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Survey of need for death preparatory education among health care providers assisting

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Abstract

This study seeks to investigate the purpose in life, fear of death and dying, death-related experiences, and the need for death education experienced by health care providers via a descriptive research design method. As a result, 86.98% of medical staff answered that they did not receive death related education. In conclusion, the health statistics connected to the annual deaths have treated death as a medical failure that did not resolve the disease rather than associating it with human finitude.

Keywords: Life-sustaining, Death Preparatory Education.

Encuesta sobre la necesidad de muerte educación preparatoria entre los proveedores de asistencia médica que asisten

Resumen

Este estudio busca investigar el propósito en la vida, el miedo a la muerte y la muerte, las experiencias relacionadas con la muerte y la necesidad de educación sobre la muerte experimentada por los

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proveedores de atención médica a través de un método de diseño de investigación descriptivo. Como resultado, el 86,98% del personal médico respondió que no recibió educación relacionada con la muerte. En conclusión, las estadísticas de salud relacionadas con las muertes anuales han tratado la muerte como una falla médica que no resolvió la enfermedad en lugar de asociarla con la finitud humana.

Palabras clave: educación vital, educación preparatoria de la muerte.

1. INTRODUCTION

Euthanasia has become an issue of contention not only in Korea but also globally. An ethical dilemma often faced in the field of medical practice is whether to persist in attempts to prolong human life or discontinue such treatment for the sake of human dignity. On February 4, 2018, the Korean government enacted the Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life, for providing legal grounds on which patients may choose to stop life-prolonging treatment by their own accord. Though its intent to preserve the dignity of the patients may be noble, compliance with the act requires much preparation. According to the act, the subject of the life-sustaining treatment decision is the patient in the end–of-life stage. The key factor is the end-of-life stage, which, according to the law, there is no possibility of regeneration, recovery is not made despite the treatment and symptoms are worsening rapidly, and death is imminent. Whether the patient is in the process of dying is evidently judged professionally by the physician. The judgment is to be made by the doctor, according to modern medical conventions.in.

Primary caregivers can play an important role in helping patients to decide whether to continue or terminate the life-sustaining treatment. Several states in the US, such as Minnesota, require patients to fill and sign the Do-Not-Resuscitate (DNR) Sheet upon admission to the hospital, indicating their choice when a decision needs to be made regarding continuing or discontinuing life-sustaining treatment, so that the health care provider can refer to the signed DNR sheet and take measures accordingly. The health care provider explains the life-sustaining treatment process in detail and- through consultation, spends plenty of time with the patients in assisting them to reflect on their death. Thus, the health care providers' knowledge, attitude, and philosophy regarding death can have significant implications on the development of patient's perceptions about death.

However, that medical professionals who frequently witness patient deaths, especially those with dignity, experience emotional and psychological distress often accompanied by physical discomfort (Aina, 2015; Gazzola, et.al. 2015; Kwegyir-Aggrey, 2016). This not only is a testimony to the anxiety induced by death for medical personnel who must experience deaths with dignity, but also highlights a mental health concern that needs to be resolved. When faced with the problem of life or death, people make decisions based on personal value systems, which are associated with their cultural or religious beliefs (Corr & Corr, 2012). Thus, the exploration of perceptions surrounding life and death of health care providers can provide the basis for defining the roles of medical personnel in preparing patients for dignified deaths.

However, there has been a dearth of research on death in relation to

health care providers. Studies on attitudes toward death (Moon, 2003), death and hospices (Kim, 2007), and nurses' attitudes toward death and hospice (Lee, 2004); an academic research employing Q methodology on subjective views held by medical practitioners (Yeun, 1999; Okumura, 2017); a comparison between passing away of clergymen and medical practitioners; and a study on medical practitioners' understanding of death (Chun, 2003), are the only relevant literature available. Although it has been recognized that the discourse on modern death is contingent upon the development of natural sciences and medicine (Chun, 2000), domestic research has been negligent in creating such a change.

This study seeks to investigate the purpose in life, fear of death and dying, death-related experiences, and need for death education experienced by health care providers who are perhaps most intimately engaged with their patients, in order to provide baseline data for death education programs that can assist patients in their decisions regarding life-sustaining treatments.

2. METHODOLOGY

2.1. Research Design

This study employed a descriptive research design to gage the purpose in life, level of death-related fear, death-related experiences, and needs for death education experienced by health care providers who are most intimately engaged with their patients, for the implementation of the Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and

Palliative Care or at the End of Life.

2.2. Research Sample and Data Collection Method

The survey was conducted from July 1, 2016 to July 31, 2016, with 389 doctors, nurses, and health care providers working at C hospital in Seoul, Gyeonggi-do, who agreed to participate in the survey. Each questionnaire took approximately 20 minutes to complete, and the recovery rate was 77.8%.

The sample size required for this study was calculated using power analysis and statistical methods Cohen (1988) and derived by setting the significance level (α) at .05, the verification power (1-β) at 0.93, and the effect size (f2) as 0.18, which resulted in the required sample size of 100as long as the sequences with an average identity higher than the threshold are detected (Semenov et al,2018).

2.3. Measurements

The purpose in life has been defined as one's aims and sense of direction in life, and something which can be found in one's past and presents. The purpose of life as being present in every living moment, and characterized it as ever-changing depending on the person, as well as one's temporal and spatial circumstances. Developed by Crumbaugh and Maholick (1969) with roots in Frankl's (1995) Logo therapy and later

adapted by Namkung (1980), the tool is known as the Purpose in Life Scale (PIL). The questionnaire consists of 20 items rated on a 7-point scale and questions 1, 3, 4, 6, 8, 9, 11, 12, 13, and 16 are inversely scored; a higher final score indicates more acute awareness of one's purpose in life. The scale's reliability was found to have Cronbach's α=.852 at the time of development, and Cronbach's α=.845 when used in this study. This study used Fear of Death and Dying Scale (FDDS) developed by Corret and Lester (2012) and revised by (Seo, 1987). Thirty-six items are rated on a 4-point scale, of which 20 are positive and 16 are negative. The negative items: 3, 6, 7, 8, 9, 10, 12, 14, 16, 18, 21, 23, 24, 25, 26, and 28 are reverse scored. High score indicates a high level of fear. Its reliability was measured to have Cronbach's α of .912 in the study by Seo (1987) and .743 in the present study.

2.4. Data Analysis Method

SPSS 20.0 program was used in analyzing the data. The general characteristics, purpose in life, fear of death and dying, and death preparatory education demands were analyzed using frequency analysis and descriptive statistics. Differences in variables according to general characteristics were measured using t-test, one-way ANOVA, and LSD post hoc test, while differences in readiness for death, according to consent for euthanasia or life-sustaining treatment was analyzed using the $\chi2$ test.

3. RESULTS

3.1. General Characteristics

The general characteristics of the sample were divided into seven nine categories: age, gender, occupation, career duration, religion, economic status, and health. The most frequent age group was of those aged 20 ~ 29 years, comprising 63.2% of the entire sample, followed by 24.2% of those aged 30 ~ 39 year, 6.4% of those aged 40 ~ 49 years, 4.4% of those aged 50 ~ 59 years, and 1.8% of those aged 60 years and older. There were more women (80.3%) than men (19.7%) in the sample. In terms of occupation, there were 73.3% nurses and 24.6% doctors, and 2.1% identified themselves as other, thus showing a majority of nurses. Those with hospital career duration between one and three years comprised 36.0%, followed by 21.6%, 16.5%, 12.6%, 6.9%, and 6.4% of those with a duration of less than a year, 10 years or more, three to five years, five to seven years, and seven to less than 10 years, respectively. The most common types of religious orientations were Christianity and No religion (34.2%), followed by Catholicism (15.7%), Buddhism (9.8%) and others (6.2%). Among those who participate in religious activities, 31.2% reported the first exposure to religion during elementary school, 26.5% before elementary school, 24.8% by birth, 10.3% during middle or high school, and 7.3% after college. When asked about religion's influence on their lives, 22.6% reported being partially influenced, 19.3% being profoundly influenced, 11.65% being moderately influenced, 5.9% as being less influenced and 1.5% as being not influenced at all. With regard to economic status, 53.1% reported theirs as normal, 24.2% as satisfactory, 20.6% as unsatisfactory, and 1% each as highly satisfied and highly unsatisfied. Concerning health, 49.0% respondents described their status as good, 39.1% as moderate, 5.7% each as excellent and poor, and 0.5% as very poor. These examinations reveal the qualitative differences between the data sets.

3.2. Health Care Providers' Experiences Related to Death

Death by disease ranked the highest as causes for the first death experienced, at 49.4%, followed by natural death at 28.3%, accidental death at 17.0%, and suicide at 2.8%, others at 1.5% and of unknown cause at 1.0%. Moreover, 74.2% experienced the loss of an important person, outnumbering those who did not (25.8%), and among those who did, 49.6% experienced it in their adolescence, followed by those who experienced it in their 20s (24.8%), pre-adolescence (18.4%), 60s and above (3.2%), and both 40s' and 50s at 0.4% each. Of those who experienced the loss of an important person, 73.1% witnessed their passing. Additionally, 80.6% participated in the funeral. The most experienced deaths were those of their grandparents at 72.0%, followed by that of parents (12.7%), friends (6.2%), and siblings (1.1%)

3.3. Purpose in Life and Fear of Death and Dying

Most subjects were found to have a vague sense of purpose in life, with an average score of 64.88 (SD=16.62) and the minimum score of 16 and maximum of 136 within the range of 20 ~ 140 points. Level of death-related fear averaged at 91.44 points (SD= 8.87), with a minimum score of 60 and a maximum of 123, within the range of 0 ~ 144 points. Fear regarding own death averaged at 2.56 (SD=0.44), that of others at 2.59 (SD=0.30), own dying at 2.60 (SD=0.38), and that of others at 2.44 (SD=0.30). The level of fear with regard to one's own dying was the highest.

3.4. Differences in Purpose in Life and Fear of Death and Dying According to General Characteristics

Purpose in life and degree of death-related fears showed significant differences by gender (t=-2.731, p=0.007), career duration (F=2.386, p=0.038), economic status (F=10.566, p= 0.000), and health status (F=6.898, p=0.000). In the LSD test, women scored higher than men, and subjects with career experience of one ~ three years did so more than those with less than one year or 10 years. Those who were not satisfied with their economic status, or reported poor or very poor health status also scored relatively high. A statistically significant difference was observed in the degree of fear, depending on the subjects' age (F=3.560, p=0.007), gender (t=-3.516, p=0.001), occupation (F=5.810, p=0.003), economic status (F=3.017, p=0.018), and health status (F=2.624, p=0.034). In sum, high level of death-related fear was observed in the following groups: aged 20 ~ 29 years; female; doctor; reporting highly satisfied, normal or not satisfied economic status; and reporting very poor health status.

3.5. Perceptions Regarding Prolonging Life and Death Preparation

The subjects' perceptions regarding life-sustaining treatment and euthanasia are illustrated in <Table 1>. An overwhelming 85.1% of the respondents refused life-sustaining treatment, while only 14.9% wanted to continue the treatment. The reasons for refusing the treatment included it is pointless (26.8%), it is painful (16.0%), it prevents a dignified death (15.2%), it will induce financial burden on family (4.3%), it defies medical limitations (1.6%), and it is unethical (1.4%). For the opinion about

euthanasia, 84.2% of the respondents were in favor of voluntary euthanasia (the administration of morphine under the condition where the subject of life either voluntarily or passively consent by his or her will to pain relief by euthanasia).

Table 1. Health care provider's death preparation for himself/herself

N=388				
		Classification	N	%
Issuing Do-Not-Resuscitate order	Agree		314	85.1
	Disagree		55	14.9
	Reasons	It is pointless	99	26.8
		It is painful	59	16.0
		It is against death with dignity	56	15.2
		It is a financial burden for family	16	4.3
		It defies medical limitations	6	1.6
		It is unethical	5	1.4
		Others	73	34.7
Euthanasia	Disagree		121	31.0
	Agree		269	69.0
	Type	Voluntary Euthanasia	234	84.2
		Involuntary Euthanasia	25	9.0
		Semi-voluntary Euthanasia	19	6.8
		Active Euthanasia	52	18.6
		Passive Euthanasia	228	81.4

3.6. Demands for Death Education

Those who had never received death education comprised the majority (86.98%). When asked about their willingness to participate in prospective death-related education, 64.32% of the respondents replied yes. With regard to desired subject matter, education related to hospice ranked the highest at 54.34%, followed by religious, philosophical, and

psychological approach to death (35.08%), grief process (18.36%), funeral (15.34%), and others (0.83%) <Table 2>.

Table 2. Death-related education demands

N=388						
		N (%)	Euthanasia		Do-Not-Resuscitate orders	
			Agree	Disagree	Agree	Disagree
			N (%)	N (%)	N (%)	N (%)
Previous experience with death education	Yes	50(13.02)	32(8.58)	15(4.02)	38(10.47)	7(1.93)
	No	334(86.98)	233(62.47)	93(24.93)	270(74.38)	48(13.22)
Willingness to participate in death education	Yes	238(64.32)	165(45.96)	65(18.11)	191(54.57)	35(10.00)
	No	132(35.68)	93(25.91)	36(10.03)	108(30.86)	16(4.57)
Religious, philosophical, and psychological approach to death	Yes	127(35.08)	90(25.71)	35(10.00)	100(29.15)	20(5.83)
	No	235(64.92)	160(45.71)	65(18.57)	194(56.56)	29(8.45)
Hospice	Yes	198(54.40)	133(37.78)	57(16.19)	158(45.93)	30(8.72)
	No	166(45.60)	117(33.24)	45(12.78)	137(39.83)	19(5.52)
Funeral	Yes	56(15.34)	42(11.90)	14(3.97)	48(13.91)	6(1.74)
	No	309(84.66)	209(59.21)	88(24.93)	248(71.88)	43(12.46)
Grief Process	Yes	67(18.36)	42(11.90)	23(6.52)	58(16.81)	7(2.03)
	No	298(81.64)	209(59.21)	79(22.38)	238(68.99)	42(12.17)
Others	Yes	3(0.83)	1(0.29)	2(0.57)	3(0.88)	0(0.00)
	No	357(99.17)	248(71.26)	97(27.87)	289(85.00)	48(14.12)

4. CONCLUSION AND SUGGESTION

For the social view that death is a medical failure of being able to handle more, 49.4% of the first cause of death experienced by medical practitioners participating in this study was a terminal illness, and the degree of death anxiety they had was 91.44 points in average, which was above the median, within the rage of 0 ~ 144 points. It is known that medical personnel with a negative perception of death have

high death anxiety, behave to avoid death, and do not provide comfortable end-of-life care for a dying patient and his or her family due to such attitude (Braun et al., 2010).

In the modern era, where the average lifespan is approaching 100 years due to medical advances, death is typically not thought to be related to myself. The health statistics connected to the annual deaths have treated death as a medical failure that did not resolve the disease rather than associating it with human finitude. Medical workers should closely deal with 74.9% of all deaths occurring in the hospital. Although the final moments of life and death routinely occur in hospitals, medical staffs and patients' families had to provide unnecessary medical care to extend the life of patients because of legal issues that might arise when the patients actually died. Under this circumstance, the Life Sustaining Treatment Determination Act was enacted in February 2018. In this study, based on the fact that 85.1% of the medical staffs agree with the denial of life-sustaining treatment and 60.3% of patients agree with the voluntary euthanasia, it is clear that this is an indispensable law at the medical field and for national emotion. Although it is the intention of patients to decide by them whether or not to take the treatment related to their death, appropriate measures for the emotional impact on the medical staff caring for the dying patients who choose to refuse treatment seem not established yet.

The age of the medical staff that cares for the patient in the hospital is relatively young. In this study, 90.2% of the medical staff

were in their 20s and 30s, and 57.6% of them had less than 3 years of hospital experience. According to their general characteristics, the degree of death anxiety has been analyzed to be significantly high for ones at the age of 20 ~ 29, females in gender, doctors in occupation, very satisfied, average, and not satisfied in economic level, and not very healthy in health status. The emotional burden of young medical staffs having limited hospital experience yet caring for a patient who is at the border between life and death is enormous. The medical staff has the burden of a guilty conscience and experiences side effects of isolation, depression, and suicidal ideation due to the stress from patients and their family members refusing life-sustaining treatment. Therefore, the author's claim that the education and the preparation at a supporting level for the medical staff is required. It is also essential to provide them with the information they need to care for their dying patients and to help them make decisions.

Only 13.02% of the medical staff participating in this study had received professional education related to death, and the remaining 86.98% answered that they did not receive death related education. Hospice education was the most wanted by 54.40% of the participants, followed by religious, philosophical, and psychological opinions by 35.08%, grieving process by 18.36% and funeral process by 15.34%, and ones who were willing to participate in the education to be implemented were surveyed at 64.32%. Although the Life Sustaining Treatment Determination Act was enforced by its necessity, the parties who are supposed to cooperate for the enforcement of the law are not well prepared, and they are aware of it and are requesting additional

education. Affecting nurses' attitudes to care for dying patients depends on palliative care, communication skills, and ability to address their emotions, decision-making, ethical guidelines, professionalism, and degree of education about the policies (Ada et al., 2008). Therefore, it should be possible to provide quality care service to the patients who are the decision makers of life-sustaining treatment and to reduce the degree of death anxiety of the medical staff by carrying out death education.

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