

THE LIVED EXPERIENCE OF PATIENTS WITH PRE-DIALYSIS CHRONIC KIDNEY DISEASE: A QUALITATIVE STUDY

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Abstract

Background: Chronic kidney disease is identified as kidney damage for more than three months with glomerulus filtration rate less than 60ml / min / 1.73 m².

Objective: This study aims to explore the experience of life of patients with pre-dialysis chronic kidney disease used Roy's adaptation model.

Methods: This study was a qualitative study using descriptive phenomenology approach in the General Hospital of Cibabat Cimahi West Java, Indonesia. Data were obtained with depth interviews involved eight participants with pre-dialysis chronic kidney disease consisting of two men and six women, aged ranged from 35 to 65 years. The years living with chronic kidney disease ranged from 1 to 2 years. Data were analyzed using Colaizzi's methods.

Results: We found nine themes, namely: physical stimulus, psychic stimulus, socio-economic stimulus, physical coping mechanisms to control the situation, a coping mechanism to maintain health function, selecting behavioral adaptation physiology, selecting a behavior adaptation of the self-concept, selecting adaptation behaviors role function, and selecting behavioral adaptation interdependence.

Conclusion: It can be concluded that the experience of patients with pre-dialysis chronic kidney disease complained physical, psychological, social, economic, and spiritual problems. Therefore, health care professionals need to design an intervention to improve patients' coping mechanism to maintain kidney function, and adapt to diet for foods and drinks, activity patterns and roles according to their conditions, which also elaborate the function of family support.

Keywords: chronic kidney disease, pre-dialysis, Roy's adaptation model, and qualitative study

INTRODUCTION

Along with the development of science, qualitative studies receive more attention, especially in the medical and nursing fields. This is because the results of qualitative research give more in-depth relevant phenomena. Usually the number of samples in this study a little in size but rich in detail the amount of data generated ([Polit & Beck, 2004](#)). Various qualitative studies have been conducted in patients with chronic kidney

disease but few studies involved patients in pre dialysis stage. In stage of pre dialysis, patients need information related to the physical and psychological aspect that may changes in their life ([Lewis, Stabler, & Welch, 2010](#)). Patients in the pre dialysis were required different needs compared with patients under hemodialysis. Patients at this stage require more specific information that is

expected to improve the management of self-efficacy and reduce fear and anxiety.

Nursing concept model provides different views about nursing in regards with the characteristics of the model. Almost all nursing models applied in professional nursing practice shared the same concept, namely humans, environmental, health, and nursing. The conceptual model can be applied in the activities of nursing practice, research, teaching ([Alligood, 2014](#)). The Roy adaptation model describes the concept of nursing that requires nurses to focus on adaptation behavior in providing care to patients. Treatment and care for patients with chronic kidney disease require long-term follow-up. Various physical and psychological changes experienced by the patient require patients to demonstrate adaptation behavior to adjust living with the disease. Life experience is the paths of belonging (relationships), doing (meaningful engagement in activities), and understanding oneself and the world ([King, 2004](#)). Therefore, this study aim is to explore the live experience of patients with the chronic kidney disease pre dialysis, which focuses on the adaptation process.

METHODS

Study design

This study adopted the Phenomenology methodology to explore live experience in patients with chronic kidney disease pre-dialysis in Indonesia. Phenomenology is an approach that focuses on the meaning of real-life human experience ([Polit & Beck, 2004](#)). It is especially appropriate when a phenomenon is to be explored or conceptualized, or when a fresh look at a phenomenon is indicated ([Polit & Beck, 2004](#)). The phenomenological perspective used is Colaizzi ([1978](#)), who advocated a descriptive approach in order to understand a description of the meaning of an experience from the participant's point of view ([Colaizzi, 1978](#)). Under the assumption that each person has understanding of the world is based on his or her own experiences,

and therefore, one way to find out their experiences that they have received is by interviewing them. Colaizzi ([1978](#)) develop his methods under Giorgi supervision ([Giorgi, 1970](#)), this approach enquiry involved a process of validating the finding-the structure of phenomenon with participant. This process require participant the researcher returning the analysis of transcripts and the structure of the phenomenon to the respective participant for review ([Saunders, Soomro, Buckingham, Jamtvedt, & Raina, 2003](#)).

Participant

Patients diagnosed with chronic kidney disease pre-dialysis were recruited form outpatient and inpatient at one public hospital in West Java, Indonesia. The researchers were used purposive sampling method for selecting research participants and continue until data saturation. The inclusion criteria: 1) adults aged ranged from 20-65 years old, 2) have been diagnosed chronic kidney disease level III (GFR 15-29 ml/minutes) or IV (GFR 30-59 ml/minutes), 3) able to communicate in Bahasa Indonesia. Patients were excluded to participate if they had the condition known to affect cognitive function (neurologic deficit, mental disorder diagnosis, renal failure requiring hemodialysis).

Procedure

Approval of protection human subjects will be obtained from Institutional Review Board of the Faculty of Nursing, Universitas Indonesia (0342/UN2.F12.D/HKP.02.04/2015). The recruitment of patients was conducted by the investigator in outpatient or inpatient. The researcher arranged a suitable environment for the interview. Then, the researcher purposively selected participant and then the researcher introduced herself, provide the required information, explain the objectives of the study, and inform the participants that they could leave the study whenever they wanted to. In addition, the patients assured confidentiality of the information and anonymous. Finally, after obtaining their willingness to participate and they signed written consent forms, we scheduled for interview.

Data collection and ethical consideration

A face-to-face interview with each participant applied in a suitable room in hospital. The interviews began with as semi-structured interviews and continue using exploratory questions. Each interview lasted for 30–60 min. With the consent of the participants, the interviews recorded using an MP3 player (Creative model). At the end of each interview, the participants informed about the likelihood of another meeting to complete and clarify the interviews. Although the participants agreed to this, a second interview necessary in only one case. The following question will be used to guide the interview process. By posing open questions, the patients invite to describe in detail their ideas, attitudes, experiences, and behavior. The following question will use to guide the interview process: could you tell me about your lived since you diagnosed with chronic kidney disease? Tell me what has been impact of diseases on your personal life? How you cope with this disease?

Data analysis

Data analysis was performed using Colaizzi's methods. There are seven steps to ensure the completion of the analysis. First, in order to acquire general feeling for experience, their statement will be read and reread (step 1). Then, the important step is extracting significant statement to generate information pertaining directly to phenomenon studies (step 2) and formulating meaning will be written in scientific language to illuminate various context of phenomenon (Step 3). Next step is categorizing into cluster of themes and validating with original text (step 4). After that, the finding will integrated into comprehensive description of the desired phenomenon (step 5), and this description will be return to participant to validate finding (step 6). The last step is incorporating any changes based on the informants' feedback (step 7).

Rigors

In this study, for validity and reliability data, Gaba and Lincoln criteria was used.

Believability of the study ensured through the researcher's long-term engagement in collecting and analyzing the data, and use of the revisions and reviews that conducted by the research associates and participants. To achieve data reliability, after being heard, implemented, and analyzed, the interviews were peer-reviewed. In addition, auditing used to achieve data neutrality and objectivity. Furthermore, given the previous experiences of the researcher in clinic, we tried not to let our views and beliefs affect the study's implementation process, tried to avoid prejudices, and do not study any similar research until the end of the analysis process. In order to achieve reliability of findings, after the hearing, implementation, and analysis of the interviews, another person, who had mastered the qualitative studies, but not involve in the study's process, were asked to help in the evaluation process. Thus, one or two of the recorded interviews together with the written form of the interviews assign to evaluate. To provide the transferability of the study, the research fully explained and the context and stages of the study fully described to the subjects by the researcher.

RESULTS

Data saturation was reached after interviewing 8 participants, including six women and two men. The ages of participants ranged from 35 to 65 years. Participants had diagnosed with chronic kidney disease ranged from one to two years. Participants were identified pseudonymously in the reports of findings. The following themes emerged from the data analysis derived from Roy's theoretical model on stress adaptation: (a) physical stimulus, (b) psychological stimulus, (c) social and economic stimulus, (d) coping mechanism related to psychological problems, (e) coping mechanism related to maintain optimal health, (f) chosen the physiological adapted behaviors, (g) chosen adapted behaviors related self-concept, (h) chosen the adapted behaviors related to role function, (i) chosen the interdependency adapted behaviors. Figure 1 shows theme of adapted behaviors of

patients with chronic kidney disease pre-dialysis.

Physical stimulus

In this study, we found that physical simulations were more focus on physical symptoms resulted from the disease. Sub-themes included patent of respiratory change such as breathless at rest or during activity, nausea and vomiting, loss appetite, and body weight loss. Fatigue and activity intolerance were major sub-themes in activity. Moreover, fluid unbalance also commonly reported by patients, as followed:

P3 said, "Feeling fatigue..., uncomfortable..., and cannot control breathless ..." P8 said, "...tired..., if walking too far I feel tired..., breathless if walking too far..., just go to toilet make me tired..., if in sever condition..., someone help me to hold..." P2 said, "...since being hospitalized..., I feel nausea..., vomiting..., just looking the rice but feel want to vomit..., only smell something but feel nausea..." P4 talked, "...If I eat..., I feel nausea..., loss appetite..." P7 said "...down..., tired..., dizziness..., if going to somewhere just try to avoid that feeling..." P8 said, "...walking is disturbed..., tired..., cannot work..." P1 said "...my feet is swollen..., yesterday bigger than now..." P5 said, "...if I drink a lot..., my feet will become bigger..."

According to our interview, participants reported that physical symptoms is disturbed their daily activities. The nutrition problems also may have negative impact on body image due to loos of body weight. Moreover, in our study also found decrease of nutrition intake has potential effect on Protein Energy Wasting (PEW) in patients with chronic kidney disease, which commonly reported and disturbed the metabolism process.

Psychological stimulus

The second theme that identified in this study is psychological simulation. One important sub-theme has been identified in this study, which is psychological distress and emotional. From those sub-themes, we found three categories including anxiety, fear, and hopeless Majority of participant describes that the sources of stress is come from the physiological situation such as kidney function and or laboratory results. Almost the

psychological distress affects their sleep as described in interview.

P3 said, ".....I feel anxiety often because my creatinine and urea not decrease yet and I feel confuse what should I do..." P8 said, ".....I feel anxiety very severe, affects to my sleep.....confuse what to do for the next..." P5 said, ".....Doctor said my kidney function is decreased.....I feel worries for hemodialysis.....".

Social economic simulation

The third theme identified in this study is the social and economic stimulus in patients with chronic kidney disease pre dialysis. Social and economic problems consists of four sub-themes including the issue of the family, could not attend social activities, sexual problems, financial problems as expressed by the following participants:

P3 said, "... All the work done in-law ..." P6 said, "... Already a month does not have sexual intercourse ..." P4 said, "I am skillful in helping women for delivery a baby ..., also have skill on take care a died body ... so I don't need to feel worry ... before all the activity well done ..., but now already decreases..."

Based on the interview, most of participants had good role function both at work and in the family of environmental.

Physical coping mechanism to control situations

The fourth theme is about coping mechanism to control the situation. We identified three sub themes, namely positive thinking, accept disease, and increased spiritual activity as expressed by the participants in the following:

P1 said, "... leisure time with grandson ..., watching television ...,join in religious activities..., become feel calm ...,..." My relationship with son and neighbors is good ..., we care each other ..." P2 said, "... Do not complain ... but I have to struggle ..., every day praying ..., must be strong to handle pain/discomfort ... stay strong ..." P7 said, "... From yesterday ... positive mind ... If it's time to die ... I will accept ..., if think about died it just make tired ..."

Eight participants noted that most participants have a positive point of view regarding the condition of the pain.

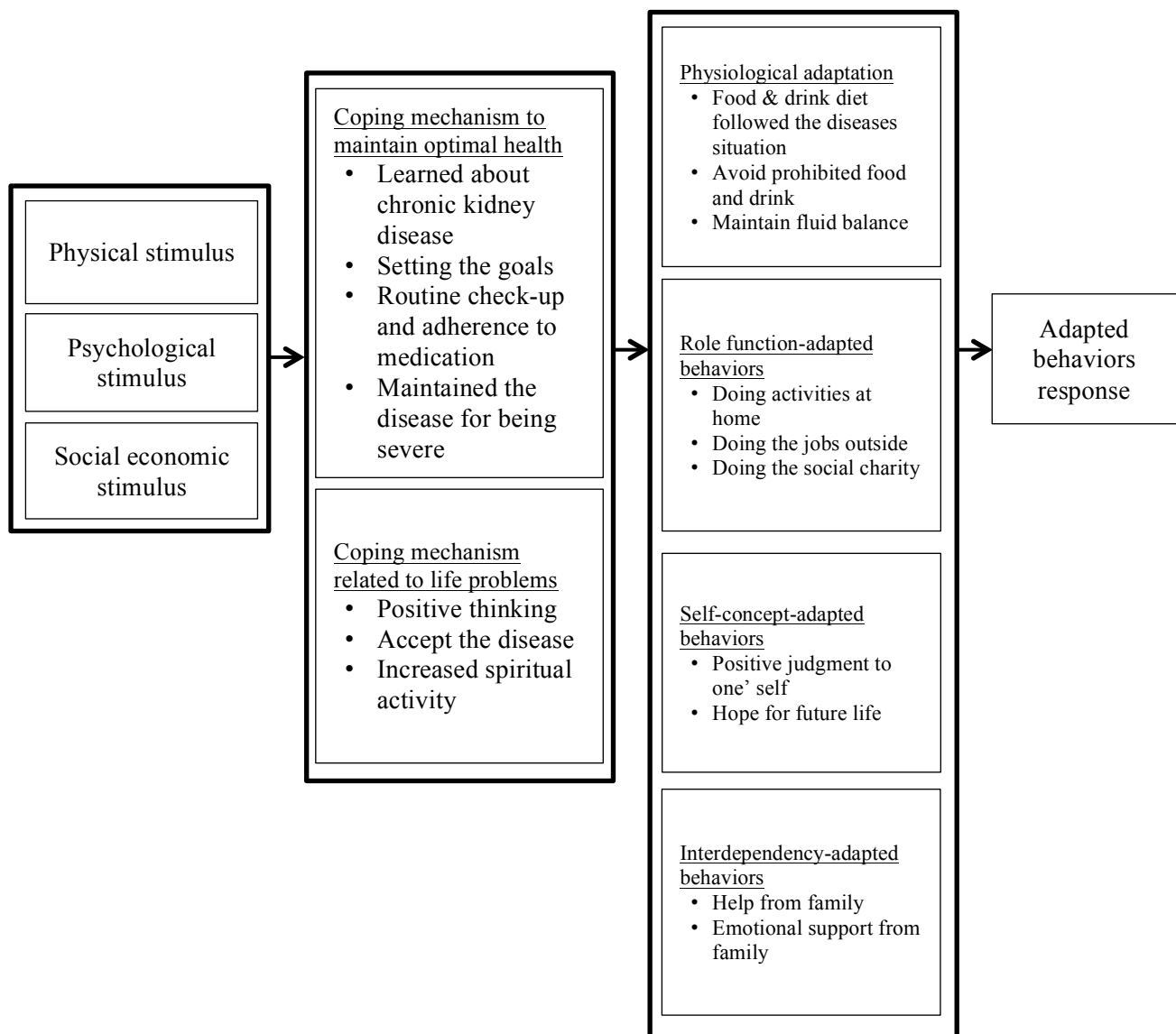


Figure 1 Adaptive behaviors of patients with pre-dialysis chronic kidney disease
*Developed by authors

Coping mechanism to manage the disease

The fifth theme is the coping mechanisms of patients which more focus on maintain health condition. We identified sub-themes including regular treatment, described in two categories: routine check and adherence to medication, as described by the following participants:

P1 said, "... I go to Salamun hospital for regular check-up ..., 2 times a week" P6 said, "..... Take medication regularly as the doctor's advice follow the recommendation for diet..... pay a lot of attention to reduce urea and creatinine....." P6 also

said, "I am sometimes confused...My sister told my disease cannot be cured....."

Selecting physiological adaptation

The sixth is related to the behaviors that participant choose as form of physiological adaptations in patients with chronic kidney disease pre dialysis. Sub-themes were identified refers to behavioral adaptations to fulfillment basic needs, which is described in four categories: diet, food restricted, drinking patterns, and drinking restricted as described by participants in the following:

P2 said, "... I eat chicken, wings ..., vegetable ...,carrots, papaya ..." P2 said, "... I eat rice ... chicken ... fish ... everyday usually only egg..., corn....., pumpkin, papaya " P5 said, "... If I drink a lot ... the swelling become bigger ..."

Based on interviews, almost all participants restrict the intake of nutrients and fluids as one of management to manage the disease become severe. Seven of the eight participants limit their intake of protein either fish or beef. Four of the eight participants limit their intake of vegetables, especially green vegetables such as spinach.

Self-concept-adapted behaviors

Seventh themes are referring to behaviors adaptation of self-concept. From this theme, we identified two sub-themes, namely the positive values to one's self and future hope as described follows:

P1 said, "... I am not ashamed..., this is from God, not self-conscious ... no being a problem ..., later my disease will be recovered ..., I accept this really ..." P2 said, "If I am still strong ... I will continue to work ..." P3 said, "... want to worship the God more, prayer ..., chanting ..Dzkir..."

Having positive value toward one self, never be ashamed because of disease, and keep hope for better future life even though suffer from chronic kidney disease is important key sub-theme of adapted behaviors.

Role function-adapted behaviors

The eighth themes are behavioral adaptation related to role function after diagnosed with chronic kidney disease pre dialysis. We identified sub-theme as doing appropriate activities, which is depend on health condition. We found two categories to describe this sub-theme, namely doing the housework and work as usual.

P4 said, "... as a wife ..., as midwife assistant ..., as a mother ... as grandmother to granddaughter ..., nothing has changed ..." P2 said, "... I still work every day ..., every day ride public transportation ..., in the workplace is nothing change ..."

Participants in this study also choose behavioral adaptations-role functions, the

participants tried to perform their role in accordance with the health conditions, if participants are in a good condition, then the participant will undertake appropriate activities of daily role. However, if the condition of the participants is unfit, the role of the participants will be replaced by other family members.

DISCUSSION

Majority of participants were complained physical and psychological problems such as respiratory pattern and anxiety. Weiss dan Weisshaar suggested that physical problems are one aspect that required more attention due to its significant impact on quality of life of patients with chronic kidney disease ([Weiss & Weisshaar, 2014](#)). Study also highlighted that management of chronic kidney disease is important aspect to prevent from any complication or make the disease getting severe ([Daugirdas, Blake, & Ing, 2012](#)). The changes in physical and psychological aspect may affect their social interaction and productivities. We thus proposed that health care professional need to design a management to minimize the physical stimulus especially in patients pre-dialysis to maintain their health condition and prevent from complication. In regards to anxiety, almost participants in our study described that the anxiety affect their sleep quality. Another study empathized that patients with chronic kidney disease complained anxiety because they felt worried about their health status and scary about the complication. Psychological support and also health education related to chronic kidney disease and its management is needed to help patients adjust their current situation, as patients with chronic kidney disease in order to improve patients' quality of life. Therefore, we need to develop a protocol for management of chronic kidney disease ([Vilaplana, Zampieron, Craver, & Buja, 2009](#)).

Some of participants have a positive value related to their lived and disease. This would be having a benefit to their health status. It

was concurrent with previous study stated that positive coping mechanism can minimized psychological problems ([Zawadzka & Byrczek, 2012](#)). It has been well known that chronic kidney disease required long-term follow up for the treatment in all stage. We also found that the participants were routinely come to clinic or hospital for their physical examination. Study suggested that screening, diagnostic examination, and staging in patients with chronic kidney disease is needed as reference to decide an appropriate treatment ([Daugirdas et al., 2012](#)). Moreover, patients also described that since they diagnosis with chronic kidney disease, they began to manage their diet including food and drink. They restrict some of food that suggested from health care professional. Therefore, adaptation behavior is required and health care professional need to facilitate patients to the changes due to disease. Assessment to the daily nutrition intake such as patient recall of food intake may be a viable solution to help patients ([Daugirdas et al., 2012](#)). However, it requires comprehensive health education from professional to help patients recognized some of important behavior changed.

The way of participants choose the change of self-concept is done by assessed their positive judgment towards their self, and never be ashamed as a patients who suffer from chronic kidney disease. Having a positive assessment of own self is very important, it can a big motivation to live in normal or usual condition and it can be a reason to keep hope for the future. Participants in this study also choose behavioral adaptations role functions, the participants tried to perform their role in accordance with the conditions, if participants are in a comfortable condition, then the participant will undertake appropriate daily activities. However, if the condition of the participants is uncomfortable, the role of the participants will be replaced by other family members. Social support is positively associated with a good treatment outcomes in various contexts of disease ([Pichon, Rossi, Ogg, Krull, & Griffin, 2015](#)). Social support can be given to patients, particularly from

close relative. The family is a collection of two or more people who have ties or marriage and blood relations who live together under one roof with their respective roles and have a social attachment ([Friedman, Bowden, & Jones, 2003](#)). One of the functions of the family is demanding maintenance health status of their members and provides care to a family member who suffered from health problems. Family support is an important factor affecting the ability of participants' activities and carrying out its role, both activities in the home and activities outside. With the family support, participants felt appreciated and acknowledged, are not regarded as weak and useless, it is very important as encouraging participants to make the necessary adaptations behavior, in order to maintain kidney function.

CONCLUSION

We tentatively concluded that the experience of patients with chronic kidney disease pre dialysis, they were suffering from such of physical, psychological, social, economic, spiritual problems. So, professional health care need to help patients to cope with the disease and some of behavior changes such as foods diet, drink, and activity patterns which also elaborate the role or support from family. We also recommend developing a model adaptation based on Roy's model in patients with chronic kidney as a reference management of patients with chronic kidney disease, especially in the pre dialysis period.

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Cite this article as: Agustiyowati, T.H.R., Sitorus, Waluyo, R.A., Besral. (2018). The lived experience of patients with pre-dialysis chronic kidney disease: a qualitative study. *Belitung Nursing Journal*, 4(2), 263-270.