

Perspectives on Hospice and Palliative Care among the Family Caregivers of Cancer Patients in South Korea

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Abstract

Background/Objectives: The utilization of hospice and palliative care services has been limited yet in South Korea. The purpose of this study is to investigate perception and needs toward hospice and palliative care. **Methods/Statistical Analysis:** A cross-sectional design was used to examine perception and needs on hospice and palliative care. Data were collected from 19th August to 30th September in 2014. 250 family caregivers of cancer patients in South Korea were surveyed from cancer wards or hospice care units using a structured questionnaire. Chi-square tests were conducted to determine the differences in the perception and needs on hospice and palliative care according to participant's characteristics. **Findings:** Around 50% of the respondents replied that they had no or vague idea on hospice and palliative care services. Over 80% of the respondents perceived that hospice and palliative care is necessary and they want to use those services. Religion of the respondents, type of ward, dependence of patient, and length of caring were related to perception on Hospice and Palliative care. Type of ward, cancer stage of patient, dependence of patient, type of insurance, length of caring were related to need on those services. Those who had more awareness on hospice and palliative care were more likely to recognize the necessity of those services. **Application/Improvements:** These findings represent that caregivers' needs on hospice and palliative care services are high, but its perception is relatively low. To improve awareness about it, public education should be required.

Keywords: Cancer Patients, Family Caregivers, Hospice, Perspectives, Palliative Care

1. Introduction

According to World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"¹. In South Korea, the prevalence of all cancer were 1,234,879 cases, and 73,759 people who were diagnosed any types of cancer died that was accounting for 27.6% of all deaths in². Therefore, to improve quality of life of patients with end-stage cancer

and help them dying dignified, hospice and palliative care is essential.

In Korea, the new law, what is called "Well-Dying Law" was passed by the National Assembly of the Republic of Korea on January 2016. Based on this new act, it enables terminally ill patients to reject treatment and die with dignity from³. Although the necessity and importance of hospice and palliative care have been emerging worldwide⁴ and right to decide how to die will be legally accepted³, the utilization of those services has been limited yet in Korea. Reasons of underutilization of those services may be from knowledge deficit or low public awareness about the services. Furthermore, a little study explored on what

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are the current levels of knowledge hospice and palliative care and needs on those services among family caregivers in Korea. The research aimed to investigate awareness and needs toward hospice and palliative care. Identified information will provide a basis for increasing utilization of palliative care in Korea, which will consequently enhance the quality of life for the people whose death is near.

2. Methods

2.1 Design

A cross-sectional design using a self-reported questionnaire was used to examine perception and needs on hospice and palliative care. Data were collected from 19th August to 30th September in 2014.

2.2 Sample

The survey was conducted on 250 caregivers of cancer patients who had admitted to the cancer ward and hospice care units. The survey questionnaire was administered to family members because usually the oldest family

Table 1. General Characteristics of the Respondents (N=250)

Variables	Categories	n (%)
Gender	Male	70 (28.0)
	Female	180 (72.0)
Age	<40	52(20.8)
	40-49	66(26.4)
	50-59	70(28.0)
	≥60	62(24.8)
Relationship with patient	Spouse	115(46.0)
	Parents	24(9.6)
	Adult children	81(32.4)
	others	30(12.0)
Monthly income (million won)	<2	86(34.4)
	2~<4	111(44.4)
	≥4	53(21.2)
Religion	Buddhism	32(12.8)
	Catholic	56(22.4)
	Protestantism	51(20.4)
	None	111(44.4)
Education	≤Middle school	44(17.6)
	High school	96(38.4)
	≥University	110(44.0)

Table 2. Caring-related Characteristics of the Respondents (N=250)

Variables	Categories	n (%)
Ward	General	125(50.0)
	Hospice/Palliative	125(50.0)
Stage of disease	1	8(3.2)
	2	23(9.2)
	3	76(30.4)
	4	140(56.0)
	None/Didn't know	3(1.2)
Recurrence	No	138(55.2)
	Yes	112(44.8)
ADL	Independent	27(10.8)
	Partially dependent	69(27.6)
	Dependent	154(61.6)
Length of admission (days)	≤10	30(12.0)
	11-20	42(16.8)
	21-30	117(46.8)
	≥31	61(24.4)
Economic burden of health care cost	High	182(72.8)
	Moderate	52(20.8)
	Low	16(6.4)
Having the helpers for caring	Yes	149(59.6)
	No	101(40.4)

Table 3. Perception and needs on hospice and palliative care services (N=250)

Variables	n (%)
Perception on hospice and palliative care	
No or vague idea	127(50.8)
Precise idea	123(49.2)
Information source (n=214)	
From a physician	48(19.2)
From a nurse	34(13.6)
From family	24(9.6)
From other people	62(24.8)
From media	36(14.4)
From internet	8(3.2)
Others	2(0.8)
Necessity for hospice and palliative care services	
No	36(14.4)
Yes	214(85.6)
Willingness to use hospice and palliative care services	
No	50(20.0)
Yes	200(80.0)

Table 4. Differences in Perception and Needs on Hospice and Palliative care according to the Characteristic (N=250)

Variables / Categories		Perception			Needs		
		No	Yes	X/t (p)	No	Yes	X (p)
Characteristics of the respondents							
Gender	Male	34(48.6)	36(51.4)	0.19 (.660)	12(17.1)	58(82.9)	0.59 (.441)
	Female	93(51.7)	87(48.3)		24(13.3)	156(86.7)	
Age	<40	29(55.8)	23(44.2)	2.67 (.446)	8(15.4)	44(84.6)	1.79 (.616)
	40-49	36(54.5)	30(45.5)		8(12.1)	58(87.9)	
	50-59	30(42.9)	40(57.1)		13(18.6)	57(81.4)	
	≥60	32(51.6)	30(48.4)		7(11.3)	55(88.7)	
Relationship with the patient	Spouse	64(55.7)	51(44.3)	2.01 (.157)	18(15.7)	97(84.3)	0.27 (.603)
	Others	63(46.7)	72(53.5)		18(13.3)	117(86.7)	
Monthly income (million won)	<2	42(48.8)	44(51.2)	.443 (.801)	7(8.1)	79(91.9)	5.73 (.057)
	2~<4	59(53.2)	52(46.8)		17(15.3)	94(84.7)	
	≥4	26(49.1)	27(50.9)		12(22.6)	41(77.4)	
Religion	Yes	61(43.9)	78(56.1)	5.99 (.014)	17(12.2)	122(87.8)	1.20 (.274)
	No	66(59.5)	45(40.5)		19(17.1)	92(82.9)	
Education	≤Middle school	27(61.4)	17(38.6)	2.58 (.275)	7(15.9)	37(84.1)	0.46 (.794)
	High school	45(46.9)	51(53.1)		12(12.5)	84(87.5)	
	≥University	55(50.0)	55(50.0)		17(15.5)	93(84.5)	
Economic burden on medical cost	High	91(50.0)	91(50.0)	0.26 (.877)	22(12.1)	160(87.9)	3.23 (.199)
	Moderate	27(51.9)	25(48.1)		10(19.2)	42(80.08)	
	Low	9(56.2)	7(43.8)		4(25.0)	12(75.0)	
Characteristics of the patients							
Type of ward	General	74(59.2)	51(40.8)	7.06 (.008)	31(24.8)	94(75.2)	21.94 (<.001)
	Hospice/Palliative	53(42.4)	72(57.6)		5(4.0)	120(96.0)	
Stage of disease (n=247)	1-2	17(54.8)	14(45.2)	0.21 (.703)	9(29.0)	22(71.0)	6.44 (.011)
	3-4	109(50.5)	107(49.5)		26(12.0)	190(88.0)	
Recurrence	Yes	52(46.4)	60(53.6)	1.55 (.132)	13(11.6)	99(88.4)	1.28 (.257)
	No	75(54.3)	63(45.7)		23(16.7)	115(83.3)	
ADL	Independent	19(70.4)	8(29.6)	7.26 (.027)	10(37.0)	17(63.0)	15.25 (<.001)
	Partially dependent	39(56.5)	30(43.5)		12(17.4)	57(82.6)	
	Dependent	69(44.8)	85(55.2)		14(9.1)	140(90.9)	
Private Insurance	Fixed costs	48(46.6)	55(53.4)	1.65 (.649)	16(15.5)	87(84.5)	8.76 (.033)
	Upfront costs	11(57.9)	8(42.1)		6(31.6)	13(68.4)	
	Both	22(50.0)	22(50.0)		8(18.2)	36(81.8)	
	None	46(54.8)	38(45.2)		6(7.1)	78(92.9)	
Caring-related characteristics							
Length of caring (year)	≤1	92(56.1)	72(43.9)	5.35 (.021)	29(17.7)	135(82.3)	4.17 (.041)
	>1	35(40.7)	51(59.3)		7(8.1)	79(91.9)	
Having the helpers for patient caring	Yes	77(51.7)	72(48.3)	0.11 (.736)	22(14.8)	127(85.2)	0.04 (.842)
	No	50(49.5)	51(50.5)		14(13.9)	87(86.1)	
Satisfaction of hospital services	Unsatisfied	25(58.1)	18(41.9)	1.12 (.290)	9(20.9)	34(79.1)	1.80 (.180)
	Satisfied	102(49.3)	105(50.7)		27(13.0)	180(87.0)	
Awareness on hospice and palliative care	No or vague idea				26(20.5)	101(79.5)	7.72 (.005)
	Precise idea				10(8.1)	113(91.9)	

member is the treatment decision maker to the matters of end-of-life care.

2.3 Analysis

Data were analyzed using IBM SPSS 20.0 program. Descriptive statistics were used to each question. Chi-square tests were conducted to determine the differences in the perception and needs on hospice and palliative care according to characteristics of the respondents, characteristics of the patient, and caring-related characteristics.

3. Results

General and caring-related characteristics of the respondents are shown in Table 1 and Table 2.

127 respondents (50.8%) had no or vague idea about hospice and palliative care services. 24.8% of total respondents replied that they get the information on hospice and palliative care from other people. 85.8% of total respondents recognized necessity of hospice palliative care and 80.0% of them desired to use those services (Table 3).

The people who had a religion were more likely to perceive hospice and palliative care. Those who had been caring the patients admitted in hospice care units, were dependent, or for more than 1 year had more likely to perceive on it and recognize the necessity of those services. Caregivers who had been caring the patient with 3rd to 4th stage of cancer were more likely to need to use those services. The people who insured for private insurance with fixed cost were more likely want to use those services. Those who had more awareness on hospice and palliative care were more likely to recognize the necessity of those services (Table 4).

4. Discussion

This study focused on the perceptions of hospice and palliative care and the need for those services among the family caregivers of cancer patients in South Korea. In this study, only about 50% of family caregivers were aware of hospice and palliative care. The levels of awareness on hospice and palliative care in this study correspond to previous result about public awareness⁵⁻⁷. On the other hand, the result of this study is respectively low compared to some studies, which showed that more than two thirds of respondents had some knowledge of palliative care^{4,8}. In this study, the needs for hospice and palliative

care services were high, but perception of hospice and palliative care was low, relatively. Also, only few people had got the information from publicity through mass media, internet, and so forth. Furthermore, perception of hospice and palliative care was associated with the need for those services. These findings implied that the strategies to enhance perception of hospice and palliative care should be enforced⁴ suggested the approaches such as publicity campaigns to foster public awareness. In prior research⁹, many people want death educational program to prepare their death¹⁰ emphasized that death anxiety could affect negatively, and, preparation for death and acceptance attitude for death could affect positively on mental and social health. To sum up, to enhance perception of hospice and palliative care, public education and advertisements about hospice and palliative care and those services are required.

People who had been caring the dependent patients or who had been caring the patients for more than 1 year were more aware of hospice and palliative care and more likely to need those services. These findings represent that the burden of patient care is associated with the needs for those services. Therefore, hospice and palliative care services could be the strategies to reduce the burden of the family caregivers.

Also, as shown in the research of⁹, most of elderly people want to be dying at home with family, naturally. Therefore, we also need to consider introduction of home hospice services in the long term.

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