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Determinants Analysis Factors Affecting the Capability of Family Healthcare of Chronic Kidney Disease with Hemodialysis

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Abstract

BACKGROUND: Family members have an important role in the healthcare of other family members, especially for hemodialysis patients.

AIM: The purpose of this study is to analyze the determinants of factors that affect the ability of families to care for patients of chronic kidney disease (CKD) with hemodialysis.

METHODS: This research was used descriptive-analytical with a cross-sectional approach. The utilized population was families of CKD patients with hemodialysis in three hospitals in East Java, Indonesia. Through multistage random sampling, 155 families were obtained. The research data were taken with family questionnaire, patient questionnaire, social support questionnaire, and health-care services questionnaire. After tabulating the data, the hypothesis was tested with Structural Equation Modeling-Partial Least Squares with a significance level of ≤ 0.05 or the value of t-statistic ≥t-table (1.96).

RESULTS: The results showed that the family factors (t = 2.527) with six indicators (Age, education, family structure and function, motivation, experience and skill, and knowledge) had a strong effect on family health-care ability, with p = 0.012. The patient factors (t = 2.355) with four indicators (physical, psychological condition, lenght of care, and disease severity) had a strong effect on family health-care ability, with p = 0.019. The social support factor (t = 8.051) with three indicators (family, peer, and health-care support) had a strongest effect on family health-care ability, with p = 0.000. The health service factor (t = 2.820) had a strong effect on family health-care ability, with p = 0.005.

CONCLUSION: Based on those results, it becomes necessary to increase the knowledge of family members. Besides that, improve the physical and psychological condition of patients by involving support from peer groups and health workers can be done. The quality of health services must also improved so the family's health-care ability of CKD patients with hemodialysis can increase.

Introduction

Hemodialysis is a burdensome and complex therapy that requires much support from family members [1]. Families often experience tremendous burdens associated with caring for hemodialysis patients. These challenges and burdens increase as the disease progresses. Families experience physical, emotional, and financial difficulties [2]. Families help patients at various stages of the disease, including physical, psychological, and mental care that are not limited to advanced stages of the disease [3]. The family burden may also have an effect on the patient as the recipient of care. Disturbances in quality of life and family burden for hemodialysis patients lead to a double burden on a family and interfere with the treatment process, reducing the ability of the family to treat chronic kidney disease (CKD) patients with hemodialysis [4]. One study reported that family care is associated with a lack of social and health support for patients and families [5]. However, the factors that affect family health-care ability, consisting of the factors of family, patients, social support, and health service, have never been studied thoroughly.

The prevalence of CKD tends to increase continuously. Patients since their initial diagnosis of CKD, as well as their families, have experienced progressive changes characterized by physical, mental, emotional, and economic difficulties [2]. The ability of families to care for hemodialysis patients is still relatively low. Lena Axelsson [6] stated that the ability of families to manage pain symptoms was found to be 32%, management of psychological symptoms in the form of anxiety was 44%, and other symptoms were 55%–84%. The majority of families stated that they were not ready for advanced care planning from the initial diagnosis of CKD to the end of life [2], [7]. Ability to discuss end-of-life was reported in 41% of patients and 71% of families [6].

According to Friedman [8], one of the functions of the family is the function of healthcare or maintenance, as the family function to maintain the health conditions of family members. Family-centered nursing care includes the processes of assessment, diagnosis, intervention or implementation, and evaluation. The

assessment includes the family factor, the patient factor, the social support factor, and the health service factor [9], [10], [11]. The family factor involves age, gender, education, structure and function, economic status or income, experience and skills, motivation, and knowledge [9], [11]. The patient factor involves age, gender, physical condition, psychological condition, length of illness, and disease severity [9], [11]. The social support factor involves family support, peer support, and health worker support [11], [12]. The health service factor involves ownership of health insurance and access to health services [11].

By understanding the factors that affect family health-care abilities, nurses can make efforts to prepare families for the care of hemodialysis patients. This includes more family-centered care, provision of appropriate education from an early age, interventions that target the readiness of care partners, effective communication focusing on readiness between health-care providers and family members of patients, and the dynamics of relationships between families and patients [13]. Families need appropriate knowledge, special skills, education, and guidance to help patients achieve better adherence to hemodialysis treatments [14].

Research Methods

This research was used cross-sectional approach. This research utilized the population of families of CKD patients with hemodialysis at Dr. Soegiri Hospital of Lamongan, Muhammadiyah Hospital of Lamongan, and Ibnu Sina Hospital of Gresik in East Java, Indonesia. Sampling utilized the multistage random technique, resulting in 155 families. The research data were taken with: Family questionnaire with six indicators (Age, education, family structure and function, motivation, experience and skill, and knowledge); patient questionnaire with four indicators (physical, psychological condition, lenght of care, and disease severity); social support questionnaire with three indicators (family, peer, and health-care support); and health-care services questionnaire. After tabulating the data, the hypothesis was tested with Structural Equation Modeling-Partial Least Squares with a significance level of ≤0.05 or the value of t-statistic ≥t-table (1.96).

Results

This table describes the characteristics of respondents which include age, gender, education, economic status, relationship with patient, and lenght of care.

Table 1 shows that for the 155 respondents, most of them were in elderly (56–65 years old) (47.7%) and male (51.6%), graduated from high school education (42.6%), and had a low economic status with incomes <Rp.2,200,000 (54.8%). Most of the family members were spouses of the patient (61.3%) and the patient were treated with hemodialysis for 3–4 years (72.9%).

Table 1: Respondent characteristics

Characteristics	Frequency (%)
Age (year old)	
36–45	36 (23.2)
46–55	45 (29)
56–65	74 (47.7)
Gender	
Male	80 (51.6)
Female	75 (48.4)
Education	
Elementary school	30 (19.4)
Junior high school	34 (21.9)
Senior high school	66 (42.6)
College	25 (16.1)
Economic status	
< Rp. 2.2 million	85 (54.8)
≥ Rp. 2.2 million	70 (45.2)
Relationship with patient	
Husband/wife	95 (61.3)
Child	38 (24.5)
Uncle/aunt	3 (1.9)
Father/mother	15 (9.7)
Sister/brother	4 (2.6)
Length of care (years)	
3–4	113 (72.9)
>4–5	13 (8.4)
>5	29 (18.7)

The results of the Table 2 showed that the family factors that have the greatest influence on family health-care abilities are experience and skills (t = 9.611). The patient factors that have the greatest influence on family health-care abilities are physical condition (t = 9.714). The social support factors that have the greatest influence on family health-care abilities are health workers support (t = 16.790). The health-care services factors that have the greatest influence on family health-care abilities are access to health services (t = 2.820).

Table 2: Frequency distribution for the family factors, patient factors, social support factors, and health-care services factors on family's health-care ability

Characteristics	Value (t)	p, t
Family factors		
Genders	4.825	0.012, 2.527
Education	4.259	
Family structure and function	9.323	
Motivation	8.210	
Experience and skill	9.611	
Knowledge	5.144	
Patient factors		
Physical condition	9.714	0.019, 2.355
Psychological condition	6.794	
Length of care	5.654	
Disease severity	5.075	
Social support factors		
Family support	11.358	0.000, 8.051
Peer support	14.821	
Health workers support	16.790	
Health-care services factors		
Ownership and use of insurance	1.620	0.005, 2.205
Access to health-care services	2.820	

Based on the results of p-value analysis, it was found that all of these factors had a major influence (p < 0,005) on family health-care abilities. However, the one with the strongest influence on family health-care abilities is social support factors (t = 8.051). It means

that social support factors (family, peer, and health workers support) are the most decisive factor in how a family health-care abilities.

Discussion

The family factors on family health-care ability

The family is the entry point for the provision of health services in society, to determine the risk of disturbances due to the influences of lifestyle and the environment. The practice of nursing conducted centrally by the family (family-centered nursing) is based on the perspective that the family is the basic unit for the individual nursing of family members. Studies with this model have examined families with subsystems of society [9], [15]. Hence, in this study, we focus on identifying whether the family is involved in patient care.

The results of this study showed that male (51.6%) and female (48.4%) patient family's members involed in the treatment process while on patient hemodialysis. It means that man or woman have an important role for patients who are undergoing routine treatment at the hospital. They are both actively involved in the care of their families who are undergoing hemodialysis. It means that the family is quite helpful in overcoming the health problems of their sick family.

The family is a system, in which if one family member has a problem, the problem will affect the system of other family members and *vice versa* [16]. Individual problems in the family are resolved through family intervention with active involvement of other family members. Thus, family intervention by a healthy family will improve the health of the society or community, because the family is a subsystem of society [9], [16].

The purpose of family nursing care is to enable the family to be independent in taking care of the health of its members. For that, the family must be able to carry out the five family health tasks: deciding on appropriate health actions for the family, caring for family members who have health problems, maintaining health at home, modifying the environment to ensure the health of family members, and taking advantage of the surrounding health service facilities for families [9]. Healthcare takes place mainly through commitment and modification of the environment and lifestyle, including experience and skills; this further strengthens the main role of the family in carrying out responsibilities for the health of family members [9].

Indicators of the family factor are education, structure and function, experience and skills, motivation, and knowledge [9], [11]. In this study, the families have graduated from high school education (43.2%). It means that most of them had a fairly good level of education. Families with good educations will help them in implementing their health functions. This can be seen from the results of this study which shows that most of them had healthy family function (89%). In addition, good family's knowledge (63.2%), motivation (90.3%), experience, and skills (86.5%) will also have a good influence on family health-care ability.

Each of indicators (gender, education, structure and function, motivation, experience and skills, and knowledge) from family factors had a strong influence ($t > 1.96$). It means that all of them had significant influence of the family factor toward family health-care ability. A better family factor is more likely to improve family health-care ability. It becomes necessary to strengthen the family factor by improving family structure and function, motivation, experience and skills, and knowledge. It becomes necessary to increase the active role of doctors and nurses in providing innovative health education to improve the knowledge as well as experience and skills of families in caring for patients.

The patient factor on family health-care ability

Indicators of the patient factor are age, physical condition, psychological condition, and disease severity [9], [11]. In this study, most of the hemodialysis patients are elderly (56–65-year-old) (61.9%). Even so, they have a good physical (55.5%) and psychological condition (55.5%). Physical and psychological conditions affect each other. Improvement of the patient factor involves not only the physical condition but also the psychological condition.

Since the initial diagnosis of CKD, patients experience progressive changes characterized by physical, mental, emotional, and economic difficulties [2]. The most common physical symptoms found in hemodialysis patients were pain (69%), followed by impaired respiratory secretions (46%), anxiety (41%), confusion (30%), shortness of breath (22%), and nausea (17%) [6]. Physical changes that occur in CKD patients undergoing hemodialysis therapy include changes in elimination patterns, changes in sleep patterns, the emergence of edema, and fatigue [17]. This study showed that the patient able to adapted and managed physical symptoms quite well. This can be seen from the result that severity of most of the patients had moderate severity of disease (69.7%). They can adapt to their conditions because most of them have enough experience in managing their symptoms, which are between 3 and 4 years (70.3%). This suggests that leght of illness can improve the patient's experience and ability to manage physical signs and symptoms.

Patients with chronic disease may be required to adjust themselves and their self-care throughout the course of the disease, for example, if the disease becomes exacerbated, a comorbid disease occurs, or further care is required. The goal of

self-care maintenance is to maintain health and prevent exacerbation of symptoms, while the goal of self-care monitoring is to recognize that a change has occurred, and the goal of self-care management is to effectively treat symptoms [11]. Complications of hemodialysis patients take the form of the non-compliance of dialysis patients in four aspects, which are non-compliance with hemodialysis programs, treatment programs, fluid restrictions, and diet programs [18], [19].

Psychological changes that occur in CKD patients undergoing hemodialysis therapy include feelings of sadness and anxiety when they are declared to have to undergo hemodialysis therapy [17]. Research findings [19] showed that at the beginning of hemodialysis, almost all patients complained of feelings of stress, sadness, anger, non-acceptance, and denial. Patients felt grief from the difficulties that they experienced. Anxiety, depression, and suicidal ideas were conveyed by the participants in this study.

This psychological disorder occurs due to stress from the experienced chronic disease conditions, as well as management – including hemodialysis – that must be carried out with time and the accompanying physical changes. Some behaviors that generally become stressors are feelings of helplessness, lifelong medication, and changes in body image [17]. Other psychological symptoms commonly experienced by hemodialysis patients include sleep disorders, restless leg syndrome, uremic pruritus, and depression [20]. In addition, the psychological symptoms found in hemodialysis patients are anxiety (41%) and confusion (30%) [6].

A better patient factor is more likely to improve family health-care ability. The indicators of age, physical condition, psychological condition, and disease severity had a strong influence on the patient factor. There was a significant effect of the patient factor on family health-care ability. However, the physical condition is indicator from patient factors that have the greatest influence on family health-care abilities (t = 9.714). Hence, we need to pay special attention to this indicator without neglecting other indicators.

The social support factor on family health-care ability

The process that results from chronic disease is the inability to carry out activities independently and freely, and thus, family support is necessary to provide care. Optimal family roles require appropriate approaches to enhance these abilities. Family support applied to chronic patients can build a collaborative system. To optimize family support, we need to focus on strengths and resources rather than family weakness, recognize family expertise in caring for patients, build empowerment rather than dependence. Another effort that can be done is to increase the sharing of information with patients, caregivers, and health services rather than having the information just being known by professionals, and create flexible and non-rigid programs [21].

According to Orem [22], family support is an important supporting factor in self-care, because the presence of family members who accompany patients during their illness will motivate the patients to be independent, especially if the family is close to and trusted by the patient. The role of the family is beneficial for both patients and health-care providers. The role of the family for patients is associated with increased behavior and self-management care as well as adherence to therapy, improved quality of life, reduced risk of mortality, reduced anxiety and depressive symptoms, and reduced chances of hospital admission. The role of the family for health-care providers is as an invaluable partner in the task of caring for patients with CKD [13]. Families experience many difficulties and challenges in caring for hemodialysis patients without prior instruction, readiness, or preparation [23].

The results of this study showed that most of them had good family support (74,8%) and good peer support (32.3%). Support from family, friends, and nurses is important to increase patient motivation. Peer support and other hemodialysis patients are also important for increasing patient morale and compliance. Social support from friends and the community also affects the independence of patients. Social support is needed by CKD patients on hemodialysis to improve their psychosocial management. Adaptive coping strategies as well as social support from family, health workers, friends, peer support groups, and the community need to be improved to prevent and overcome psychological, social, and spiritual problems in CKD patients on hemodialysis [20]. Hence, it becomes necessary to increase social support by strengthening primary family support and facilitating peer group activities.

The nursing practitioner listens and respects the views and choices of patients. The knowledge, values, beliefs, and cultural backgrounds of patients and their families are incorporated into nursing plans and interventions. Nursing practitioners communicate and share useful information in a correct and impartial manner to patients and families. Patients and families receive timely, complete, accurate information to participate in care, and decision-making. Nurses collaborate with patients and families in policymaking and program development, implementation and evaluation, and design of health facilities and professional education, especially in the delivery of care [21].

The social support factor has the indicators of family support, peer support, and health worker support [11], [12]. The results of this study showed that good support from health workers (56.8%). The indicators of family, peer, and health workers supports had a strong effect on the social support factor. A better social support factor is more likely to improve family health-care ability. The main support provider is the closest family members (husband/wife, parents, and

children). The indicators of social support factors that have the greatest influence are health workers support (t = 16.790). This showed that health workers have an important role in providing support for patients undergoing hemodialysis. Support from health workers is not only curative but also palliative in the biological, psychological, social, and spiritual aspects. Adequate healthcare will contribute to the resolution of psychological problems and improve the quality of life [20]. Hence, social support is also needed in health-care management.

The health service factor on family health-care ability

Based on the results of this study, the indicators of health-care services factors showed that most of them had ownership and using insurance (99.4%). The patients has made good use of insurance facilities. The existence of insurance really helps reduce the burden of hemodialysis costs which are quite high. The patients also had good access to health-care services (74.2%). So that, they can get a good health services.

Ministry of Health Republic Indonesia (2018) state that access to health services is one indicator of the assessment of public health status. For this reason, the government seeks to improve health services through health service facilities, especially health centers and auxiliary health centers, and the provision of health workers who are able to reach all levels of society, including remote areas. The ease of access to health services by the people, in this case the family, is related to severa1 determining factors, including place of residence and travel time to health facilities, as well as the socioeconomic and cultural status of the people.

One of the main tasks of family nursing is being able to utilize health-care facilities. The ability to utilize health-care facilities is influenced by several factors. These are predisposing factors that include knowledge, attitudes, beliefs, ideas, values, and perceptions. The supporting factors are the availability of health care services, affordability of health care costs, distance from health care services, and transportation to health care services. The reinforcing factors are manifested in attitudes and behavior of health workers, support from leaders, community leaders, families, or parents [24]. According to Friedman, family healthcare is the level of public health nursing that is centered on the family as a unit to care for the health of its members, with the goal of service and care being an effort to prevent disease, including utilizing access to existing health services [8].

Ease of access and perceived comfort are also the reasons why many people choose traditional healers, as well as recommendations from others about the obtained success and benefits [25], [26]. Economic principles also affcct the choice of access to health services; although medical treatment provides progress to the health condition ot' palients, families will still choose alternative medicine, because it is cheaper and more affordable.

It is indicated that the health service factor had a strong influence on family health-care ability (p = 0.005). There was a significant influence of the health service factor on family health-care ability. The health-care services factor has the indicator of access to health services [11]. A better health service factor, as the access to health services, tends to improve family health-care ability. Hence, it becomes necessary to improve the quality of health services in the hemodialysis room, in terms of both increasing trained human resources and health services to patients and families.

This study showed that all of these factors (family, patient, social support, and health-care services) had a major influence (p < 0.005) on family health-care abilities. However, the one with the strongest influence on family health-care abilities is social support factors (t = 8.051). It means that social support factors (family, peer, and health workers support) are the most decisive factor in how a family health-care abilities. So that, real efforts such as forming social groups that can help them are needed. Hence, social support for patients and families of patients of CKD with hemodialysis can increase.

Conclusion

The social support factor (Indicators: family, peer, and health-care support) had a strongest effect on family health-care ability. The family factors (Indicators: Age, education, family structure and function, motivation, experience and skill, and knowledge), the patient factors (Indicators: physical, psychological condition, lenght of care, and disease severity), and the health service factor had a strong effect on family health-care ability. So, it becomes necessary to increase social factor, such as the knowledge of family members. Besides that, improve the physical and psychological condition of patients by involving support from peer groups and health workers can be done. The quality of health services must also improved so the family's health-care ability of CKD patients with hemodialysis can increase.

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