Research Article

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The Role of Family Meeting In Dealing With Rejection Towards Hospital Discharge of Terminally Ill Cancer Patients

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ABSTRACT

Background: Rejection towards discharge planning of terminally ill patients and the role of family meetings to overcome such issue has not been evaluated. The aims of this study were to identify who and the reasons of rejection, to evaluate the effectiveness of family meetings, and to assess the important aspects in preparing homecare.

Methods: This is an interventional study using queasy-experimental design. Samples of the study were family members of terminally ill patients who refused patient discharge from 1st of May to 31st of October 2016. Paired-Sample T-test was applied to analyze the result.

Result: Rejections of discharge planning was mostly by the families. The most reason of rejection was lack of knowledge and skills in taking care of the terminally ill patients (40%). Family meetings solved the problem of rejection. The total score of 10 aspects needed in taking care of terminally ill patients was significantly increased (p=0.000).

Conclusion: Family meetings effectively changed the attitude towards hospital discharged

INTRODUCTION

End-of-life care has become an important aspect in cancer management (1-3). Evidenced-based end-of-life quality metrics includes a high proportion of deaths outside of the hospital, a low length of stay of hospitalization, low number of patient at end-of-life in intensive care unit, and a high rate of hospice enrollment greater than 72 hours prior to death (1,2). On the contrary, low involvement of palliative care, short interval of the last cancer treatment or initiation of cancer treatment to patient's death are associated with poor quality of end-of-life care (2,3).

Early integration of palliative care in oncology has been suggested by various oncology and palliative care associations such as American Society of Clinical Oncology (ASCO), European Society of Medical Oncology (ESMO), the National Comprehensive Cancer Network (NCCN), the European Association of Palliative Care (EAPC), as well as by Institute for Clinical System Improvement (ICSI) (4), and was aimed to achieve best possible quality of life and quality of death, including the place for end-of-life care and death according to the patient's preference (5). Unfortunately, palliative care at Dharmais Cancer Hospital is often consulted at the end of the disease trajectory when curative treatment has been exhausted, which potentially results in suboptimal pain and symptoms management, increase suffering, failure to discuss or adhere to advance care planning, and unplanned hospital deaths (6,7).

Patients with advanced and terminal stage of disease have distinct problems and needs to those in earlier stages in fulfilling the quality of their remaining life (8,9). An adequate information and involvement in decision making become priorities in delivering high quality end of life care (10,11). In palliative care, the patient and their family are regarded as a unit of care. Therefore, communication should be delivered to both patients and their family to prevent psychological distress, lack of shared decision making and mistrust of health care provider. Standard

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practice on communication in palliative care includes information exchange, assessment of the patient's and family's needs, and preparation for discharge (11).

A number of patients at Dharmais Cancer Hospital rejected their discharge planning. The potential impacts of such rejection include increased of disease burden due to nosocomial infection and unnecessary hospital routines that cannot be avoided as well as inadequate terminal care and inefficiency of hospital bed. The benefits of family involvement in discharge planning have been reported by Pearson et al. (12). Until recently, home care is the only service available for terminally ill patients who do not need hospitalization. Hospice as a system of care for terminally ill patients who do not need hospital intervention but cannot be cared at home for some reasons has not been established yet. Unfortunately, home care services is not under the National Health Insurance (JKN = Jaminan Kesehatan Nasional) coverage. In Indonesian culture, most families are concerned about their perspective on negative impact of frank discussion with the patient. Therefore, initiating an open discussion with the family is important to respond to their concerns and needs and to prepare them for their role in caring terminally ill patients at home.

Family meeting is an important approach in clinical practice to facilitate communication for people with advanced and terminal stage of disease. Family meeting is conducted by health care professionals, to discuss with the family and the patient if possible to clarify the goal of care based on the diagnosis and prognosis after evaluation of a given treatment, to provide psychological and social support based on the needs as well as to prepare discharge planning and to develop a care plan for the patient and their family (13). Family meetings are recommended as a core intervention within the context of palliative care provision (14). The rejection towards discharge planning of terminally ill patients and the role of family meeting to overcome such an issue in Dharmais Cancer Hospital has not been evaluated. This study aimed to identify who made the rejection of discharge planning, to assess the reasons of those rejections, to evaluate the effectiveness of family meetings in dealing with the rejection and to understand the important aspects needed in preparing homecare.

MATERIAL AND METHOD

This is a quantitative study using One-Group Pre-test Post-test to evaluate who rejected the discharge planning more, whether the patients or the family, the reasons of the rejections and how they were ordered. Access, knowledge and skills to give care to terminally ill patients were scored before and after intervention were given. Family members of terminally ill inpatients who refused patient discharge planning and consulted to palliative care unit from 1st of May 2016 to 31st of October 2016 were offered to participate in this study. The inclusion criteria were family members who are responsible for the decision making of the patient, age above 21 years old, literate, agree to participate in this study. Exclusion criteria included extended family members and professional caregiver who will be responsible for the care.

We gave the participants a questionnaire developed by Palliative Care Team of Dharmais Cancer Hospital. The questionnaire consists of two parts. First part consists of two open ended questions regarding who refused the discharged planning and the reason(s) of the rejections. The second part includes 10 questions regarding their understanding about the diseases and the aspects related to home care to assess the information and preparation of their needs to take care of terminally ill patients at home. The answer of the 10 questions was categorized into 4 score; do not understand (score =1), partly understand (score=2), mostly understand (score=3) and fully understand (score 4). After they completed the questionnaire, a family meeting between a palliative care physician and the family members (without the patients) was held. During the family meeting, palliative care team made assessment of the medical and nursing aspects, activity of daily living, and also the psychosocial and spiritual aspects in the family's perspectives, as well as their concerns and needs for the patient's condition and caring the patients. Approaches and interventions required was performed during the family meeting such as correcting the misunderstanding facts about the patient's condition, explaining the purpose and advantages of homecare; giving direction to access drugs and medical equipment as well as access to contact palliative care team and volunteers; and improving their knowledge and skills to care for patient at the patient's bed. After the family meeting, the same persons were requested to complete the part 2 of the same questionnaires in their convenient time.

RESULTS

Forty family members of 40 patients who refused discharge planning participated in this study. Fifty five percent of the participants were female, age divided into age group (30-39, 40-49, 50-59, 60-69, and above 70), median age was in age group of 50-59 years old. The participants were spouse (42%), children (36%), siblings (175) and others (5%). Primary sites of the tumor were mostly at the uterine cervix and lung (17.5% each), followed by breast, unknown primary and others as much as 15%, 7.5% and 42.4% consecutively. Reasons of discharge planning made by the oncologists includes no further cancer treatment (57.5%), deterioration state (27.5%), financial problems (10%), rejection of cancer treatment (5%) and others (12.5%). Rejections of discharge planning made purely by the families were 45%, by the patients at 12.5% and by both the patients and their families at 42.5%. The reasons of rejection towards

hospital discharge were lack of knowledge and skills to give care for terminally ill patients at home (40%), followed by fear of facing relative's death at home (40%) and financial problem to provide medical equipment (22.5%). Other reason of refusal includes uncontrolled symptoms, fear of discontinuation of the care, fear of having no access to hospital, and having no caregiver (20%, 7.5%, 5%, and 2.5% respectively).

After the family meetings and the involvement of the palliative care team, change of the families and the patients attitudes toward discharged planning was noted. All patients and their families finally accepted the discharged planning. Most patients and their families needed 3 days to accept the discharge planning. The shortest period was directly after family meeting and the longest was 2 weeks. The result of the family meetings and the involvement of palliative care team in increasing the understanding of the family about patient's condition and awareness of terminal stage were escalated. Their understanding about the reason of hospital discharge, how and when to contact palliative care team and the role of home care such as the continuing care where patient is still eligible for hospital service, how to access drugs and medical equipment increased significantly. After the family meeting, the knowledge and skills in basic care, drugs administration and medical equipment used also improved significantly. The total score of the 10 variables was significantly increased after the family meeting (p=0.000). Before and after family meetings mean were 22.5 and 31.12; SD 8.06 and 6.63; SE 1,36 and 1.05. The three most increasing score were found in these variables respectively, given the contact person and telephone number of 24/7 services, having knowledge to access drugs and medical equipment and having skills in basic caring.

Table 1. Access, knowledge and skills score before and after the family meeting

Ranked of increased score	Variable	Score before family meeting	Score after family meeting	Deviation
1	Having access to contact health care professionals	88	133	45
2	Knowledge to access drugs and medical equipment	81	126	45
3	Knowledge and skills in basic care	84	124	40
4	Knowledge and skills in medical equipment use	82	122	40
5	Knowledge and skills in medication use	80	120	40
6	Knowledge about symptoms and condition which need health care professional assistance	87	125	38
7	Knowledge about the purpose of homecare	94	128	34
8	Knowledge about the reason of discharge planning	94	122	28
9	Knowledge about patient's condition	107	128	21
10	Awareness of the terminal stage	97	117	20
	Mean	22.35	31.17	
	SD	8.06	6.63	
	SE	1.36	1.05	
	P value 0.000			
	N	40	40	

DISCUSSION

Discharge planning is a routine procedure when a patient is considered no longer needing any hospital interventions. However, discharge planning of terminally ill patients with uncontrolled irreversible symptoms as expected by the patients or their families is challenging for both health care professionals and the family unit. Hospice homecare provided by palliative care team, which is not known in most society, is the only continuing care available until recently. Referral back to the referring doctor or institution has not been commonly done by doctors at a Top referral hospital, while primary health services are not familiar with terminal care.

When the patient is cared at home, the responsibility is in the family's hand and it becomes a family's burden. In our previous study, most terminally ill patients wanted to be cared at home. This study showed that rejection of hospital discharges came more from the family rather than the patients. It was reconfirmed by our previous finding. Most reasons of the rejection are specifically related to the patient's condition and not to the family caregivers themselves. Misunderstanding about homecare and unpreparedness of the family were the basic reasons of the rejection. The reasons of rejection found in this study were the fear of patient deterioration and death due to fear of not knowing what to do and fear of being blamed.

The second reason was no knowledge and skills in caring a terminally ill patient who demand medical

equipment and various medications. Most families have no caring background or experiences, so that giving care of patients was perceived as burdens, particularly with several symptoms and various problems that has not been well controlled. The third reason was financial problems. Home care until recently was not covered under the National Health Insurance. All medical expenses will become the family responsibility while as inpatient, they have them free of charge. As palliative care services have not been formally accepted and adapted in the health care system scheme, fear of discontinuation of care by hospital and having no access to hospital services had become the fifth and sixth reasons of rejection toward discharge planning. The last reason of rejection was having no caregiver. As the family model in Indonesia has slowly changed from extended to nuclear family, few number of patients, particularly those who moved from other cities, had no family caregiver and refused discharge planning. Some interesting finding in this study regarding aspects that perceived important when preparing discharge planning were shown in the table. Information about contact person to consult and how to access drugs and medical equipment were the most increased score achieved after family meetings. Knowledge and skills in basic care, as well as administration of drugs and medical equipment use that they had during hospitalization, were improved by palliative team, thus increasing their confidence to take care of the patient at home. Information given by the primary physicians or oncology team regarding diagnosis and prognosis were adequately delivered, but not the reasons for discharge planning and the purpose of homecare. Clarifications in this matter during family meetings become the reason of acceptance of hospital discharge. Information given to the patient and family may be the same, but the way the information delivered will influence the decision.

Besides providing information, knowledge and skills mentioned above, an adequate symptoms control and confirmation that palliative care at home is a continuing care program of the hospital that can be accessed 24 hours a day, 7 days a week were perceived important to accept discharge planning.

CONCLUSION

An adequate family meetings effectively changed the attitude of the patients and their family from rejection to acceptance of hospital discharges. Besides, family meetings were able to help the families in making decisions and preparing a family caregiver.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The institutional review board (the ethical committee) of Dharmais Cancer Hospital provided an approval for the study through the ethical clearance number 077/KEPK/XI/2016 and the eligible participants signed the informed consent.

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