

The Comparison of Family Member's Satisfaction of Palliative Care and Standard Care for Patients With Incurable Cancer

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Abstract

Background: Palliative care is essential for cancer patients. Palliative care programs reduce distress, promote patients' improvement, increase family satisfaction, reduce hospitalization time and finally reduce costs and increase productivity.

Objectives: The aim of this study was to compare the effect of palliative care and routine care on the satisfaction level of family members of patients with end stage cancer.

Patients and Methods: This quasi-experimental intervention study was conducted in two teaching hospitals of Tehran during year 2014 through convenience sampling on 80 families of patients with end stage cancer. The intervention group received palliative care and the control group received standardized routine care for at least three months. The Famcare questionnaire was used for assessing family satisfaction and statistical t-test and chi-square analysis were used for analyzing the data.

Results: The mean satisfaction of the family members in the intervention and control groups was respectively, 82.8 ± 7.8 and 65.8 ± 9.07 , which was statistically significant ($P = 0.001$). The patients' family satisfaction of palliative care in the intervention and control groups was respectively 62.5% and 12.5%.

Conclusions: The level of family members' satisfaction of palliative care was more than routine care. The findings of this study help nurses learn more about palliative care of cancer patients and consequently improve nurses' performance and increase patients' families' satisfaction.

Keywords: Palliative Care, Incurable, Cancer, Satisfaction, Patients' Family Members

1. Background

Cancer is the third cause of death throughout the world. It has been estimated that more than 15 million people will experience cancer until 2020 (1, 2). There are 48 - 112 cancer incidences per one million people in the female population and 51 - 144 cancer incidences per one million people in the male population (3). Early cancer detection is still a lethal incidence for patients and more than one-third of the patients experience anxiety and depression. The effect of cancer is not limited only to the patients; it also influences life of a patient's spouse, children, family members and friends. Cancer is stressful both for the patient and their family to the same level; it also influences the economical status and daily performance of the family to a large extent (4, 5). Palliative care is an extended service set for treating symptoms, stresses and illnesses caused by cancer diseases, and is performed after initial

treatment of the patients. Palliative care has been developed for patients with advanced diseases; it focuses on improvement of life quality. The world health organization (WHO) considers palliative care as an active and complete care for patients whose disease does not respond to curative treatment (6). Palliative care is a necessity for those who have cancer; its main job is reducing patient's pain and suffering (7). The aim of palliative care is something beyond creating a comfortable death. Palliative care considers pain and other symptoms, emotional and spiritual support, cultural requirements and improvement of patients' performance status. Wishes and desires of patients' family members are the control of pain, better communication and the availability of doctors and nurses. Dissatisfaction with the quality of care directly influences family members' health and performance (8). Data from several studies show that palliative care programs reduce distress, promote patients' improvement, increase families' satis-

faction and reduce hospitalization time and finally reduce costs and increase efficiency (9). Taking care of a dying patient is a big challenge for nurses; it does not only influence interaction between a nurse and a patient and their family, but also influences nurse's feelings about themselves and their performance at the time of taking care of a dying patient. When a patient's death is close, nurse's ability in terms of on time change of the method from therapeutic care to palliative care is important (10). Currently in Iran, the main problem of the nursing system regarding palliative care of cancer patients is lack of clarity of the framework of such care for the nurses; also it is not offered as part of any formal training program. It seems that one of the causes of this problem is shortage of comprehensive studies in this regard in the country and it limits using the term of palliative care for these patients (11).

2. Objectives

Considering the modern nature of care, the aim of this study was to compare the effect of palliative care and routine care on satisfaction of end stage cancer patients' family members.

3. Patients and Methods

The current study was a semi-experimental interventional research conducted during year 2015. Research samples included 80 family members of end stage cancer patients hospitalized at the oncology ward of Shohadaye Tajrish and Firozgar hospitals of Tehran. Samples of the study included family members of above 18 year-old patients, with stage 4 prostate, breast, digestive or lung cancer, resistant to hormonal therapy and chemotherapy, and prognosis of having a lifetime of less than three months. After selecting samples of the study and obtaining an informed consent from the samples who qualified for the study, samples were divided to two intervention (40 families whose patients accepted palliative medicine for continuing treatment of end stage cancer) and control groups (40 families whose patients had the usual treatment). The palliative medicine services included; first visit, family justification, physician visit, telephone counseling, telephone visit, psychological counseling, nutrition counseling, physiotherapy and nursing services, which were provided by the palliative medicine team for the patients and their families. The studied family members were responsible for taking care of the patient and were the main caregiver such as a spouse, a child, etc. The FAMCAR questionnaire was used for data collection (12); it includes two parts; the first part includes demographic and clinical features, which consists of 20 questions about the caregiver and the patient,

the second part is according to the aims of the study and includes 20 questions. This questionnaire is scored from one to five with a five-item Likert scale; the scores range from completely dissatisfied to completely satisfied. The scoring method is in the range of 20 - 100, which is categorized from complete satisfaction to dissatisfaction.

Reliability and validity of this questionnaire have been measured in foreign studies (13, 14). This questionnaire was translated to Persian and again translated to English by the project managers. Translation stages were assessed and confirmed by an English professor. Content validity of the questionnaire was assessed by ten faculty members and in terms of reliability, a pilot study was done on 24 caregivers apart from the samples of the study whose patients were receiving care; the questionnaire was distributed and filled out by the 24 caregivers. The questionnaire's reliability was determined as 0.953 through Cronbach's alpha coefficient. All the Helsinki ethical principles were considered in this study. This study was confirmed by the ethics committee of the research department of Golestan Medical Sciences University. In order to compare the average of variables, ANOVA was used in the control and intervention groups. $P < 0.05$ was considered statistically significant.

4. Results

Among 80 family members of the study in the control and intervention groups, there were 52.5% and 60% male and female caregivers, respectively. Most of the patients' caregivers in the two groups were female and married; most of them were in the age range of 35 to 59 years old and most of them had a Diploma and associate degree. There was no statistically significant difference between the two groups in terms of demographic information (Tables 1 and 2).

The average of care satisfaction scores among patients' family members in the intervention and control groups was respectively 82.8 with standard deviation of 7.8 and 65.8 with standard deviation of 9.07 (Table 3). There was a significant statistical difference in terms of care satisfaction average between the two intervention and control groups through the independent t-test ($P = 0.001$). In other words, palliative care increases satisfaction in patients' caregivers compared with standard and routine care.

Furthermore, 62.5% of the family members in the intervention group were completely satisfied with the care and 37.5% were relatively satisfied; there was nobody who was relatively or completely dissatisfied with the care. On the other hand, 12.5% of the family caregivers in the control group were completely satisfied with the care and 67.5% were relatively satisfied and 20% were relatively dissatisfied.

Table 1. The Demographic Variables of the Family Members of End Stage Cancer Patients in the Intervention and Control Groups^a

Variables of the Study	Intervention Group	Control Group	P Value Chi-Square Test (Between Two Groups)
Gender			0.49
Male	19 (47.5)	16 (40)	
Female	21 (52.5)	24 (6)	
Age, years old			0.16
18 - 24	1 (2.5)	7 (17.5)	
25 - 34	13 (32.5)	11 (27.5)	
35 - 59	19 (47.5)	15 (37.5)	
Above 60	7 (17.5)	7 (17.5)	
Marital status			0.64
Single	17 (42.5)	15 (37.5)	
Married	23 (47.5)	25 (62.5)	
Ethnicity			0.77
Persian	23 (57.5)	24 (60)	
Tork	13 (32.5)	11 (27.5)	
Others	4 (10)	5 (12.5)	
Education			0.91
Illiterate and primary	5 (12.5)	4 (10)	
Middle and high school	9 (22.5)	5 (12.5)	
Diploma and higher	15 (37.5)	18 (45)	
BA and higher	11 (27.5)	12 (30)	
Residence			0.55
City	39 (97.5)	38 (95)	
County	1 (2.5)	2 (5)	
Occupation			0.56
Employed	18 (45)	13 (32.5)	
Self-employed	12 (30)	10 (25)	
Worker	1 (2.5)	2 (5)	
Others	9 (22.5)	15 (37.5)	
Income			0.25
Less than 300 thousand Tomans	4 (10)	8 (20)	
300 - 600 thousand Tomans	4 (10)	5 (12.5)	
600 - 900 thousand Tomans	22 (55)	23 (57.5)	
More than 900 thousand Tomans	10 (25)	4 (10)	
Religion			0.31
Shia	40 (100)	39 (97)	
Sunni	0	1 (2.5)	
Relationship with the patient			0.40
Spouse	12 (30)	16 (40)	
Child	17 (42.5)	15 (37.5)	
Sister-brother	8 (20)	6 (15)	
Relative	3 (7)	1 (2.5)	
Friend	0	2 (5)	
Number of the relatives			0.80
One	15 (37.5)	15 (37.5)	
Two	16 (40)	16 (40)	
Three	3 (7.5)	5 (12.5)	
Four and more	6 (15)	4 (10)	

^a Values are expressed as No. (%).

fied; there was nobody who was completely dissatisfied with the care (Table 4).

Table 2. The Demographic Features of End Stage Cancer Patients in the Intervention and Control Groups^a

Variables of the study	Intervention Group	Control Group	P Value Chi-Square (Between the Two Groups)
Gender			0.49
Male	22 (55)	25 (62.5)	
Female	18 (45)	15 (37.5)	
Age, y			0.36
18 - 24	0	1 (2.5)	
25 - 34	0	2 (5)	
35 - 59	12 (30)	12 (30)	
Above 60	28 (70)	25 (62)	
Marital status			0.59
Single	10 (25)	8 (20)	
Married	30 (75)	32 (80)	
Ethnicity			0.54
Persian	24 (60)	20 (50)	
Tork	12 (30)	12 (30)	
Others	4 (10)	8 (20)	
Education			0.47
Illiterate and primary	21 (52.5)	15 (37.5)	
Secondary and high school	5 (12.5)	7 (17.5)	
Diploma and higher	13 (32.5)	14 (35)	
BA and higher	1 (2.5)	4 (10)	
Residence			0.39
City	38 (95)	36 (90)	
County	2 (5)	4 (10)	
Insurance Coverage Status			0.15
Having insurance	40 (100)	38 (95)	
Lack of insurance	0	2 (5)	
Type of health insurance			0.41
Social security	27 (67.5)	23 (57.5)	
Health services	9 (22.5)	13 (32.5)	
Army	2 (5)	0	
Bank	1 (2.5)	1 (2.5)	
Others	2 (2.5)	3 (7.5)	

^a Values are expressed as No. (%).**Table 3.** Satisfaction Level of Care Among Family Members of end Stage Cancer Patients Based on Intervention and Control Groups

Groups	Mean \pm SD	T Statistic	P Value
Intervention	82.8 \pm 7.8	8.9	0.001
Control	65.8 \pm 9.07	8.9	0.001

There was no statistically significant relationship between demographic features of the patients' family members including age, gender, ethnicity, education level, economical status and family members' satisfaction through t-test and ANOVA.

5. Discussion

The findings of this study showed that there is a significant statistical difference between palliative care and routine care in terms of satisfaction level of end stage cancer patients' family members. In other words, satisfaction level of end stage cancer patients' family members was higher with palliative care compared to routine care. In a study conducted by Gelfman et.al. most of the family members of the patients who had received palliative care were satisfied compared with those who had received routine care (9). On the other hand, in another study, it was shown that participants who had received palliative care had better quality of life and behavior compared with those who had received oncology routine care, but it did not influence improvement of symptoms, allergy and reduction of

Table 4. Satisfaction Level of Care Among Family Members of End Stage Cancer Patients in the Intervention and Control Groups^a

Satisfaction with the Care Provided for the Patient	Scoring	Intervention Group	Control Group
Complete satisfaction	80 - 100	25 (62.5)	5 (12.5)
Relative satisfaction	60 - 79	15 (37.5)	27 (67.5)
Relative dissatisfaction	40 - 59	0	8 (20)
Complete dissatisfaction	20 - 39	0	0

^aValues are expressed as No. (%).

hospitalization days at the oncology and emergency departments (10). The study of Gallagher et al. showed that the bereaved family members of the group who received routine care were dissatisfied with most of unmet requirements such as lack of information regarding patient's condition, death process, performed actions at dying time and lack of patients and family members' emotional support; this is while the least unmet requirements were reported in the intervention group (15). Ringdal et al. in their study reported that patients' family members were more satisfied with palliative care at the end of their patients' lifetime; satisfaction with pain treatment, receiving information regarding pain management, patients' tests and disease prognosis were higher in patients' family members of the intervention group compared with the control group (16). Namasivayam et al. in their study found that families' different expectations was the main problem of nurses in providing palliative care, which required families' involvement in assessing and solving them; this study was done to emphasize on the importance of creating a relationship with incurable patients' families and supporting them and also to provide a guideline that may be used by nurses and caregivers for responding to families' concerns and requirements. This study suggests educational needs for providing formal palliative care including taking care of the family and enabling nurses in providing effective and appropriate care for incurable patients and their families (17). A study, which was done in Osaka in Japan, it was explained that family members are satisfied with palliative care services provided by Japan palliative care association members. In this study, it was found that factors such as nursing system, nurses' on duty at night and the presence of staff of social medicine (nursing care), patient's age and number of physicians (relieving symptoms), available space for admission (facilities), admission duration and extra cost for a private room (cost) were important regarding families' satisfaction level (12). The present study indicated that 20% of the family members of the intervention group were completely satisfied with palliative care, yet only 5% of the control group was completely satisfied with care. On the other hand, there was no body in the interven-

tion group dissatisfied with care; this is while in the control group, 8% of the family members were relatively dissatisfied with care. Studies in this regard have shown that intervention programs are more useful for families compared with individual counseling (18, 19).

Findings of the study of Mardani et al. also showed that nurses believe that palliative care for cancer patients includes relieving physical pain and mental pain (11). Watercamper and Ribenitez suggested that pain due to cancer initially emerges in the physical dimension and then in the psychological dimension. Therefore, it is necessary for the nurses that are providing palliative care for cancer patients to be aware of different types of pain that these patients are experiencing (20).

In this study, the level of satisfaction with palliative care was more in family members who were siblings or children of the patients compared with those who were spouses and relatives of the patients. Diagnosing cancer in children follows adverse effects for the families; this disease is unique in terms of creating sense of helplessness and deep fear among people. Cancer patients' families experience stressful events and continuous and ongoing state of anxiety (3, 11). In a study done by Klasen et al. it was shown that parents, who have a child with cancer, have weaker quality of life compared with the general population, and experience higher stress. It is recommended to consider direct interventions regarding parents as a part of the health plan for patients with cancer (21, 22). However, when a patient's medical diagnosis is showing lack of treatment possibility death, the patient and physician will be encountered with difficult conditions for decision-making regarding medical interventions. Although medical sciences advancement has promoted physicians' ability regarding issues related to medical care of patients' in the midst of death, this area of medical science was never considered, as it should. Priority of trying to find a cure should not be overlooked, also palliative treatments and enabling physicians for addressing medical and psychological aspects of incurable disease should be considered. Death stage should be recognized and respected as an important part of a person's life. Along with pressure of gen-

eral thought regarding legalization of euthanasia to end the suffering caused by incurable diseases, the necessity of considering ethical principles in improving palliative cares has been more felt.

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