kamar, F. B., Tam-tham, H., Thomas, C. A. (2017). Description of Advanced Chronic Kidney Disease Patients in a Major Urban Center Receiving Conservative Care.
- Lin, C., Tsai, F., Lin, H., Hwang, S., & Chen, H. (2013). Effects of a self-management program on patients with early-stage chronic kidney disease : A pilot study. *Appl Nurs Res* [Internet]. 2013; 26(3):151–6. Available from: <http://dx.doi.org/10.1016/j.apnr.2013.01.002>.
- Malm, D., Wikby, K., & Ahlstrom, G. (2011). The experience of empowerment in the patient – staff encounter : the patient' s perspective. 2011;15, 897–904.
- Manjula, G. (2018). Healthy way of life style through Siddha system of medicine [நோயில்லா நெறிக்குச் சித்த மருத்துவம்]. *Muallim Journal of Social Sciences and Humanities*, 2(2), 156-160.
- Parameswary, S. (2018). A study on medical references that are found in Tamil proverbs [தமிழ்ப் பழமொழிகளில் காணப்படும் மருத்துவக் குறிப்புகள் ஓர் ஆய்வு]. *Muallim Journal of Social Sciences and Humanities*, 2(4), 286-294.
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., & McCorkle, R., et al.



(2012). Processes of Self-Management in Chronic Illness. *J Nurs Scholarsh.* 2012;44(2):136–44.

Stevens, L. A., Greene, T., & Levey, A. S. (2006). Surrogate end points for clinical trials of kidney disease progression. *Clin J Am Soc Nephrol.* 2006;1(4):874–84.

Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in Nursing: advancing the humanistic imperative.* Fifth ed. Wolters Kluwer.

Teasdale, E. J., Leydon, G., Fraser, S., Roderick, P., Taal, M. W., & Tonkin-crine, S. (2017). Patients' Experiences After CKD Diagnosis: A Meta-ethnographic Study and Systematic Review. *Am J Kidney Dis* [Internet]. 2017;1–10. Available from: <http://dx.doi.org/10.1053/j.ajkd.2017.05.019>.

Tong, A., Sainsbury, P., Chadban, S., Walker, R. G., Harris, D. C., & Carter, S. M, et al. (2015). Patients' Experiences and Perspectives of Living With CKD. *J Med Liban* [Internet]. 2015;63(2):81–6. Available from: <http://dx.doi.org/10.1053/j.ajkd.2008.10.050>.

Walker, R., Marshall, M. R., & Polaschek, N. (2013). Improving self-management in chronic kidney disease : a pilot study. *Ren Soc Australas ...* [Internet]. 2013;9(3):116–25.