Formation of the Family Cadres as the Main Nurse of Palliative Patients at Home in Kalirandu Village, Bangunjiwo, Kasihan,Bantul, Yogyakarta

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FORMATION OF THE FAMILY CADRES AS THE MAIN NURSE OF PALLIATIVE PATIENTS AT HOME IN KALIRANDU VILLAGE, BANGUNJIWO, KASIHAN, BANTUL, YOGYAKARTA

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ABSTRACT

Palliative care is a treatment that is carried out to improve the quality of life of patients and families in the face of patients who have life-threatening diseases both physical, psychosocial, and spiritual. There are 40 million people in the world each year who need palliative care, especially in non-communicable diseases. Most families of patients who care for palliative patients at home feel burdened both physically and psychologically. This is because the daily activities that must be done are limited because all activities are focused on being a caregiver. This makes it important for the family cadres who have the knowledge and skills to provide primary care to palliative patients at home. The establishment of the family cadres as the main nurse for palliative patients at home is one manifestation of community empowerment and is the right step in optimizing government health programs in improving the quality of life for palliative patients. The method of activity is based on the health promotion model, where activities are focused on efforts to improve the ability of the community through community learning. The formation of the family cadres was initiated by a socialization activity and then the cadres were given health education in the form of counseling and skills training. The result of the activity was that all cadres (100%) were able to handle the symptoms of palliative patients at home and could re-practice palliative care at home after attending the training. The follow-up plan of activities is an effort to maintain cadre performance. The need to collaborate with hospitals or Puskesmas (the Indonesian community health service center) which will send palliative patients back after hospitalization so that the quality of caregivers can be continued by family cadres and health cadres. The implementation of the activity received appreciation from the government officials present.

Keywords: family cadres, caregivers, palliative patients

INTRODUCTION

The increasing number of patients with incurable diseases such as cancer, degenerative diseases, chronic obstructive pulmonary disease, cystic fibrosis, stroke, Parkinson's, heart failure, genetic diseases and infectious diseases such as HIV / AIDS that require palliative care is the challenges that must be faced (Kementerian Kesehatan RI, 2007). Patients with chronic diseases not only experience various physical problems such as pain, shortness of breath, weight loss, or activity disturbances, but also experience psychosocial and spiritual disorders. This is the reason why palliative care needs to be provided to achieve a good quality of life (Doyle, et.al., 2003). Palliative care not only has an impact on palliative care patients but also on the families of palliative patients who act as family caregivers (Barrow, 1996). Family caregiver palliative care patients face many potential challenges in caring for palliative care patients. Family caregivers must provide care to patients including drug

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administration, wound care and dressing, assistance when using the toilet, bathing, washing, preparing food, looking for alternative medicines, assisting in the mobility process, and providing emotional support to patients. At the same time, the family caregiver also must work for themselves, including dealing with and coping with the emotional state of their own, to deal with uncertainty, struggle in accepting the disease and compensation for personal time. Family caregivers must also demonstrate interpersonal skills and other social tasks such as interacting with medical professionals, meeting needs with other family members, interacting with other experts, managing finances, and other tasks. A family caregiver plays an important role in maintaining patient welfare at home. A family caregiver plays a role when the patient cannot communicate or convey what is felt, the family caregiver will represent or replace in reporting symptoms felt by the patient and making medical decisions (Doris, 2007).

From the description above it can be concluded that the palliative patient's problem needs to be a priority and a concern of all parties. The situation where the palliative care provided to the community is not yet optimal is also faced by Bantul Regency, especially in Kalirandu Village. Based on interviews with health cadres in Kalirandu 6 people have had a stroke, 5 people who have diabetes, 2 people who have breast cancer, 2 people who have kidney failure, and 1 person with dementia. A stroke patient with an age range between 55-87 years with the condition bedrest as much as 4 patients and 2 patients had to move although not entirely. Then, stroke patients who experienced bed rest 3 palliative patients did a health examination by bringing in a doctor at Kalirandu Village with independent costs which are usually done about 1-2 times in 1 month. Then, for 1 bad palliative patient, the family said they had never had a health check again because the patient only lived with a husband who was both elderly and the patient's husband said it was not working so it was a barrier for patients to get health services.

The absence of the role of community health service center such as Puskesmas in Kalirandu in providing knowledge about palliative care at home causes a lack of family knowledge in palliative care for meeting patient needs such as patient personal hygiene, preparing nutritious food for patients, and helping patient activities that are as it should be. Residents in Kalirandu village are on average educated in SR (an elementary school level in Japanese's colonialism era in Indonesia) or Junior High School. Also, residents in Kalirandu Village earn a middle-class income because most of the residents in the village work as laborers, construction workers, farmers, factories, and traders, thus hindering the treatment process due to expensive home care costs.

Health promotion efforts (promkes) are mandatory health efforts that must be held by Puskesmas. However, in Kalirandu village, the health promotion efforts were still not optimal so that the active role of the community was needed. The establishment of the family cadres then become a form of community empowerment and the right step in the village Kalirandu. This activity includes a variety of activities, including health education about the care of patients palliative home, the process of formation of cadres, and the training of cadres of palliative patients symptom management skills.

CONTEXT AND REVIEW OF LITERATURE

Palliative care is a treatment carried out to improve the quality of life of patients and families of patients with diseases that have no hope of being cured and are life-threatening physically, psychosocially and spiritually (World Health Organization, 2017). Palliative care is all active actions taken to ease the burden on patients, especially in patients who cannot be cured

anymore such as relieving pain and other complaints and seeking improvements in psychological, social and spiritual aspects to improve the quality of life of patients for the better. All active actions aimed at alleviating the suffering of patients, especially those that cannot be cured, are called palliative care. The active action in question is to eliminate pain and other complaints, and seek improvements in psychological, social and even spiritual aspects (Irawan, 2013).

Palliative care can meet the needs of improving the quality of life of sufferers and their families through treatments that not only emphasize physical symptoms such as pain, but also emotional, psychosocial and spiritual aspects. Many cases are found when cancer sufferers are ashamed to socialize and are not confident in living their lives. This condition requires palliative care to improve the quality of life for the better. In addition to sufferers, palliative care also provides support to all family members and other caregivers (Taher, 2010).

METHOD

The solution to the problems faced by partners is community empowerment, so the method used here is a model of health promotion according to the Ministry of Health of the Republic of Indonesia (2011). Health promotion in this activity is an effort made in Kalirandu village community so that their ability to treat palliative patients at home increases. Health education in the form of counseling is given to the community to understand the care of palliative patients at home. Some people who have family members of palliative patients are selected and designated as the family cadres, and then given health education about palliative care at home and training on how to manage symptoms in palliative patients. The formation of the family cadres as the main nurse of palliative patients at home has been carried out with activities including socialization, counseling, and training. This community service activity was attended by 10 family cadres and 7 health cadres. The material provided at the time of the activities of this includes the role of the family, drug delivery, handling pain, shortness of breath, and fatigue.

FINDINGS

The results of community service activities show that 10 people have been gathered in a group called the family cadres as the main nurse of palliative patients at home. The initial forming process of the family cadres is the subsequent socialization of cadres' formation and counseling as well as training.

Table 1 below shows that the average age of cadres is 40-50 years with the female sex of 100%. Educational background as much as 80% including the secondary education category. The cadres were then given training aimed at being able to handle symptoms in palliative patients at home.

Table 1. Characteristic description of family cadres who have palliative patients (N = 10)

Characteristics	Frequency	Percentage (%)
Age		
40-50	8	80%
50-60	2	20%
Sex		
Male	0	0%
Female	10	100%
Education		
SD	2	20%
SMP	0	0%
SMA	8	80%

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Table 2. The ability of family cadres to handle symptoms in palliative patients in Kalirandu Village (N = 10)

Ability	Category	Frequency	Percentage (%)
Before Training	Inadequate	10	100%
	Adequate	0	0%
After Training	Inadequate	0	0%
	Adequate	10	100%

Table 2 shows that all cadres (100%) have not been able to make the handling of patient's symptoms palliative home on prior training. But after the training, the number of cadres capable of handling palliative patient symptoms at home increased by 100%.

DISCUSSION

The presence of family cadres is very important in palliative patient care because the family is the closest person to the patient who will assist patients in providing daily care at home. The team has socialized this program to the community. The outreach was attended by the head of Kalirandu village, the health cadres, and families who have family members who need palliative care. The community seemed enthusiastic when participating in the activity. After the socialization, the team then formed the family cadres and provided health education. The material provided in the form of family roles, drug administration, pain management, shortness of breath, and fatigue. The team then provides training specifically for selected cadres. Then the cadre's family recorded as many as 10 people. They are expected to be the primary care of palliative patients at home. The training provided to cadres focused on how they were able to deal with symptoms in palliative patients when they were home. The improvement of cadres' abilities can be seen from the evaluation conducted by the team after the training is finished. The cadres do demonstration practice on how to handle symptoms of palliative patients at homes such as handling pain, shortness of breath, and fatigue. The cadres were initially unable to manage symptoms in palliative patients. This result can be seen in table 2 where all cadres have not been able to handle symptoms in palliative patients. Therefore, the team provided health education and training to the cadres. After health education and training, all the cadres seemed the ability to perform management of symptoms in patients with palliative. According to Sandiyani and Mulyati (2011, in Kosasih, Isabella, & Sriati, 2018) the training that conducted was related to the behavior of information delivery. The cadres of families have a responsibility as primary caregivers of palliative patients at home. Thus the formation of family cadres is very useful for improving the quality of life of palliative patients in Kalirandu Village.

The next most important activity to improve and maintain cadres' performance. The urgency to collaborate with hospitals or health centers, that will send back palliative patients after hospitalization so that the quality of caregivers, can be continued by the family cadres and health cadres in the community.

CONCLUSION

The activities to form the family cadres in Kalirandu Village have been carried out but still need cooperation with the local health center or hospital, so the cadres can continue to provide nursing care. The activities to form the family cadres in Kalirandu Village have been carried out but still need cooperation with the local health center or hospital, so the cadres can continue to provide nursing care.

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