

Overview of Self-Care of Patients with Chronic Kidney Disease based on a Family Perspective

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Abstract

CKD patients undergoing hemodialysis have limitations in physical, psychological and mental care. However, patients with chronic diseases such as CKD do not automatically have the ability to treat themselves. Their families must be able to independently carry out palliative care at home. The purpose of this study is to describe the self-care of patients with chronic kidney disease based on family perspective

This study was a quantitative research with descriptive approach. The sample consisted of 95 respondents determined using consecutive sampling from the population in hemodialysis room. This study used patient self-care variables consisting of self-maintenance, self-management, and self-confidence domains. Research variables were measured using the Self-Care of CKD Index and analyzed using descriptive analysis

The results show that the highest percentage of self-care level is wholly compensatory (47.4%) and all self-care domains exist at the level of wholly compensatory systems, namely self-maintenance (47.4%), self-management (42.1%), and self-confidence (42.1%). The ability of CKD patients to perform self-care while at home shows low dependence. Self-maintenance is the biggest domain among other self-care domains. The family has an important role in self-care as a support system at all domain, especially in self-managemen.

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Introduction

Physical and psychological limitations can become a disturbance for CKD patients undergoing hemodialysis in performing self-care independently. CKD patients undergoing hemodialysis need skills in self-care. Currently, the ability of patient self-care is of global concern along with an increase in the incidence of chronic disease, an increase in medical costs and an insufficient number of educators, which are important reasons for self-care in improving the quality of life of patients, families and communities¹. The ability of CKD patients to do self-care cannot be explained.

The prevalence of CKD sufferers tends to continue to increase. According to the Global Burden of Disease study, CKD contributed 956,200 deaths worldwide, an increase of 134% from 1990². Indonesia is a country with a high rate of CKD sufferers; the Indonesian Nephrology Association (PERNEFRI) estimates that there are 70,000 people with CKD in Indonesia. This number will continue to increase by about 10% every year³. According to data from Riskesdas in 2018, the prevalence of CKD in Indonesia is 0.38% of total diagnoses and the proportion of hemodialysis is 19.33% of diagnoses⁴. The prevalence of ESRD continues to increase and patients with ESRD have unique and unmet needs for palliative care⁵. However, the family caregiver's ability to provide care is negatively affected⁶. Negative factors of palliative care are seen from a family perspective, namely the burden of family caregiver and family caregiver independence in providing care assistance independently (family self-care).

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Family caregivers in patient palliative care often experience enormous physical, emotional and financial responsibilities associated with providing care. The caregiver burden increases over time in a nonlinear manner from the start of diagnosis to the death of the patient⁷. The family burden when caring for CKD patients undergoing hemodialysis is included in the no-burden or low-burden category for 55 families (57.9%). There is a burden felt by 40 families (42.1%)⁸. The care provided by giver's family care is necessary in all domains of quality of life (physical, psychological, social, spiritual)⁹. The high burden of disease experienced by patients physically and psychologically and the high burden of care experienced by the family make it important for the patient's ability to perform self-care. The self-care approach that is carried out in palliative care is related to three behaviors, namely maintenance, management and self-confidence which will affect the self-care ability of patients and their families in caring for patients with chronic kidney disease with hemodialysis¹⁰. This study aimed to describe the self-care of patients with chronic kidney disease based on family perspective.

Materials and methods

Study Design

This study was a quantitative research with descriptive approach. This research was conducted January 2020 in hemodialysis unit of the Muhammadiyah Hospital, Lamongan city, Indonesia.

Population, Samples, and Sampling

The population in this study were all family CKD patients undergoing hemodialysis. The sampling method in this study was conducted using consecutive sampling technique. The sample recruited from family CKD patients with hemodialysis In Rumah Sakit Muhammadiyah Lamongan for two months were 95 persons.

Instruments

The instrument used to assess family self-care in performing palliative care at home is self-care of CKD index. This questionnaire has three domains, including self-maintenance, self-management, and self-confidence. The number of questions is 26 items. Each question item is scored with Likert scale from 1-4, with a score of 25-50 (wholly compensatory system), 51-76 = (partial compensatory system) and 77-100

(supportive compensatory system).

Procedure

Collecting data uses a measuring instrument in the form of a questionnaire. Primary data are taken directly from respondents (family caregivers). Respondents who met the inclusion criteria served to fill out the questionnaire. The researcher explains the questionnaire filling technique and researchers and research assistants directly fill out and retrieve the completed questionnaires.

Data Analysis

The data obtained were descriptively analyzed by presenting data on frequency, mean and standard deviation.

Results

The results of the study discussed the demographic characteristics of the patient, the level of self-care and the self-care domain. Most of the categories of respondents in this study were in the age range > 45 years (48%), the most gender was female (60%), with the highest level of education senior high school (64.2%), and the highest salary of <2 million rupiah (Table 1).

Demographic data	n	%
Age		
Teenagers (< 25 th)	15	15.8
Adult (25 th – 45 th)	34	35.8
Elderly (> 45 th)	46	48.4
Gender		
Female	57	60
Male	38	40
Educational level		
Junior high school	18	18.9
Senior high school	61	64.2
University	16	16.8
Salary		
< 2 million/month	41	43.2
> 2 million/ month	54	56.8

Table 1. Demographic Data Characteristics of Family CKD Patients at Hemodialysis Room, January 2020 (n=95).

Based on Table 2, it shows that the highest percentage of self-care level is wholly compensatory (47.4%), the next level is moderate compensatory (37.9%) and the lowest is support compensatory (14.7%). In the Self-Care Approach Viewed from a Family Perspective based on the Self-Care of CKD Index, it was found that all self-care domains were at the full compensation system level, namely self-care maintenance (47.4%), self-management (42.1%), and self-confidence. (42.1%) (Table 3).

Self-Care	Frequency	Percentage (%)
Wholly compensatory	45	47,4
Partial compensatory	36	37,9
Support compensatory	14	14,7
Total	95	100

Table 2. The Level of Self-Care of CKD Patients Undergoing Hemodialysis at Hemodialysis Room based on Family Perspective, January 2020 (n = 95).

Domain Self-Care	n	%	Mean	SD
Self-Maintenance				
Wholly compensatory	45	47,4%		
Partial compensatory	32	33,7%	19,56	6,872
Support compensatory	18	18,9%		
Self-Management				
Wholly compensatory	40	42,1%		
Partial compensatory	16	16,8%	13,34	5,632
Support compensatory	39	41,1%		
Self-Confidence				
Wholly compensatory	40	42,1%		
Partial compensatory	17	17,9%	19,99	9,122
Support compensatory	38	40,0%		

Table 3. Self-Care Approach Viewed from a family perspective of CKD patients Undergoing Hemodialysis at Muhammadiyah Hospital, Lamongan based on the domain in self-care of CKD index.

Discussion

The results showed that some patients with hemodialysis therapy showed a low level of dependence. Patients can still carry out self-care activities independently. This is supported by research¹¹, which showed that patients on hemodialysis were more likely to have minimal dependence. The factors affecting the self-care of hemodialysis patients are age, education level and family income. Education level and family income are the factors that are most strongly associated with the ability of self-care in managing nutritional diets in patients undergoing hemodialysis¹¹. This is because nutrition is closely related to the patient's financial ability and patient knowledge about good nutrition for patients with hemodialysis therapy.

Most patients on hemodialysis require full support in self-care. Patients with chronic diseases, such as CKD, will rely heavily on family or caregivers to meet their daily needs¹². Patients who are highly dependent will need a family or caregiver during the treatment period, both at

home and in the hospital. The role of the family / caregiver is in the form of providing support, influencing patient decision-making, guided reflection of what the patient has experienced, contextual factors that are present at the time of symptoms, and facilitating discussions about changes in future actions¹³.

Based on the mean value, CKD patients who are undergoing hemodialysis therapy have a higher self-confidence domain than the other two self-care domains. Self-care confidence is a mediator to achieve self-maintenance and self-management¹⁴. Self-care confidence is a person's ability to perform self-care tasks. The findings of this study indicate that self-care confidence is the key to successful self-care in chronic diseases¹⁴. Self-care confidence is a major determinant of self-care in patients. Therefore, doctors and other health professionals must use strategies to increase patient self-confidence¹⁴.

The lowest mean value is found in the self-care domain of self-management. The results of this study are supported by research¹⁵ which shows that of the three self-care domains, the self-management domain has the lowest percentage. Self-management is an important component of successful outpatient chronic disease management¹². Self-management is an important concept in disease control, emphasizing health guidelines that direct patients to focus on their own problems¹⁶. Patients with high self-care management will easily make decisions that will be taken during the treatment period. In contrast, patients with low self-management will need a family or caregiver role to accompany them. The role of the caregiver is not only focused on helping patient self-care, but also related to patient care management at home¹². Self-care management is closely related to the contribution of carers or families who tend to their independent care¹². Roles and family support include escorting hemodialysis patients to do self-care management including diet monitoring, stress management, safe food, exercise, good habits, shunt care, therapeutic diets and observation of care instructions¹⁷. Self-management is also a prerequisite for humans to provide health care for patients with chronic diseases¹⁶.

Most patients on hemodialysis have high self-care maintenance. This is contrary to previous research. Previous studies conveyed

the largest adequate self-maintenance compared to other domains¹⁵. Self-care maintenance refers to behaviors that aim to maintain the stability of their health¹² and improve patient wellbeing¹⁴. These behaviors include taking medication as prescribed, adhering to a diet, and monitoring symptoms¹². Factors that influence self-care are physical and emotional quality of life, comorbidity, ADL disorders, cognition, number of hospitalizations, quality of patient-caregiver relationships, gender of caregivers, and social support for caregivers¹².

The results of this study imply that patient self-management needs to be improved. High self-management will increase the independence of patients with chronic diseases in caring for themselves. The family role is a vital part in improving patient self-management. Families can facilitate and supervise diet, exercise, and healthy living behaviors. The motivation provided by the family can provide psychic support and emotional support. Nurses can monitor the patient's self-management through the patient's physical condition. Health education provided by nurses will be able to change the knowledge and behavior of the patient. Health education should be given repeatedly so that patients are aware of the importance of changing lifestyles to be healthier. This study was only conducted on CKD patients undergoing hemodialysis, so it cannot represent self-care of CKD patients who do not undergo hemodialysis.

Conclusions

The ability of CKD patients to perform self-care while at home shows low dependence. Patients can still carry out self-care activities independently. Some CKD patients have greater self-maintenance than other self-care domains. Most patients in Indonesia have extended family structures that can provide more emotional support, awards and information, which will increase the patient's independence and trust in taking care of themselves. The role of the family is very big in caring for CKD patients at home. The family becomes the patient's support system, both in care management, making decisions related to patient care, and changing the patient's lifestyle.

Declaration of Interest

There is no conflict of interest.

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