

Palliative Care Based-on Family-Centered Nursing Affects the Level of Dependency of The Patients Undergoing Hemodialysis

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Abstract

Background and Aim: Hemodialysis is a burdensome and complex therapy, which can cause physical and psychological stress and has an impact on the patient's level of dependence in the patient's daily activities. The purpose of this study was to determine the relationship between palliative care based on family-centered nursing and the level of dependence of patients with chronic kidney disease on hemodialysis at Ibnu Sina Gresik General Hospital.

Methods: This research design uses a correlational analytic method with a cross-sectional approach. The population is patients and their families with chronic kidney disease on hemodialysis. The samples were taken using a consecutive sampling technique of 120 patients and their families. Data were taken using a questionnaire. Data analysis using Spearman rank correlation test.

Results: The results showed that 43 (35.8%) families had adequate family-centered nursing-based palliative care skills and 107 patients (89.1%) had mild dependence. The results of the analysis using the Spearman test showed a correlation coefficient of -0,348 with a significant value of $0.007 < (\alpha = 0.05)$, which means that there is a relationship between family-centered nursing-based palliative care on the level of dependence of chronic kidney disease patients with hemodialysis in Ibnu Sina Gresik General Hospital.

Conclusion and Recommendation: Patients with chronic kidney disease who begin to experience dependence in fulfilling their daily activities need family-centered nursing-based palliative care skills by the family.

Keywords: Chronic Kidney Disease; Family-Centered Nursing-based Palliative Care; Hemodialysis; Level of Patient Dependence

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INTRODUCTION

Hemodialysis is a burdensome and complex therapy that requires a lot of support from the family (Gilbertson, 2019). Moreover, the families assist patients at various stages of the disease, including physical, psychological, and mental care that is not limited to advanced stages. (Rabiei, 2016). The majority of families experience independence in the care of hemodialysis patients due to a lack of knowledge and skills (Rabiei, 2016).

After being hospitalized, the majority of people with chronic kidney disease will return home to live with their families (Ulfiana, Has, & Rachmawati, 2018). Due to some decreased body functions experienced by patients with chronic kidney disease on hemodialysis therapy, which can cause clients to feel unable and helpless due to their physical limitations to carry out daily activities, patients will rely on their families to undergo treatment therapy and fulfill their daily needs (Nugroho & Sabarini, 2019). If this is problems not handled properly, they will have an impact on the worsening of the condition of the patient and family (Jafari, 2018). The existence of the family can provide a very meaningful motivation to the patient when the patient has various problems of changing life patterns that are complicated and boring with all their health programs (Trihandayani, 2019).

The prevalence of chronic kidney disease increasing year by year in the global and Indonesian. According to the Global Burden of Disease (2013) reported that CKD was responsible for 956.200 deaths worldwide, this number represents an increase of about 134% from 1990 (Naghavi M, Wang H, Lozano R, 2015). Furthermore, Indonesia has a

high number of CKD patients based on the report from the Indonesian Nephrology Association (PERNEFRI) estimates that there are 70.000 CKD patients in Indonesia. This number will continue to increase by 10% per year (PERNEFRI, 2013). Moreover, data from research and development agency (Riskesdas) in 2018 showed that the prevalence of CKD in Indonesia is 0.38% of total diagnoses and the proportion of hemodialysis is 19.33% of diagnoses (Riskesdas, 2018).

Science being diagnosed with CKD the patients and their families have experienced progressive changes in their life, including physical, mental, emotional, and financial difficulties (Maddalena, O'Shea and Barrett, 2018). The hemodialysis process also causes psychological and physical stress that interferes with the neurological system, resulting in symptoms such as weakness, fatigue, anxiety, decreased concentration, disorientation, tremors, pain in the soles of the feet, and behavioral changes (Suprihatiningsih, Al-Irsyad, Cilacap, & Korespondensi, 2018). Furthermore, patients with chronic kidney disease who receive hemodialysis have an impact on their ability to fulfill daily activities (activity daily living) such as eating and drinking, bathing, dressing, toileting, and mobilization (Deddy & Maria, 2019).

The high burden of illness experienced by patients physically and psychologically as well as the high burden of care experienced by the family causes the importance of a palliative nursing model based on family centered nursing. The palliative nursing model can be applied starting from early palliative care from the time the diagnosis is made to the end of life. The provisions of palliative care can be

applied to patients with serious illness at any age and at any stage of the disease and are not specifically provided for patients who have decided to discontinue therapy (Grubbs, 2014). The palliative nursing model based on family centered nursing includes assessment, diagnosis, intervention/implementation, and evaluation. The assessment consisted of family factors, patient factors, social support factors and health service factors. The diagnosis that emerges is the ability to care for family health at home by carrying out five family health tasks (Friedman, 2003). The intervention provided is palliative nursing by the family which consists of primary and special palliative care. Palliative care by the family consists of patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical, psychological, social, and spiritual symptoms, advance care planning and end of life preparation.

The final purpose or evaluation is to achieve family independence in caring for chronic kidney disease patients on hemodialysis. Palliative care is required as comprehensive care that is integrated with kidney care from diagnosis to death and grief. CKD patients' needs not only physical symptom treatment, but also support for psychological, social, and spiritual needs, which are met through an interdisciplinary approach known as palliative care (Dhina Widayati & Nove Lestari, 2015). According to *World Health Organization* (WHO, 2019) defines palliative care is an approach that is given to improve the quality of life of patients and their families who are experiencing life-threatening problems, through preventive measures, pain management, and the cessation of suffering and problems related to

physical, psychological, social, and spiritual aspects.

The palliative nursing model can be applied from the time a diagnosis is made until the patient's death. Early integration of palliative care into standard nephrology care can help patients with advanced CKD and their families make more informed decisions, plan follow-up care, and provide end-of-life care (Eneanya, Paasche-Orlow & Volandes, 2017).

Family support is an important part of palliative care for hemodialysis patients (L Axelsson, 2018). Palliative care is intended for both patients and their families. Family-Centered Nursing is one of the concepts of family empowerment that is following the theories and concepts of palliative nursing that can be applied to families.

METHODS

A cross-sectional study design was used in this study. The population consisted of families and patients with chronic kidney disease undergoing hemodialysis at RSUD Ibnu Sina Gresik. A total of 120 families and patients were sampled using the consecutive sampling technique, with the inclusion criteria were a family member who is a caregiver for chronic kidney disease patients on hemodialysis, living in the same house with chronic kidney disease patient on hemodialysis, families of patients with chronic kidney disease who have undergone hemodialysis for 3 years, domiciled in Lamongan and Gresik Regencies, carer age 36 - 65 years old, physically healthy, able to communicate well and don't have mental illness. A questionnaire was used to collect data. The data was also tabulated and analyzed using the Spearman rank correlation test (Nursalam, 2020).

Social demographic information included sex, age, educational level, personal monthly income, relation with patients, persons who provide care, the length of care, and duration of hemodialysis were asked using the demographic and health information questionnaire. Moreover, the palliative care based on Family-Centered Nursing skills and patient's dependency level were asked using the palliative care based on Family-Centered Nursing questionnaire developed by the researcher. This measurement of patient care was carried out by providing a modified self-care of CKD index questionnaire, consist of helping activity daily leaving, taking medications, kidney diet, HD routines and controls treatment, liquid management. This questionnaire uses a Likert scale, namely 1 = never, 2 = sometimes, 3 = often and 4 always or every day. Then the measurement results are categorized into 3 categories, namely 1: low, 2: moderate, 3: high.

The Palliative care based on Family-Centered Nursing questionnaire was tested for validity and reliability (Cronbach's $\alpha = 0.7$) the Palliative care based on Family-Centered Nursing questionnaire consisted of 47 questions divided into 8 subscales. Moreover, the level of family independence is seen from the seven ability criteria that have been achieved by the family based on the Indonesian Ministry of Health, 2006. The dependency of the patients was measure using the index Barthel modification questionnaire that cover the patient's level of dependence to carry out daily activities/ADL which includes helping with eating, bathing, dressing and assisting mobility/exercise. The modified

Barthel index consists of 10 activity functions, namely controlling bowel movements, urinating, cleaning oneself, using the toilet, eating and drinking, moving, walking, dressing, going up and down stairs and bathing. Each function is scored (0-2) according to the patient's ability then the sum of the scores is categorized into 5 categories, namely 1: independent (score 20), 2: mild dependence (scores 12-19), 3: moderate dependence (scores 9- 11), 4: heavy dependence (5-8) and 5: total dependence (0-4).

The study protocol was approved by the health research ethics committee faculty of nursing at Airlangga University. Study procedure, voluntary nature of participation, participants' right to withdraw, and autonomy of the participants were explained, and written informed consent was obtained from the participants before their interviews.

RESULTS

Based on table 1, it can be explained that most of the families of patients with chronic kidney disease on hemodialysis are 46-65 years old (45.8%), female (57.5%), high school education (37.5%), income > 2.200.000 (55%), have a husband/wife relationship with the patient (65%), length of care for 3-4 years (72.5%), duration of HD for 3-4 years (72.5%). Palliative care based on family-centered nursing is grouped into 3 categories, including good, sufficient, and poor. Most families have family-centered nursing-based palliative care skills with a sufficient category of 43 families (35.8%) (Table 2). Based on table 3, it can be explained that the majority of patients with chronic kidney disease with hemodialysis have mild dependence as many as 107 patients (89.1%).

Table 1. Characteristic Respondent

Characteristic	Frequency	Percentage (%)
Age		
26-35 Year	30	25.0
36-45 Year	35	29.2
46-65 Year	55	45.8
Sex		
Male	51	42.5
Female	69	57.5
Education Level		
Elementary School	31	25.8
Junior High School	31	25.8
Senior High School	45	37.5
College	13	10.8
Income		
<2.200.000	54	45.0
>2.200.000	66	55.0
Relation with Patients		
Husband/wife	78	65.0
Child	33	27.5
Parents	4	3.3
Sibling	5	4.2
Length of caring		
3-4 Years	87	72.5
>4-5 Years	14	11.7
>5 Years	19	15.8
Duration of HD		
3-4 Years	87	72.5
>4-5 Years	14	11.7
>5 Years	19	15.8

Table 2. Palliative care based on Family-Centered Nursing

Palliative care based on Family-Centered Nursing	Frequency	Percentage (%)
Good	37	30.8
sufficient	43	35.8
Poor	40	33.4
Total	120	100

Table 3. Patient Dependency

Patients Dependency	Frequency	Percentage (%)
Independent Dependency	2	1.7
Mild Dependency	107	89.1
Medium Dependency	7	5.8
Severe Dependency	2	1.7
Total Dependency	2	1.7
Total	120	100

Based on the results of the analysis using the Spearman Rank test, the Spearman correlation coefficient

value (rs) = -0.348 which indicates that it has a strong relationship and the value of Sig 2 tailed = 0.007 where $p <$

0.05 then H1 is accepted which means there is a strong enough relationship between palliative care based on family-centered nursing on the level of dependency of chronic kidney disease patients undergoing hemodialysis.

DISCUSSION

The results showed that most of the families had family-centered nursing-based palliative care skills with a sufficient category of 35.8%. which describe as the ability of the family to taking care of patient care includes the ability of the family to assist with daily activities/ADL, taking medication, kidney diet, routine HD and independent fluid control and restriction, assess the bio-psycho-socio-spiritual aspects including the ability of families to recognize physical, psychological, social, and spiritual symptoms in CKD patients independently.

Manage the physical symptoms includes the ability of the family to prevent and manage physical symptoms in CKD patients independently, stress management includes the ability of the family to manage stress in CKD patients independently, management of social and spiritual problems includes the ability of families in managing problems of social and spiritual relationships with God in CKD patients independently, advance care planning the ability of the family with the patient to determine the goals of follow-up care, end of life preparation includes the ability of families to prepare patients and other family members to face terminal conditions, death, grieving and loss.

Palliative care is a type of care that emphasizes the importance of early palliative care integration to properly address physical,

psychological, and spiritual issues (Suprihatiningsih et al., 2018). According to the Indonesian Ministry of Health (2015), several principles of palliative care for patients include: assessing physical, psychological, social, and cultural, and spiritual aspects; determining patients and families understanding and expectations; determining patient care goals; providing information and education on patient care; performing symptom management, and psychologizing. assisting patients with advanced care planning (testament); and providing services to patients in terminal stages (Anita, 2016).

Family-centered nursing-based palliative care carried out by the family is an important element in the well-being of patients and can protect and support patients in carrying out their daily activities (Mitchell, Chaboyer, Burmeister, & Foster, 2009). The goal of applying family-centered nursing theory is to make the family self-sufficient in maintaining the health of their family members. The research conducted by (Alkhudairi, 2020) reported that a person with a high education has good knowledge and awareness about family-centered nursing-based palliative care, therefore, the families who have good knowledge of care will be able to recognize and understand the problems that exist in patients.

The results showed that most patients with chronic kidney disease undergoing hemodialysis had a dependency level with a mild category of 89.1%. in addition the mild category of the dependency of the patients were describe as patients that can be independent or almost do not need help with the criteria were: patients be able to go up and down the bed, able to ambulate and walk alone, able to eat

and drink alone, able to bathe alone/partial bath with assistance, able to clean mouth (brush own teeth), able to dress and make up with minimal assistance, able to defecate and urinate with assistance a little help.

The dependency of the patients was measure using the index Barthel modification questionnaire that cover the patient's level of dependence to carry out daily activities/ADL which includes helping with eating, bathing, dressing and assisting mobility/exercise. Families assist patients at various stages of the disease, including physical, psychological, and mental care that is not limited to advanced stages. (Rabiei, 2016). As treatment partners, family members are frequently involved in the treatment of chronic kidney disease patients. As care partners, family members are involved in a variety of important activities, including medication administration, medication adherence, assisting with day-to-day care activities, scheduling and providing transportation to medical appointments, monitoring patient health, advocating for patients, and providing emotional support (Hoang, Green & Bonner, 2018).

Caring for hemodialysis patients will face several challenges and problems, including frequent hospitalizations and the administration of various drugs to patients (Rabiei, 2020). Complications in hemodialysis patients include non-compliance with dialysis patients, which includes four aspects: non-compliance with the hemodialysis program, medication program, fluid restriction, and diet program (Efe & Kocaöz, 2015; Widiantara, 2017). Patients with chronic kidney disease undergoing hemodialysis show a high level of dependency because of the

complications of the disease and also the cumulative side effects of dialysis itself (Jassal, 2016). The need for care and dependency on caregivers is increasing, but their ability to provide care for tasks is negatively affected (Alnazly, 2018).

The research conducted by (Amaliyah, Karlina, & Andhini, 2019) shows that one of the factors that affect activity daily living, was the length of time on hemodialysis, the longer the patient undergoes hemodialysis, the greater the patient's dependence on the family due to functional disorders that will naturally arise and impede daily activities. The majority of patients with chronic kidney disease had HD for 3-4 years, and a small percentage of patients with chronic kidney disease had HD for more than 5 years. The results of the analysis using the Spearman Rank test obtained the Spearman correlation coefficient value (r_s) = -0.348 which indicates that it has a strong relationship and the value of Sig 2 tailed = 0.007 where $p < 0.05$ then H_1 is accepted which means there is a strong relationship between palliative care based on family-centered nursing on the level of dependency of patients with chronic kidney disease undergoing hemodialysis.

The key domains for a palliative approach to dialysis care include setting patient care goals; management of physical, psychological, and spiritual symptoms; patient and family satisfaction; and family support/caregiver (Grubb, 2014).

Renal palliative care (kidney palliative care) is a developing subspecialty of nephrology. Renal palliative care specifically addresses the stress and burden of advanced kidney disease by providing symptom management, caregiver support, and

advanced care planning to optimize patients' and families' quality of life. To address the multidimensional impact of advanced kidney disease on patients, palliative care must be integrated. When compared to other serious chronic illnesses, patients with advanced kidney disease have higher rates of care and a worse end-of-life experience.

Currently, renal palliative care is scarce (Daniel Y. Lam, 2019). Many kidney disease patients have an unmet need for palliative care, which includes both physical and emotional symptoms (Bansal, 2018). Family members generally do not understand the concept of palliative care. They generally do not consider dialysis patients to be terminally ill or to be receiving dialysis as a palliative treatment (Maddalena et al., 2018).

The majority of patients who receive home palliative care die at home. The two most commonly reported symptoms were pain and dyspnea, and while home palliative care appeared to improve pain control over time, it only had a positive effect on dyspnea in one study (Nordly, 2016).

Families play an important role in providing care to people whose health is deteriorating. When caring for a patient whose condition is deteriorating and who is becoming more dependent and in need of care, the caregiver must perform more complex care tasks. As a result, caregivers play a critical role in the care of people with illnesses or disabilities throughout the disease trajectory. To address this issue, family-centered care has been proposed, which would meet the needs of not only patients but also their family members (Kokorelias, 2019).

The role of the family in the care of patients is associated with improved behavior and self-management care and adherence to therapy, improved quality of life, lower risk of mortality, lower anxiety, and depressive symptoms, and lower chances of hospitalization. For health care providers, the role of the family is a very valuable partner in the task of caring for patients with chronic kidney disease (DePasquale, 2019).

The research conducted by (Prawita, 2017) showed that Physical factors such as complaints or physical symptoms that interfere with physical activity, social factors, cultural factors, spiritual factors, and psychological factors all influence palliative care needs. As a result, there is a high need for palliative care to support the quality of life of chronic kidney patients undergoing hemodialysis, at least one of whom can perform daily activities independently.

Patients who have been on hemodialysis for a long time have poor ADL abilities, therefore, they require a lot of support and palliative care from their families to ensure that their basic needs are met. Furthermore, families who can provide palliative care based on family-centered nursing are quite beneficial to patients due to the level of patients' dependency decreases, and patients can carry out daily activities independently without relying on family.

CONCLUSION

Families of chronic kidney disease patients undergoing hemodialysis can provide palliative care based on family-centered nursing, which is mostly sufficient. Moreover, patients undergoing hemodialysis have a mild level of dependency. At Ibnu Sina Hospital Gresik, there was a

relation between palliative care based on family-centered nursing and the level of dependency of chronic kidney disease patients undergoing hemodialysis.

RECOMMENDATION

Health workers are expected to be able to provide knowledge, special skills, education, and guidance on palliative care based on family-centered nursing to patients and their families thus the families and patients can apply it in their daily lives.

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