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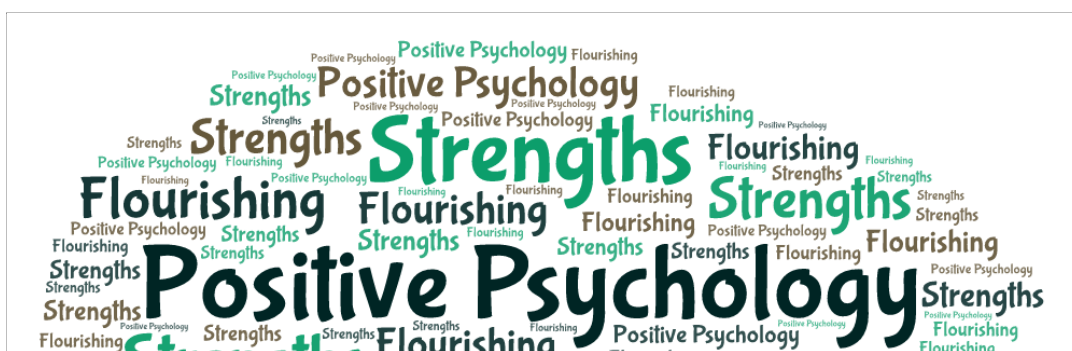
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Effect of the Family-Centered Nursing-Based Palliative Nursing Model on Family Independence Caring for Chronic Kidney Disease Patients with Hemodialysis

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Abstract

Hemodialysis is a complex and long-term therapy that requires support from the family in the form of physical, psychological, and socio-spiritual. The majority of families experience a lack of independence in caring for hemodialysis patients due to a lack of knowledge and skills. This requires a family-centered nursing-based palliative care model that can increase family independence in caring for patients with chronic kidney disease. This study used a quasi-experimental design with a pre-post-test control group design. The population in this study were patients and their families with chronic kidney disease undergoing hemodialysis at Muhammadiyah Lamongan Hospital. The samples were taken by purposive sampling as many as 24 patients and caregivers in the intervention group and 24 patients and caregivers in the control group. The independent variable in this study is a palliative nursing model based on family-centered nursing with an instrument in the form of a training module, while the dependent variable is the independence of family caring as measured by a seven-aspect questionnaire. The analysis uses Friedman's nonparametric. The results of the study shows that in the intervention group, all indicators increased in the good category and decreased in the poor category from pretest to posttest 2. This did not occur in the control group. The results of the Friedman statistical test analysis in the intervention and control groups on the seven indicators were equally significant. However, the effectiveness of giving palliative nursing models based on family-centered nursing is higher than family education. This is evidenced by the statistical value and the average post in the intervention group was higher than in the control group. The palliative nursing model intervention based on family-centered nursing is able to increase the independence of the family in caring for chronic kidney disease patients with hemodialysis.

Keywords: Family-Centered Nursing Based Palliative Nursing Model, Family Independence Caring, Chronic Kidney Disease, Hemodialysis.

INTRODUCTION

Hemodialysis is a burdensome and complex therapy that requires a lot of support from the family [1]. More than 90% of patient care is assisted by the family. Families help patients at

various stages of the disease, including physical, psychological, and mental care that is not limited to advanced stages of the disease [2]. Rabiei's research also reports that the majority of families experience independence

in treating hemodialysis patients due to a lack of knowledge and skills [2]. If it is not handled properly, it will have an impact on the worsening of the condition of the patient and family [3]. There is a need for palliative care as comprehensive care that is integrated with kidney care from diagnosis to death and bereavement.

Family support is an important component of palliative care for hemodialysis patients [4]. The results of the literature review found that there was an application of palliative care in patients with chronic kidney disease called kidney palliative care [5]. However, Kidney Palliative Care is not yet family-centered. Meanwhile, research by [6] in the United States, [7] in India, and [8] in Denmark have also implemented home palliative care that can control symptoms and reduce treatment costs but has not involved independent families in inpatient care. Renal palliative care in Indonesia can be said to be not optimal and is still limited to the management of physical symptoms in hospitals as stated in the Nursing Care Guidelines or Standard Operating Procedures (SOP). The palliative care model based on family-centered nursing has not been developed and its effect on increasing family independence in caring for patients with chronic kidney disease has not been explained.

The prevalence of Chronic Kidney Disease (CKD) tends to continuously increase. According to the Global Burden of Disease research (2013), CKD accounted for 956,200 deaths worldwide, an increase of about 134% from 1990 [9]. Indonesia is a country with a high rate of CKD patients, the Indonesian Nephrology Association (PERNEFRI) estimates that there are 70,000 people with CKD in Indonesia. This number will continue to increase by around 10% every year [10]. Data to Riskesdas in 2018, the prevalence of CKD in Indonesia was 0.38% of total diagnoses and the proportion of hemodialysis was 19.33% of diagnoses [11]. The prevalence of CKD in East Java in the population aged 15 years is 0.29% and the proportion of hemodialysis in the population aged 15 years is 23.14% [11].

Since the initial diagnosis of CKD, patients and their families experience progressive changes characterized by physical, mental, emotional, and economic difficulties [12]. The pain was the most common symptom (69%), followed by impaired respiratory secretions (46%), anxiety (41%), confusion (30%), shortness of breath (22%), and nausea (17%) [4]. Families experience many difficulties and challenges in caring for hemodialysis patients without prior instruction, readiness, or preparation [13]. The ability of families to care for hemodialysis patients is the main symptom management [12]. Lena Axelsson stated that the family's ability to manage pain symptoms was stated at 32%; management of psychological symptoms in the form of anxiety at 44%; and other symptoms at 55% - 84% [4]. 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 [13] [14]. Ability to discuss end of life was reported in 41% of patients and 71% of families [4].

One of the impacts of the inability of the family to care for hemodialysis patients is that the family will bear a significant burden of care as a result of treating patients with chronic diseases, which can affect their quality of life. The results showed that 42.7% of families had a moderate level of care burden, 32.5% had a high level, and 4.9% with a very high level [3]. A systematic review by [1] concluded that the burden and quality of life for families are worse than the general population and comparable to other chronic diseases. The burden of care for hemodialysis patients is comparable to that of peritoneal dialysis patients [1].

A systematic review study by Chae showed that the factors that influence the ability and independence of families in caring for our economic status and family characteristics [15]. The results of another study by Coppetti show that the ability of families to care for is associated with the demographic and clinical characteristics of patients undergoing treatment, as well as the sociodemographic characteristics of the caregivers themselves and with the care they provide [16]. Caregivers of elderly patients who have higher education and

do not have partners show greater ability to care.

Caring for patients on hemodialysis faces various difficulties and problems, including frequent hospitalizations and the administration of various drugs to patients [13]. There are also complications in hemodialysis patients in the form of non-compliance with dialysis patients which include 4 (four) aspects, namely non-compliance with hemodialysis programs, treatment programs, fluid restrictions, and diet programs [17]. Chronic kidney disease patients on hemodialysis show a high level of dependence due to complications of the disease and also the cumulative side effects of dialysis itself [18]. The need for care and dependence on caregivers is increasing, but their ability to provide care for tasks is negatively affected [19]. In the end, it will affect the ability of health care by the family and the independence of the family in treating chronic kidney disease patients with hemodialysis.

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 to start 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 any stage of the disease and are not specifically reserved for patients who have decided to discontinue therapy [20]. Early integration of palliative care into standard nephrological care can help improve informed decision making, planning of follow-up care, and end-of-life care for patients with advanced CKD and their families [21].

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 [22]. The intervention given is palliative

nursing by the family. 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 goal or evaluation is the achievement of family independence in caring for chronic kidney disease patients with hemodialysis.

Methods

This study used a quasi-experimental design with a pre-post-test control group design. At the time of the study, the treatment group was given a module and palliative nursing intervention based on Family-Centered Nursing, while the control group was given a standard intervention in the form of family education. Both groups measured the independence of the caring family before and after the intervention. The population in this study were patients and their families with chronic kidney disease who underwent hemodialysis at the Muhammadiyah Lamongan Hospital. Purposive sampling was carried out by sampling. The sample size for the control group is 24 patients and caregivers; the intervention group of 24 patients and caregivers. The independent variable in this study is the family-centered nursing-based palliative nursing model, while the dependent variable is the independence of the caring family. The instruments used for palliative nursing interventions are based on family-centered nursing care in the form of a palliative nursing module for hemodialysis nurses and a module for families or caregivers provided through training. The training method was carried out several times, namely the first to deliver material for family-centered nursing-based palliative nursing modules and the second to demonstrate the application of the module. The instrument used for caring for family independence is a questionnaire about the level of family independence which consists of 7 aspects, namely a. Patient care, b. Bio-psycho-socio-spiritual assessment, c. Management of Physical Symptoms, d. Stress Management, e. Management of social and

spiritual problems, f. Advance care planning, g. End-of-life preparation. Assumptions of normality and homogeneity of variance for inferential statistics are carried out before proper statistical analysis is applied. The assumption of normality will be tested using Shapiro Wilk's test. While the assumption of homogeneity will be tested using Fisher's exact test. Because the data are not normally distributed, the alternative for repeated

measurement is to use Friedman's nonparametric analysis.

Results and Discussion

Results

The following are the characteristics of patient and family respondents .

Table 1. *Respondent Characteristics*

Characteristics		Group				Total		F-count	Homogenitas
		Treatment		Control					
		f	%	f	%	f	%		
Patient Characteristics									
Age	36-45 years	2	8,3	4	16,7	6	12,5	0,5	Homogen F-table 2,01
	46-55 years	7	29,2	3	12,5	10	20,8		
	56-65 years	15	62,5	17	70,8	32	66,7		
Gender	Man	9	37,5	12	50	21	43,75	0,9	
	Woman	15	62,5	12	50	27	56,25		
Marital Status	Not married yet	1	4,2	1	4,2	2	4,2	0,5	
	Married	23	95,8	22	91,7	45	93,7		
	Widower/Widow	0	0	1	4,2	1	2,1		
Profession	Work	14	58,3	10	41,7	24	50	1,0	
	Doesn't work	10	41,7	14	58,3	24	50		
Long time sick	3-4 years	19	79,2	19	79,2	38	79,2	0,8	
	>4-5 years	2	8,3	1	4,2	3	6,2		
	>5 years	3	12,5	4	16,7	7	14,6		
Patient Characteristics									
Age	36-45 years	7	29,2	8	33,3	15	31,2	0,9	Homogen F-table 2,01
	46-55 years	6	25	8	33,3	14	29,2		
	56-65 years	11	45,8	8	33,3	19	39,6		
Gender	Man	15	62,5	7	29,2	22	45,8	1,1	
	Woman	9	37,5	17	70,8	26	54,2		
Marital Status	Not married yet	1	4,2	3	12,5	4	8,3	-0,2	
	Married	23	95,8	19	79,2	42	87,5		
	Widower/Widow	0	0	2	8,3	2	4,2		
Profession	Work	6	25	4	16,7	10	20,8	1,4	
	Doesn't work	18	75	20	83,3	38	79,2		
Total		24	50	24	50	48	100		

The results showed that the majority of patient respondents were 56-65 years old (66.7%), female (56.25%), married (93.7%), and sick for 3-4 years (89.2%). In the work status of the intervention group, most of the respondents

worked (58.3%), but in the control group, most of the respondents did not work (58.3%). While the majority of family respondents are 56-65 years old (39.6%), female (54.2%), married (87.5%), and not working (79.2%).

Table 2. *Category Variables Family Independence Caring*

Indicator	Category	Pretest				Posttest 1				Posttest 2			
		Intervention		Control		Intervention		Control		Intervention		Control	
		f	%	f	%	f	%	f	%	f	%	f	%
Patient care	Not enough	2	8,3	2	8,3	0	0,0	1	4,2	0	0,0	1	4,2
	Enough	9	37,5	8	33,3	6	25,0	7	29,2	4	16,7	6	25,0
	Well	13	54,2	14	58,3	18	75,0	16	66,7	20	83,3	17	70,8
Bio-psycho-socio-spiritual assessment	Not enough	3	12,5	3	12,5	0	0,0	2	8,3	0	0,0	1	4,2
	Enough	5	20,8	6	25,0	6	25,0	7	29,2	3	12,5	7	29,2
	Well	16	66,7	15	62,5	18	75,0	15	62,5	21	87,5	16	66,7
Management of Physical Symptoms	Not enough	3	12,5	2	8,3	0	0,0	1	4,2	0	0,0	2	8,3
	Enough	5	20,8	8	33,3	6	25,0	8	33,3	4	16,7	6	25,0
	Well	16	66,7	14	58,3	18	75,0	15	62,5	20	83,3	16	66,7
Stress Management	Not enough	1	4,2	0	0,0	0	0,0	1	4,2	0	0,0	1	4,2
	Enough	9	37,5	9	37,5	5	20,8	6	25,0	3	12,5	5	20,8
	Well	14	58,3	15	62,5	19	79,2	17	70,8	21	87,5	18	75,0
Management of social and spiritual problems	Not enough	1	4,2	0	0,0	0	0,0	1	4,2	0	0,0	1	4,2
	Enough	11	45,8	11	45,8	6	25,0	9	37,5	3	12,5	10	41,7
	Well	12	50,0	13	54,2	18	75,0	14	58,3	21	87,5	13	54,2
Advance care planning	Not enough	2	8,3	1	4,2	0	0,0	1	4,2	0	0,0	1	4,2
	Enough	8	33,3	8	33,3	6	25,0	8	33,3	3	12,5	6	25,0
	Well	14	58,3	15	62,5	18	75,0	15	62,5	21	87,5	17	70,8
End-of-life preparation	Not enough	9	37,5	11	45,8	0	0,0	8	33,3	0	0,0	7	29,2
	Enough	5	20,8	4	16,7	8	33,3	4	16,7	5	20,8	5	20,8
	Well	10	41,7	9	37,5	16	66,7	12	50,0	19	79,2	12	50,0

Based on the data presented in Table 2, it is known that from a total of 24 respondents in each group, it is known that in the intervention and control groups both at pretest, post-test 1, and post-test 2, most of them have patient care, assessment of bio-psycho-socio aspects - spiritual, physical symptom management, stress management, social and spiritual problem management, advance care planning, and end of life preparation in the good category. In the

intervention group, all indicators increased in the good category from pretest to posttest 2. And vice versa decreased in the poor category at pretest to posttest 2. In the control group, both categories on all indicators tended not to increase significantly, there was even a decrease from the pretest up to post-test 2. And vice versa with the less likely category to stay even increased during the pretest to posttest 2.

Table 3. *Descriptive Variable Independent Family Caring*

Indikator	Pretest				Posttest 1				Posttest 2			
	Intervention		Control		Intervention		Control		Intervention		Control	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Patient care	22,46	5,12	23,25	4,59	24,92	3,62	24,79	4,19	25,04	3,508	25,08	4,04
Bio-psycho-socio-spiritual assessment	22,71	5,83	22,42	4,94	25,50	3,23	24,21	4,75	25,71	2,97	24,54	4,28
Management of Physical Symptoms	22,58	5,72	22,58	4,18	25,25	3,23	24,67	4,39	25,46	3,02	24,71	4,66
Stress Management	22,75	4,96	22,83	3,60	25,42	3,06	24,75	4,56	25,58	2,86	24,88	4,49
Management of	21,63	4,54	23,50	4,13	25,83	3,27	24,13	4,42	26,13	2,91	23,88	4,53

social and spiritual problems													
<i>Advance care planning</i>	22,33	4,90	23,04	4,10	25,04	3,20	24,71	4,33	25,33	2,87	24,92	4,17	
End-of-life preparation	18,42	6,88	16,17	8,48	24,50	3,84	19,88	8,67	24,75	3,66	19,96	8,62	

Based on the data presented in Table 3, it is known that from a total of 24 respondents in each group, it is known that between the values of pretest, post-test 1, and post-test 2 there is an increase in the value. From the results, it is also

known that the average value of Family Caring Independence after being given intervention in the intervention group is higher than in the control group.

Table 4. *Friedman Test Results*

Indicator	Group	Mean Post 2	Statistics	Sig.	Meaning
Patient care	Intervention	25,04	10,842	0,004	Significant
	Control	24,79	8,435	0,015	Significant
Bio-psycho-socio-spiritual assessment	Intervention	25,70	16,305	0,000	Significant
	Control	24,54	7,311	0,026	Significant
Management of Physical Symptoms	Intervention	25,45	9,696	0,008	Significant
	Control	-24,70	4,092	0,129	Not Significant
Stress Management	Intervention	25,58	8,577	0,014	Significant
	Control	24,87	7,684	0,021	Significant
Management of social and spiritual problems	Intervention	26,12	28,373	0,000	Significant
	Control	23,87	1,265	0,531	Not Significant
<i>Advance care planning</i>	Intervention	25,33	12,426	0,002	Significant
	Control	24,91	9,882	0,007	Significant
End-of-life preparation	Intervention	24,75	20,727	0,000	Significant
	Control	19,95	8,414	0,015	Significant

Based on the table above, it can be seen that the results of the statistical test analysis with the Friedman intervention group on the indicators of patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end-of-life preparation. of life resulted in a significance value $< \alpha$ (5% or 0.05). Therefore, it can be stated that there is a significant difference in Independent Family Caring (patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end of life preparation).) at pretest posttest 1 and posttest 2. The average results after being given the family-centered nursing palliative nursing model were higher than before and with the control group indicating that the family-centered nursing based palliative nursing model can significantly increase the family-centered nursing

independence (patient care, Assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end of life preparation). So it can be concluded that the provision of a family-centered nursing-based palliative nursing model is effective in increasing family independence. Caring includes patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end-of-life preparation. of life.

The results of statistical test analysis with the Friedman control group on indicators of patient care, assessment of bio-psycho-socio-spiritual aspects, stress management, advance care planning, and end of life preparation resulted in a significance value of $< \alpha$ (5% or 0.05). Therefore, it can be stated that there is a significant difference in Family Caring

Independence (patient care, assessment of bio-psycho-socio-spiritual aspects, stress management, advance care planning, and end of life preparation) during pretest-posttest 1 and post-test 2. Results the average after being given family education is higher than before, indicating that family education can significantly improve family care independence (patient care, assessment of bio-psycho-socio-spiritual aspects, stress management, advance care planning, and end of life preparation). So it can be concluded that the provision of family education is effective in increasing the independence of caring families including patient care, assessment of bio-psycho-socio-spiritual aspects, stress management, advance care planning, and end of life preparation. However, the effectiveness of providing a palliative nursing model based on family-centered nursing is higher than family education. This is evidenced by the statistical value and the average post in the intervention group was higher than in the control group.

Discussion

The results of statistical test analysis with Friedman in the intervention and control groups on indicators of patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end-of-life preparation resulted in scores significant. So it can be concluded that the provision of a family-centered nursing-based palliative nursing model is effective in increasing family independence. Caring includes patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end-of-life preparation. of life. Providing family education is also effective in increasing the independence of caring families including patient care, assessment of bio-psycho-socio-spiritual aspects, stress management, advance care planning, and end-of-life preparation. However, the effectiveness of providing a palliative nursing model based on family-

centered nursing is higher than family education. This is evidenced by the statistical value in the intervention group being higher than the control group.

Palliative care is an approach to improve the quality of life of patients and their families in dealing with problems related to life-threatening problems, through the prevention and ending of suffering through early identification and assessment, treatment of pain, and other problems, such as physical, psychological, social and spiritual [23]. Kidney palliative care is a growing discipline in kidney science. Renal palliative care specifically addresses the stress and burden of advanced kidney disease through the provision of symptom management, caregiver support, and advanced care planning to optimize the quality of life of patients and their families. The integration of palliative care is needed to address the multidimensional impact of advanced kidney disease on patients. Patients with advanced kidney disease have higher rates of care and a greater end-of-life experience compared to other serious chronic diseases [5]. Early integration of palliative care into standard nephrology (kidney) care can help improve informed decision-making, follow-up care planning, and end-of-life care for patients with advanced CKD and their families [21]. Key aspects of 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 [20]. Renal supportive care includes a wide range of skills and services because patients with kidney disease have a wide range of needs, ranging from symptomatic, and psychosocial support to intensive communication about complex treatment options [24]. Family-centered nursing-based palliative nursing is an intervention to develop a family-centered nursing-based palliative nursing model that is assessed from patient care, assessment of bio-psycho-socio-spiritual aspects, management of physical symptoms, stress management, management of social and spiritual problems, advance care planning, and end-of-life preparation.

Research [1] states that educational interventions lead to an increase in caregiver knowledge, educational programs can reduce caregiver burden, sustainable care models increase perceptions of QoL, and supportive and cognitive behavioral therapy helps maintain psychosocial adjustments over time. Nurses and clinicians identify the need for increased palliative care late and early approach. The results highlight the need and possibility of training, counseling, and support from health care professionals in the context of dialysis. Furthermore, multi-professional palliative care collaborations should be developed to improve the coordination and organization of end-of-life and palliative care of patients and their families. A climate that enables conversation about advanced care planning across the disease trajectory could facilitate the gradual integration of palliative care alongside life-prolonging treatments to increase patient and family support (Axelsson et al., 2019). Providing family/caregiver educational interventions about the care needed can ease the burden and improve care outcomes. Recommendations are made that health professionals should assess the burden on families/caregivers, and meet their physical and mental health needs. Families/caregivers should also be regularly educated about routine parenting duties to ease their burden [19].

Many intervention programs are designed to support caregivers, reduce the negative aspects and enhance the positive aspects of care. Interventions such as training, support, and psychotherapy can reduce caregiver fatigue, and improve the quality of care provided, as well as the caregiver's physical and mental health. The training program is recommended as a useful solution to support and provide information to caregivers. Carer training can include providing information about illness and using communication and coping and problem-solving skills. Group training programs are widely recommended as a valuable strategy to support caregivers [25].

The palliative nursing model based on family-centered nursing is more effective in increasing family independence in caring for chronic kidney disease patients with hemodialysis

compared to family education. The palliative nursing model based on family-centered nursing is more holistic and includes not only curative needs but also palliative care in preparation for death. Nurses need to provide gradual and continuous training on palliative care to families of patients with chronic kidney disease on hemodialysis considering the complexity of care.

Conclusion

In the intervention group, all indicators increased in the good category and decreased in the poor category from pretest to posttest 2. This did not occur in the control group. The results of the Friedman statistical test analysis in the intervention and control groups on the seven indicators were equally significant. However, the effectiveness of giving palliative nursing models based on family-centered nursing is higher than family education. This is evidenced by the statistical value and the average post in the intervention group was higher than in the control group. So that the palliative nursing model intervention based on Family Centered Nursing is able to increase the independence of the family in caring for chronic kidney disease patients with hemodialysis.

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