



ORIGINAL

## Early-Stage Chronic Kidney Disease Patients Experiences of Self Management on A Cultural perspective: A Qualitative Study

### Experiencias de Autogestión de Pacientes con Enfermedad Renal Crónica en Estadio Inicial Desde una Perspectiva Cultural: Un Estudio Cualitativo

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Cite as: Dwi Hartanti R, Yetti K, Yona S, Martha E. Early-Stage Chronic Kidney Disease Patients Experiences of Self Management on A Cultural perspective: A Qualitative Study. Salud, Ciencia y Tecnología. 2025; 5:1141. <https://doi.org/10.56294/saludcyt20251141>

Submitted: 05-03-2024

Revised: 19-07-2024

Accepted: 21-11-2024

Published: 01-01-2025

Editor: Prof. Dr. William Castillo-González 

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#### ABSTRACT

**Background:** self-management is the gold standard of care for early CKD patients which is useful for preventing complications and slowing down the decline in kidney function. The experience of early CKD patients in carrying out self-management is very important to improve the ability, independence and right decision making in carrying out self-management. This study aimed to explore the self-management experience in adults diagnosed early chronic kidney disease in culture perspective of Javanese.

**Method:** this study is a qualitative with a phenomenological approach, using semi-structured in-depth interviews with 27 adult patients diagnosed with early stage 1-3 chronic kidney disease. Data were analyzed using thematic analysis with the Colaizzi analysis method.

**Results:** the results of the analysis reveal the experiences of early chronic kidney disease patients with self-management, consist of 4 main themes: 1) family support in self-management, 2) Care decision making with family, 3) unhealthy eating habit, and 4) using traditional medicine in kidney health maintenance.

**Conclusion:** the results of the study concluded that the Javanese culture that is in line with self-management in early chronic kidney disease patients is family relationships and traditional medicine. Family relationships in Javanese culture has high philosophical values and supports health care. Traditional medicine is also still the choice of early chronic kidney disease patients with Javanese ethnicity in carrying out self-management. This study recommends the need for nursing interventions that are tailored to the patient's culture by integrating family care practices and traditional medicine to improve self-management in early chronic kidney disease patients.

**Keywords:** Chronic Kidney Disease; Cultural; Perspectives; Self-Management.

#### RESUMEN

**Introducción:** el autocuidado es el estándar de oro de la atención para los pacientes con ERC temprana, que es útil para prevenir complicaciones y frenar el deterioro de la función renal. La experiencia de los pacientes con ERC temprana en la realización del autocuidado es muy importante para aumentar la capacidad, la independencia y la toma de decisiones correctas en el autocuidado. Este estudio tuvo como objetivo explorar la experiencia de autogestión en adultos diagnosticados de enfermedad renal crónica temprana en la perspectiva cultural de los javaneses.

**Método:** este estudio es cualitativo con un enfoque fenomenológico, utilizando entrevistas en profundidad

semiestructuradas con 27 pacientes adultos diagnosticados de enfermedad renal crónica en etapa temprana 1-3. Los datos se analizaron utilizando análisis temático con el método de análisis de Colaizzi.

**Resultados:** los resultados del análisis revelan las experiencias de los pacientes con enfermedad renal crónica temprana con la autogestión, que consisten en 4 temas principales: 1) apoyo familiar en la autogestión, 2) toma de decisiones de atención con la familia, 3) hábito alimentario poco saludable y 4) uso de la medicina tradicional en el mantenimiento de la salud renal.

**Conclusión:** los resultados del estudio concluyeron que la cultura javanesa que está en línea con la autogestión en pacientes con enfermedad renal crónica temprana son las relaciones familiares y la medicina tradicional. Las relaciones familiares en la cultura javanesa tienen altos valores filosóficos y apoyan la atención médica. La medicina tradicional sigue siendo la opción preferida por los pacientes de etnia javanesa con enfermedad renal crónica en etapa temprana para llevar a cabo el autocuidado. Este estudio recomienda la necesidad de intervenciones de enfermería que se adapten a la cultura del paciente mediante la integración de prácticas de atención familiar y medicina tradicional para mejorar el autocuidado en pacientes con enfermedad renal crónica en etapa temprana.

**Palabras clave:** Enfermedad Renal Crónica; Cultura; Perspectivas; Autocuidado.

## INTRODUCTION

Self-management is an effective care intervention in chronic kidney disease.<sup>(1)</sup> Self-management in early CKD patients is defined as the individual's proactive management, in planning care management and treatment of the disease.<sup>(2)</sup> This proactive approach aims to help patients identify strategies that can be used to manage their disease condition and help patients remain active and productive.<sup>(3)</sup> Self-management in early CKD patients is very important to slow the decline in kidney function,<sup>(4)</sup> reduce the risk of complications, and slow disease progression.<sup>(5)</sup>

The effectiveness of early CKD patient self-management is associated with better quality of life and improved overall patient well-being.<sup>(6)</sup> Essential components of early CKD patient self-care include symptom management, lifestyle modification, physical and psychological management, and medication management to manage chronic disease.<sup>(7)</sup> The ability of early CKD patients to manage themselves in their disease care is the key to successful self-management.<sup>(8)</sup> However, in reality, the ability and practice of self-management of CKD patients are influenced by many factors, including age, duration of illness, social support, sources of meaning in life, patient perception and patient culture.<sup>(9)</sup> The biggest factor influencing self-management is the perspective and culture of health care.<sup>(10)</sup> Culture influences a person's behavior in carrying out CKD care such as adherence to treatment, dietary compliance and compliance with lifestyle modifications. Culture can also influence a person in making decisions about their health care.<sup>(6)</sup> As in CKD patients with Javanese culture, where the Javanese culture possessed by the patient can provide a negative or positive perspective on a person's perspective on dealing with their disease care.

The Javanese community in Indonesia is the largest community in Indonesia. More than 50 % of Indonesia's population is Javanese.<sup>(11)</sup> The strong cultural customs and upholding of the Javanese community towards health care such as health beliefs, family and kinship ties, cultural norms will influence the way patients interpret and respond to symptoms of illness and carry out self-management of their disease.<sup>(12)</sup> Exploring the experiences of early CKD patients in self-management from a cultural perspective can help patients and doctors or nurses make more appropriate treatment choices and care interventions, resulting in better and quality patient care. This study aimed to explore the self-management experience in adults diagnosed early chronic kidney disease in culture perspective of Javanes.

## METHOD

### Design

Qualitative descriptive phenomenology approach was used in this study. This study aims to explore and understand the experiences, adaptations made and obstacles of early CKD patients in implementing self-management based on Javanese cultural perspective.

### Participants and sampling

Early CKD patients were recruited from Primary Health Care (Puskesmas) in Pekalongan, Central Java, Indonesia. Purposive sampling was used to select participants. The inclusion criteria specified: age 18 years old or older, diagnosed early CKD stage 1-3, Javanese ethnicity, willing to be participants, and able to use Indonesian or Javanese. The interview process in data collection is directly by the researcher to the agreement

of the participants.

### Data Collection

The interview process with participant was conducted face to face directly by the researchers. All researchers have experience in research and publication and all were female. The primary researcher has a background as a researcher, nurse, and lecturer. All researchers had no relationship with the participants. The research began by explaining the purpose and procedures of the research to the participants and asking for proof of the participants' willingness to participate in the research by signing an informed consent.

Participants were recruited from June to September 2023. The interviews were used in-depth, semi-structured using an interviews guide. Interview guidelines were developed by researchers based on literature review in early CKD patients self management. The questions focused on participants' experiences of early CKD self-management in Javanese culture context (table 1). The questions in the interview guide use open questions that are probed by the researcher to enrich the data. The interview guide is equipped with participant demographic data to determine participant characteristics. Interviews were conducted face to face directly by researchers. All the interview were digitally audio-recorded and field noted (documenting non-verbal data such as facial expressions and body language during interviews). The interview duration of each interview the range 45 until 70 minutes for each participant. Interviews were conducted until the data was saturated and no new information was obtained. Data collection was stopped after the data was saturated and 27 participants were obtained.

Triangulation in data collection was conducted by researcher triangulation and methodological triangulation. Researcher triangulation was conducted by interviewing three Javanese community leaders to gather additional information about health care in the context of Javanese culture. Meanwhile, methodological triangulation was conducted by using a digital recorder and field notes during the interview process. The results of the interview recordings were then recorded verbatim and validated together with the second, third and fourth authors.

Table 1. Semistructured Interview guide	
Semistructured interview guide	
1.	How is your experience in self-management?
2.	How do you adapt self-management to the Javanese culture you have?
3.	What are the strategies for self-management according to Javanese culture?
4.	How to care for kidney health in javanese culture?
*Including lifestyle, diet, exercise, medication, psychological management	

### Data Analysis

The data analysis using thematic analysis with the Colaizzi method, which consists of seven stages including: 1) reading and transcribing interview data and combining field notes during interviews to integrate the data obtained, 2) extracted meaningful statements and field findings related to self-management culture in early CKD patients, 3) Formulate the meaning of significant statements by bracketing so that the resulting categories do not reduce the meaning of the phenomena conveyed by participants, 4) Organizing the formalized aggregate of meanings into subthemes and themes, 5) merging the formed themes and describing them in detail, 6) removing redundant coding and stating culture of self-management in early CKD patients and culture adapted to self-management, 7) verification of themes arranged with research objectives <sup>(13)</sup>.

### Ethics of Study

Approval was obtained the Faculty of Nursing Health, Universitas Indonesia, Services Ethics Commissions with certificate number KET-244/UN2.F12.D1.2.1/PPM.00.02/2022.

## RESULTS

### Characteristics of Respondents

A total of 27 participants with adult patients with early CKD were recruited from two primary health center (Puskesmas). Based on table 2, participant characteristics majority were female with age range is 51-60 years old (59,2 %), middle school backgrounds educational (51,8 %) and married (85,2).

**Table 2. Participants Characteristics**

Characteristic	Total (n = 27)	%
Gender		
Male	7	25,9
Female	20	74,1
Age (years old)		
41 - 50	7	25,9
51 - 60	16	59,2
61 - 70	4	14,8
Education		
Elementary (SD-SMP)	10	37,1
Secondary (SMA)	14	51,8
College	3	11,1
Occupation		
Civil servant	2	7,4
Private employee	4	14,8
Entrepreneur	3	11,1
Laborer/trader	6	22,2
Not working / Housewife	12	44,4
Marital Status		
Married	23	85,2
Not married	4	14,8

**Thematic Findings**

Four cultural themes of CKD patients’ self-management were obtained from the analysis of participant narratives including : 1) family support in self-management, consists of subthemes health care by family and health support by family, 2) Care decision making with family, encompassing sub-themes of *rembug* in problem solving with family and familial connections 3) unhealthy eating habits, including sub-themes such as eating according to taste and feast traditions, and 4) using traditional medicine in kidney health maintenance, including subthemes of complementary medicine and traditional Javanese medicine. The identified themes are presented in a thematic chart (figure 1).

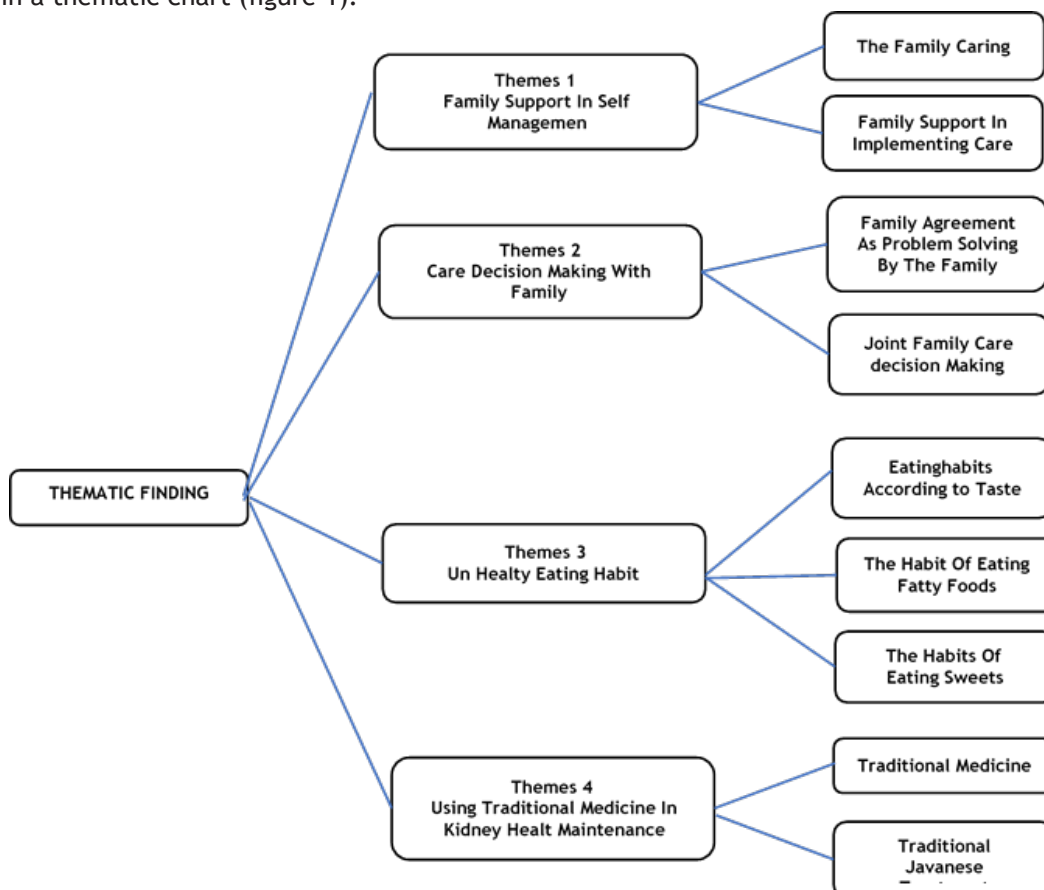


Figure 1. Thematical Chart

### Theme 1: Family support in self-management

Participants perceived family support as support or assistance provided by the family in implementing lifestyle management, activity management, medication management and health checks. This is illustrated from the resulting themes including care by the family and family support in implementing care. The family caring which is indicated by the following keywords : “all care decisions are discussed first with the family (p3)” and “Yes, if he is sick, he takes care of his wife and children (p24)”. Family support in care is described as the role of the family in self-management of early CKD patients as described in the following quote: “The children are all attentive to me” (p13) and “Oh all the family, motivate, are attentive and help with my care” (p27).

### Theme 2: Care decision making with family

Family care decision making in this study is described as a joint agreement between all family members in determining health care. This is mentioned as a sub-theme of joint family care decision-making, from the participant’s statement : “I follow the family’s decision on what is best for my care”(p3)”. This participant vividly described family decision-making to be part of the culture involving partners, children and extended family, as seen from quotation : “I follow my husband and children for the best decision, they also sometimes discuss with the extended family to decide what is best (p11)”

In Javanese culture, decision-making through joint family agreement is called *rembug sedulur* (Hartanti et al., 2024). This explains the subtheme of family agreement as problem solving by the family, from the participant’s reviews “if there is a serious problem, the family will provide a solution through family discussion” (p22).

### Theme 3. Unhealthy eating habits

Unhealthy eating habits are eating patterns that do not meet the body’s nutritional needs adequately. Participants described their unhealthy eating habits in a food culture that is depicted in subthemes such as eating according to taste and feast traditions. Eating habits according to taste indicate the selection of a menu according to the participant’s wishes and without dietary regulation according to the participant’s quotation: “if I eat, I still eat as I please, according to my taste or desire. I never regulate my eating” (p17), and “I never choose what I eat, I eat all my food well. I have no restrictions on any food” (p25).

The expressions conveyed by participants about eating habits according to taste will form eating behavior patterns that become habits and cultures in eating. Participants also showed eating behaviors that became their habits such as the habit of eating sweets and eating fatty foods. participant’s quotation: “Drinking sweet drinks such as sweet tea and coffee is a habit since childhood. It is very difficult to break the habit. However, I have tried to reduce drinking sweet drinks” (p9) and “my favorite food is often food with coconut milk” (p13).

Unhealthy eating habits in participants are also described by feast traditions. Participants expressed that the tradition of feasting is a Javanese cultural tradition that shows respect for guests (Hartanti, 2024). The participant’s quotation is : “There are several food for the guests and special event” (p11), and “We drink the tea as a respect to the host“(p18). The tradition of hosting relatives is a societal habit of providing feasts to guests or relatives who come (family, siblings, and friends) as a show of honor and affection. The participant quotation : ” If we go for a walk we are invited to visit. We are asked to drink and eat the snack. I am shy to denied” (p3) and “Feel bad if we do not drink“ (p7).

The Javanese community has a custom of hosting guests or relatives at ceremonies or festivals. This tradition involves serving a variety of special meals as a sign of respect with quotation : ” Providing snack for several event, it must be a sweetness”(p11) and “If there are guests, they also serve sweet tea. There are also events where sweet tea is served”. (p24)

### Theme 4: Using traditional medicine in kidney health maintenance

Early CKD patients in Javanese community use non-medical treatment approaches for kidney care. This non-medical treatment is rooted in the cultural traditions of early CKD patients in Javanese community which are passed down through generations. The use of this traditional medicine is described in the sub-themes of complementary treatment and traditional Javanese treatment. Complementary treatment in Javanese community refers to the use of non-medical treatment by combining modality treatment and Javanese community beliefs. Various complementary treatments that are often used by early CKD patients with Javanese community are cupping therapy (*bekam*), traditional herbal concoctions, nerve acupressure therapy, massage therapy. This is explained in the participant’s statement: “I have also tried cupping therapy several times when I was sick” (p11) and “Once when I was sick, I tried drinking herbal medicine and doing nerve acupressure. The result was that my body felt fresher after drinking herbal medicine and trying nerve acupressure” (p17).

Meanwhile, Traditional Javanese treatment is referred to as a cultural treatment that is passed down from generation to generation (Setiawan & Kurniawan, 2017). Traditional Javanese treatment is a socio-cultural Javanese belief treatment involving supernatural processes such as seeking help from spirits and using

supernatural weapons that are passed down from through generation. Early CKD patients also use Javanese medicine (*kejawan*) such as believing in elders or traditional figures to treat diseases.<sup>(14,15)</sup> As described in the following participant statement: *"And finally, I hire shaman to cure"*(p2) and *"Still ask holly water from kyai and ustad"*(p14).

## DISCUSSION

Family support in self-management is described as assistance received by family members from family, friends, neighbors and close relatives including physical assistance, informational and emotional support.<sup>(16)</sup> The function of the family in self-management is a multidimensional concept.<sup>(17)</sup> The family in self-management in early CKD patients has the function of communicating, solving problems,<sup>(16)</sup> helping with financial care, regulating family relationships and making care decision.<sup>(17)</sup> Family in Javanese culture has a very important meaning and high philosophical value in life. In addition to having strong social ties, families in Javanese society have a normative maintenance role in life from generation to generation.<sup>(18)</sup> The family in Javanese society functions as a safe haven, building economic strength and health care.<sup>(19)</sup> Family support in health care includes physical, social, emotional and economic resilience dimensions in the family during health care.

In Javanese society, family relationships also function as a crucial factor in health care decision-making. This is reflected in the results of the study in the second theme, joint family care decision-making. Health care decision-making in early CKD patients with Javanese culture is carried out through family deliberation culture. Deliberation is carried out by all family members led by the oldest family member. Highlighting the importance of family deliberation in decision-making in early CKD patients with Javanese culture will affect the choice of care, behavior, motivation, readiness and ability of early CKD patients in self-management. This has an impact on effective care management for kidney health, so nurses and health workers need to involve families in self-management interventions for early CKD patient care.

Unhealthy eating habits are part of the self-management culture in early CKD patients in Javanese society. Unhealthy eating habits in early CKD patients describe the daily eating habits of patients that are formed from the eating culture patterns of Javanese society. These unhealthy eating habits are described as a sub-theme of eating according to taste or no eating arrangements in diet management and the tradition of feasting. Eating according to taste is described as consuming food that is liked without following the rules of diet management. Eating according to taste is influenced by the eating patterns that become a person's eating habits. Habits regarding eating patterns affect a person's perspective in meeting their eating needs including appetite.<sup>(20)</sup> The tradition of feasting (eating together) in the social life of early CKD patients is described as a tradition in the social life of society with eating together activities that show social togetherness, respect and family banquets.<sup>(20)</sup> Eating together in family banquets serves foods that are rich in fat and carbohydrates, dishes made with coconut milk and tend to be salty with drinks that are all sweet. Eating together has an important meaning in the life of Javanese society. Eating together is a Javanese tradition that contains Javanese cultural values and has the meaning of togetherness in the family, kinship ties, a symbol of hospitality, and gratitude.<sup>(21)</sup> The habit of eating according to taste and eating together has an impact on self-management, especially in regulating eating patterns.

The use of traditional medicine in early CKD patients in Javanese society is a culture and belief in the treatment of early CKD patients as Javanese people. Javanese people believe that traditional medicine that they believe in from generation to generation can cure diseases.<sup>(15)</sup> The use of traditional medicine in early CKD patients in Javanese society is described as a sub-theme of complementary medicine and traditional Javanese medicine (*kejawan*). Complementary medicine refers to non-medical treatment in the form of modality therapy based on the patient's beliefs and beliefs.<sup>(22)</sup> Complementary therapy is a conventional treatment of the Javanese people which includes cupping therapy, massage, acupuncture and herbal drinks (*jamu*).<sup>(23)</sup> Complementary medicine is a treatment option for early CKD patients when patients feel that medical treatment does not show improvement in their condition. However, the use of traditional medicine by consuming herbal drinks (*jamu*) requires caution, especially in early CKD patients because it has the potential to reduce and worsen kidney function.<sup>(24)</sup> In addition to complementary medicine, Javanese people also believe in traditional medicine (*kejawan*). Traditional medicine (*kejawan*) is a treatment that is rooted in the Javanese ancestral belief tradition. Traditional medicine (*kejawan*) is known as a treatment that believes in the supernatural powers possessed by ancestors. Traditional medicine (*kejawan*) includes supernatural treatment with mystical rituals. Elders who provide traditional medicine (*kejawan*) have charisma attached to them. Early CKD patients who feel that their condition is not getting better generally try traditional medicine (*kejawan*) to reduce their symptoms.<sup>(25)</sup> CKD patients who feel that there is no improvement in their condition will switch and try treatment using traditional medicine.

Review of patient experiences in carrying out self-management according to their culture is a strength that has an impact on patient self-efficacy in carrying out their care. Cultural values held by early CKD patients can be a strength to increase patient compliance in self-management. Although culture is one of the factors

that strengthens self-management, this can be a unique practical challenge related to habits that have been deeply ingrained since birth. However, by adapting to self-management such as adapting self-management with transcultural nursing, it can increase the role of early CKD patient culture in self-management compliance.

## CONCLUSION

This study provides valuable insights into self-management practices of early CKD patients from a Javanese cultural perspective. The findings underline the importance of family support in self-management that is oriented towards family assistance. In addition, decision-making for care through family deliberation as a cultural practice that plays an important role in health care decision-making in CKD self-management. This cultural practice reflects family relationships in Javanese society. Unhealthy eating habits in diet management are characterized by eating habits according to taste and feasting as a form of Javanese cultural eating habits. This study also found the use of traditional medicine involving complementary medicine and Javanese medicine (kejawen) in self-management practices in early CKD patients. The cultural practices produced in this study describe cultural experiences that provide valuable insights for health professionals in self-management of early CKD patients. This study recommends the need for holistic and culturally sensitive CKD patient self-management interventions by considering patient culture, family dynamics, and more effective traditional care practices.

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#### **FINANCING**

This study supported by University of Muhammadiyah Pekajangan Pekalongan, and the Indonesian Education Scholarship (BPI).

#### **CONFLICT OF INTEREST**

The authors report that they have no conflicts of interest for this study.

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