

Meaning of Cancer and Hospice among Health Service Providers: Conflict or Congruity?

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Abstract: This Q methodological study identified the subjective structure of the meaning of cancer and hospice and explored the relationship between the two concepts. Thirty three participants completed a 33-item Q sort representing their understanding of cancer. And thirty six participants completed a 30-item Q sort representing their understanding of hospice. Four subjective factors for the meaning of cancer and five subjective factors for the meaning of hospice were identified. Factor interpretations are presented and compared. Several considerations for nursing educators and nurses involved in hospice care are discussed.

Introduction

Cancer is the number one cause of death in Korea, accounting for 23.5% of total deaths (Korean National Statistical Office 2001). As the number of cancer patients increases, various remedies are being developed and we gain access to information about the various stages from diagnosis and treatment through symptom control and hospice care for terminal patients (Kim 2000). Cancer reminds people of pain and death, and thus is a taboo that people usually do not want to mention. This common reaction makes it difficult for patients and their families to acquire appropriate treatment.

In Korea, cancer patients and their families have difficulty maintaining good quality in the mental, social, and spiritual aspects of life. Because some medical professionals lack understanding of palliative care for terminal cancer, patients frequently are not properly referred to hospice or a palliative care team for management of severe, disease-related pain and other forms of assistance to promote good quality of life (Cho, 2002).

Previous studies have examined the individual meanings of cancer and hospice care in population subgroups, however, they have not clarified the

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relationship between patient feelings about these subjects. This subjectivity has been overlooked, and comprehension of this relationship is important because it could influence decisions about the development of hospice and palliative care programs in the country's health care delivery system.

The purpose of this study was to identify the subjective structure regarding the meaning of cancer and hospice. This includes the individual's 1) understanding of concepts — terminology and responses on an intellectual level, 2) attribution of significance — understanding of functions and emotional reactions, and 3) how individual feelings and beliefs about one concept influence subjective reactions to the other. Research questions are:

- What is the level of knowledge about cancer?
- How does the individual respond subjectively to cancer?
- What is the level of knowledge about hospice?
- How does the individual respond subjectively to hospice?
- How do individual feelings about cancer influence feelings about hospice, and vice versa?

Theoretical Background

Perceptions of Cancer

Cancer is a disease of tumors, new tissue (neoplasm), characterized by abnormal growth. Tumors result from uncontrolled, progressive multiplication of cells that serves no physiologic function. Tumors are classified as benign or malignant, and malignant tumors are called cancer (Cancer Research Institute of Seoul National University 2001). The etiology of cancers may be either *internal* or *external*. Internal causes may be related to heredity, age, and immunity. Progress in the understanding of human genes and their roles in diseases lead some medical scientists to expect that internal causes can be conquered. The most frequent cancers in Korea occur in the stomach, liver, and lungs. External carcinogenic initiators may include dietary habits, smoking, drinking, air pollution, drugs, radiation, ultra violet rays, and viruses (National Cancer Center 2001).

In *Study on the Perception of Cancer* (2002), Cho reports that a diagnosis of *cancer* is commonly synonymous with *death* to doctors, nurses, and patients. Health care practitioners report great mental stress and hesitation to discuss death with cancer patients. Even so, they realize they also may get cancer someday, and the necessity to tell patients about an incurable illness forces them to confront the thought of their own deaths. Although health care providers have made the commitment to care for cancer patients, nonetheless, they may experience confusion when facing individuals whose illness they perceive so negatively. Some health care practitioners may be reluctant to be present, or to have others present when a patient is dying. Cancer is immediately perceived as an incurable disease from the time of diagnosis. It

evokes patient fears of pain and death, threatens the well-being of their families, reduces physical, social, psychological, economic, and spiritual wellness, and negatively influences their whole lives (Kim 1997). The recent trend emphasizing palliative care, where medical treatment and nursing focus not on curing the disease, but rather on managing symptoms and living with cancer while maintaining a relatively functional and high quality life, requires a profound change in thinking.

Status and Perceptions of Korean Hospice

Hospice care is based on respect for terminal patients and attempts to enhance their quality of life. It is an established medical philosophy and strategic system of care in most advanced countries. In Korea, though, hospice is not uniformly understood or available. A few large hospitals have hospice-specialized wards where professionals care for terminal cancer patients, and some hospitals managed by religious organizations operate hospice-specialized wards for the poor. Hospice care has not become more widely available because appropriate models and concrete performance guidelines are lacking, and because insufficient awareness exists among the general public.

Most Koreans do not know about hospice, and those who do think of it simply as an asylum where dying patients are institutionalized out of public view for religious reasons. Thus most terminal Korean cancer patients are still reluctant to get aid from a hospice even when it is recommended. This makes it difficult to raise funds for hospice operation or mobilize public opinion in support of developing hospice as a more mainstream part of the health care system. Many doctors feel that caring for cancer patients is an unworthy waste of time (Hong 2000). They think hospice care should best be left as a function of other health practitioners or retired doctors.

Enormous human resources are needed to operate a full-scale hospice system. In this era of nuclear families, patient care functions that would formerly have fallen to the extended family require the assistance of volunteers from various fields (Cho 2000). For the hospice development to proceed toward the achievement of positive goals, it is necessary to create a public perception that will encourage patients to use the services and help raise funds to maintain and expand a national hospice care system. Professionals then must find appropriate models and develop concrete guidelines for delivery of services and care so patients will be able to access this medical resource and obtain good quality life services (Cho 2000).

Method

Cancer

The Q Sample: A concourse of one hundred and thirty statements about the meaning of cancer was based on research by Cho (2002) and Kim (2001)

and in-depth interviews with five terminal cancer patients. Thirty three statements were selected and modified for the Q sample.

The Participants: All participants were practitioners or students in health professions, but not all were involved or interested in hospice service. The thirty three participants performing the Q sort were: Nine hospice volunteers who received training for hospice care and took care of hospice patients, seven nurses who received training for hospice care but did not take care of hospice patients, seven professionals who received training for hospice care and took care of hospice patients, three non-professionals, and seven nurses who took care of hospice patients without previously having received training for hospice care. Demographic characteristics and weighted factors of participants are reported in the Appendix.

Hospice

The Q Sample: A concourse of ninety three statements about hospice was based on research by Kim (1996), Lee (1995), and Choi (1991), as well as interviews in depth with two hospice professionals, two non-professionals and six volunteers. Thirty statements were selected and modified for the Q sample.

The Participants: The thirty six participants included the same thirty three subjects who sorted the statements on the meaning of cancer, plus three more volunteers who had hospice training.

Q sorts

All participants were asked to model their feelings by sorting the statements within a predetermined response matrix which ranged from strong agreement to strong disagreement. Participants were requested to supplement the Q sort data with answers to certain free response question, and these responses were considered as useful supplementary material to the emergent Q factors.

Analysis

The completed Q sorts were analyzed using the QUANL PC program, which employs a principal component factor analysis and classification of factors by varimax rotation to demonstrate discrete and coherent factors.

Results

Meaning of Cancer: Factor Analysis and Characteristics

Meaning of cancer: Q sort distribution (n = 33)

| | | | | | | | | | |
|--------------------|----|----|----|----|---|---|---|---|---|
| <i>frequency</i> | 2 | 3 | 4 | 5 | 5 | 5 | 4 | 3 | 2 |
| <i>weight</i> | -4 | -3 | -2 | -1 | 0 | 1 | 2 | 3 | 4 |
| <i>QUANL score</i> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

Four factors explained 61% of the total variance in the cancer Q sorts. Definers' Q sorts for each factor were assigned by the QUANL PC program as those whose |weighted score| (z) was 1.0 or more on the factor of interest. See Appendix for details.

Factor 1: Death Associating

Ten of the thirty three participants loaded on Factor 1; three were definers. Factor 1 loaders thought: Anybody can get cancer (11); and, receiving that diagnosis would cause terrible psychological stress (6). A healthy life style is

Table 1. Meaning of Cancer Factor 1: Death Associating

| No. | Statement | Z |
|-----|--|------|
| 6 | A cancer diagnosis causes great mental stress, even if it is not life-threatening. | 1.6 |
| 20 | If I were a terminal cancer patient, I would want to tell my family and prepare them for my death. | 1.5 |
| 11 | Anyone, even I, can get cancer. | 1.5 |
| 14 | When a cancer diagnosis is reached, the first priority is to notify the patient and family. | 1.5 |
| 10 | It is best to prevent cancer by maintaining a healthy lifestyle. | 1.4 |
| 13 | In terminal cancer, both patient and family should be notified so they can prepare for death. | 1.4 |
| 21 | I think about my own health when I see a cancer patient. | 1.1 |
| 25 | I would want to deal with cancer in my own way, without any hospital treatment. | -1.0 |
| 12 | Cancer therapy must continue for the rest of the patient's life. | -1.0 |
| 32 | Folk remedies are more effective for cancer than are modern medicines. | -1.1 |
| 30 | This disease occurs in naïve people and those who cannot express themselves easily. [‡] | -1.1 |
| 28 | Miracle cures happen, even in the last stage of cancer. | -1.1 |
| 9 | It is not much different from other diseases, because it can be cured by modern medicine. | -1.3 |
| 4 | It is a curse from God and punishment for sin. | -1.8 |
| 31 | I don't want to get near a cancer patient, because I might get it. | -1.8 |

[‡] The reference here is to people who do not have medical knowledge and are unquestioningly trustful and obedient with medical professionals.

the best way to prevent cancer (10), because it is not curable (8) and treatment is not worthwhile (9). There are no miracle cures (28); cancer patients should prepare for death (13, 20). Three loaders on this factor had cancer and received training in the *theory* of hospice, but did not have *experience* in this form of care. For them, cancer meant preparation for death and unbearably painful disease.

Factor 2: Positive-coping

Eleven participants loaded on Factor 2 with six definers. These sorters indicated: They would notify patients and their families about the diagnosis with concrete explanations (13). They thought medical professionals had the responsibility to do so (26). Three typical respondents were current hospice professionals caring for cancer patients. They thought medical professionals should care for cancer patients from initial notification of diagnosis throughout their illness (26). Cancer could be a blessing from God (24).

Table 2. Meaning of Cancer Factor 2: Positive-coping

| No. | Statement | Z |
|-----|--|------|
| 20 | If I were a terminal cancer patient, I would want to tell my family and prepare them for my death. | 1.8 |
| 13 | In terminal cancer, both patient and family should be notified so they can prepare for death. | 1.6 |
| 14 | When a cancer diagnosis is reached, the first priority is to notify the patient and family. | 1.5 |
| 11 | Anyone, even I, can get cancer. | 1.3 |
| 26 | Medical professionals should be the ones to tell the patient and family about a cancer diagnosis. | 1.3 |
| 10 | It is best to prevent cancer by maintaining a healthy lifestyle. | 1.2 |
| 22 | Telling a patient he has terminal cancer destroys hope. | -1.1 |
| 19 | In some cases of terminal cancer, mercy killing is justified. | -1.2 |
| 8 | Cancer cannot be cured completely. | -1.2 |
| 31 | I don't want to get near a cancer patient, because I might get it. | -1.2 |
| 25 | I would want to deal with cancer in my own way, without any hospital treatment. | -1.4 |
| 1 | Cancer is incurable. | -1.4 |
| 4 | It is a curse from God and punishment for sin. | -1.9 |

Factor 3: Pain-fearing

Factor 3 had six loaders and three definers. These individuals said: They did not want to talk about cancer (5); the word “cancer” reminded them of fear and anxiety (16) and caused great mental stress (6). Cancer causes patients to die painfully (33). Three of these respondents expressed their pain when one of their family members died of cancer. They did not even want to imagine cancer (5).

Table 3. Meaning of Cancer Factor 3: Pain-fearing

| No. | Statement | Z |
|-----|--|------|
| 5 | I don't want to think or talk about cancer. | 1.8 |
| 16 | Cancer causes much pain and anxiety. | 1.7 |
| 6 | A cancer diagnosis causes great mental stress, even if it is not life-threatening. | 1.4 |
| 11 | Anyone, even I, can get cancer. | 1.4 |
| 10 | It is best to prevent cancer by maintaining a healthy lifestyle. | 1.3 |
| 33 | Most people think cancer causes painful death. | 1.0 |
| 21 | I think about my own health when I see a cancer patient. | 1.0 |
| 24 | It may be a blessing from God, although it is very painful. | -1.0 |
| 1 | Cancer is incurable. | -1.0 |
| 25 | I would want to deal with cancer in my own way, without any hospital treatment. | -1.0 |
| 32 | Folk remedies are more effective for cancer than are modern medicines. | -1.2 |
| 31 | I don't want to get near a cancer patient, because I might get it. | -1.5 |
| 8 | Cancer cannot be cured completely. | -1.5 |
| 4 | It is the curse of God and punishment because of sin. | -2.1 |

Factor 4: Escaping

The six loaders (one definer) on Factor 4 responded: Anybody can get cancer (11). It is a frightening disease that robs people of everything (23), but patients and their families should be told about the diagnosis so they can prepare for death (13). Factor loaders typically had been told about the diagnosis of a cancer patient in their family. They seemed to hope for a miraculous cure (28), and they did not reject the possibility of mercy killing (19).

Table 4. Meaning of Cancer Factor 4: Escaping

| No. | Statement | Z |
|-----|--|------|
| 10 | It is best to prevent cancer by maintaining a healthy lifestyle. | 1.5 |
| 6 | A cancer diagnosis causes great mental stress, even if it is not life-threatening. | 1.5 |
| 13 | In terminal cancer, both patient and family should be notified so they can prepare for death. | 1.4 |
| 16 | Cancer causes much pain and anxiety. | 1.3 |
| 23 | It is a frightening disease that robs patients of every-thing. | 1.2 |
| 26 | Medical professionals should be the ones to tell the patient and family about a cancer diagnosis. | 1.1 |
| 20 | If I were a terminal cancer patient, I would want to tell my family and prepare them for my death. | 1.0 |
| | | |
| 25 | I would want to deal with cancer in my own way, without any hospital treatment. | -1.0 |
| 8 | Cancer cannot be cured completely. | -1.2 |
| 24 | It may be a blessing from God, although it is very painful. | -1.4 |
| 30 | This disease occurs in naïve people and those who cannot express themselves easily. [†] | -1.7 |
| 31 | I don't want to get near a cancer patient, because I might get it. | -2.0 |
| 4 | It is a curse from God and punishment for sin. | -2.1 |

[†] The reference here is to people who do not have medical knowledge and are unquestioningly trustful and obedient with medical professionals.

Consensus Statements

Among the four factors there were 13 consensus statements on the meaning of cancer (see Table 5). QUANL PC designates consensus as a *range of statement |z| scores* not exceeding 1.0 across all the factors. The highest positive consensus item was “Preventing cancer by maintaining healthy life style is best” (10). The most negative item was “Cancer is a curse and punishment of God because of sin” (4). Other significant consensus statements receiving negative responses were: “I don’t want to get near a cancer patient, because I might get it” (31); “I would want to deal with cancer in my own way, without any hospital treatment” (25); and “Folk remedies are more effective for cancer than are modern medicines” (32).

Meaning of Hospice

Meaning of hospice: Q sort distribution (n = 30)

| | | | | | | | | | |
|--------------------|----|----|----|----|---|---|---|---|---|
| <i>frequency</i> | 2 | 3 | 4 | 5 | 5 | 5 | 4 | 3 | 2 |
| <i>weight</i> | -4 | -3 | -2 | -1 | 0 | 1 | 2 | 3 | 4 |
| <i>QUANL score</i> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

Table 5. Meaning of Cancer: Consensus Items

| No. | Statement | Z | Range |
|-------|---|-------|-------|
| 10 | It is best to prevent cancer by maintaining a healthy lifestyle. | 1.36 | 0.3 |
| 21 | I think about my own health when I see a cancer patient. | 0.94 | 0.3 |
| 26 | Medical professionals should be the ones to tell the patient and family about a cancer diagnosis. | 0.77 | 0.9 |
| 3 | Treatment is so expensive that it causes loss of property. | 0.54 | 0.8 |
| 7 | Medical professionals have difficulty telling patients they have cancer. | 0.39 | 0.5 |
| 18 | Medical professionals find cancer more stressful to treat than other diseases. | 0.20 | 0.8 |
| ----- | | | |
| 17 | Neither patients nor professionals want to mention the word 'cancer.' | -0.10 | 0.7 |
| 2 | The word 'cancer' reminds me of death. | -0.13 | 0.6 |
| 22 | Telling a patient he has terminal cancer destroys hope. | -0.89 | 0.4 |
| 32 | Folk remedies are more effective for cancer than are modern medicines. | -1.01 | 0.4 |
| 25 | I would want to deal with cancer in my own way, without any hospital treatment. | -1.09 | 0.4 |
| 31 | I don't want to get near a cancer patient, because I might get it. | -1.62 | 0.8 |
| 4 | It is a curse from God and punishment for sin. | -1.97 | 0.3 |

Factor Analysis and Characteristics

In the results of the Q sorts on the meaning of hospice, five factors were found that explain 63.4% of total variance. Those Q sorts whose |weighted score| were over 1.0 were designated as definers. See Appendix for details.

Factor A : Experience and Practice

Thirteen of the thirty six respondents loaded on Factor A, with eight definers. All were professional hospice trainers with practical experience in hospice roles. They characterized hospice in functional terms: Hospice care is a special service calling that most people cannot perform (13). Hospice allows patients and their families to prepare psychologically and spiritually for death (1, 9, 6) and provides a measure of comfort in the remainder of lives (1).

Table 6. Meaning of Hospice Factor A: Experience and Practice

| No. | Statement | Z |
|-----|--|------|
| 1 | They help terminal patients and their families prepare for death and make the rest of their lives comfortable. | 1.6 |
| 5 | They enhance the quality of life for terminal patients and their families. | 1.4 |
| 9 | They are very important in helping dying patients make spiritual preparations. | 1.3 |
| 6 | They do their best to ease the physical and mental stresses associated with terminal cancer. | 1.1 |
| | | |
| 20 | Hospice care is only for patients who know they are dying. | -1.1 |
| 15 | A hospice is responsible for funeral arrangements when a patient dies. | -1.5 |
| 28 | I don't know the meaning of 'hospice,' as it is mainly used in Western culture. | -1.7 |
| 8 | Terminal cancer patients know the purpose of a 'hospice' is to help them prepare for death. | -1.7 |
| 30 | Hospice service providers remind me of the imminence of death. | -1.7 |
| 2 | 'Hospice' is a reminder of 'death' or 'dying.' | -1.9 |

Factor B: Guardian Angels

Five participants loaded on Factor B, but none met the criteria as a definer, as established by the QUANL PC program. Nevertheless, the factor maintains an interesting perspective and is reported. These individuals viewed hospice work as “guardian angel service” for patients and their families (1, 9, 12). They thought that spiritual preparation was very important to dying patients (9), but they felt *hospice* was a reminder of death and dying (2). For the most part, these respondents were in Factors 3 (Pain-fearing) and 4 (Escaping) in the Q sort on cancer. They said they did not intend to work in a hospice setting and felt those who did must be sent as guardian angels from God, because hospice work is so difficult.

Factor C: Ambiguous

Factor 3 had eight loaders, five definers, and was characterized by statements indicating: Hospice is professional nursing preparing for death (7). It is important to offer pure palliative care for dying patients avoiding religious viewpoints (10). The most distinguishable difference between this factor and the others was their negative view about statements that hospice would help

Table 7. Meaning of Hospice Factor B: Guardian Angels

| No. | Statement | Z |
|-----|--|------|
| 1 | They help terminal patients and their families prepare for death and make the rest of their lives comfortable. | 2.2 |
| 9 | They are very important in helping dying patients make spiritual preparations. | 1.7 |
| 5 | They enhance the quality of life for terminal patients and their families. | 1.5 |
| 12 | Hospice workers are sent from God. | 1.3 |
| 7 | They have professional nurses specially trained to help terminal patients and their families. | 1.1 |
| 25 | More facilities should be established to provide wider access to hospice care. | 1.1 |
| | | |
| 16 | Hospice includes caring for the family after a patient's death. | -1.0 |
| 28 | I don't know the meaning of 'hospice,' as it is mainly used in Western culture. | -1.0 |
| 20 | Hospice care is only for patients who know they are dying. | -1.1 |
| 23 | Caring for patients in a hospice is a selfless and uplifting experience. | -1.2 |
| 30 | Hospice service providers remind me of the imminence of death. | -1.6 |
| 11 | They should leave spiritual matters to specially trained religious leaders. | -1.7 |
| 15 | A hospice is responsible for funeral arrangements when a patient dies. | -1.9 |

patients to have spiritual preparation (11), it is “guardian angel service” (12), and a blessing from God (19). Two individuals in this factor wanted to avoid cancer because they had fear of it (were on Factor 3 in the Cancer Q sort). Factor 3 loaders knew little about either theory or practice of hospice. The fact that this group included volunteers who had not yet received training contributed to its “Ambiguous” nature.

Factor D: Theorist

Factor D had five loaders and one definer. This group emphasized that hospice service should be performed by those with a strong sense of the value of death (17) and that rigorous hospice training was needed (27). They thought *hospice* was a meaningful word that caused them to take stock of

Table 8. Meaning of Hospice Factor C: Ambiguous

| No. | Statement | Z |
|-----|--|------|
| 1 | They help terminal patients and their families prepare for death and make the rest of their lives comfortable. | 1.8 |
| 27 | Hospice service providers should have rigorous hospice training. | 1.4 |
| 25 | More facilities should be established to provide wider access to hospice care. | 1.4 |
| 7 | They have professional nurses specially trained to help terminal patients and their families. | 1.3 |
| 4 | They emphasize companionship to keep patients from feeling they are alone. | 1.2 |
| 13 | Hospice care is a special service calling that only a few people are able to perform. | -1.1 |
| 12 | Hospice workers are sent from God. | -1.2 |
| 15 | A hospice is responsible for funeral arrangements when a patient dies. | -1.2 |
| 8 | Terminal cancer patients know the purpose of a 'hospice' is to help them prepare for death. | -1.2 |
| 19 | The process of dying is also a blessing from God. | -1.3 |
| 11 | They should leave spiritual matters to specially trained religious leaders. | -1.5 |
| 28 | I don't know the meaning of 'hospice,' as it is mainly used in Western culture. | -1.5 |
| 30 | Hospice service providers remind me of the imminence of death. | -1.6 |

their own lives (18). Four subjects in this factor had obtained systematic training in hospice *theory* through Graduate level courses.

Factor E: Religious

Four respondents loaded on Factor E with one being a definer. Factor E sorters thought hospice service was a blessing from God (14). They had strong religious beliefs about hospice and thought even the last minute of a patient's life to be a blessing from God (19). All subjects in this group were religious Christians and they strongly voiced Christian opinions on hospice.

Table 9. Meaning of Hospice Factor D: Theorist

| No. | Statement | Z |
|-----|---|------|
| 16 | Hospice includes caring for the family after a patient's death. | 1.4 |
| 7 | They have professional nurses specially trained to help terminal patients and their families. | 1.4 |
| 17 | Hospice workers understand the significance of death. | 1.2 |
| 29 | They can nurse not only last phase cancer patients but all people who are dying. | 1.3 |
| 18 | The term 'hospice' causes me to reflect on my own life. | 1.2 |
| 27 | Hospice service providers should have rigorous hospice training. | 1.2 |
| 15 | A hospice is responsible for funeral arrangements when a patient dies. | -1.0 |
| 2 | 'Hospice' is a reminder of 'death' or 'dying.' | -1.1 |
| 20 | Hospice care is only for patients who know they are dying. | -1.2 |
| 28 | I don't know the meaning of 'hospice,' as it is mainly used in Western culture. | -1.6 |
| 11 | They should leave spiritual matters to specially trained religious leaders. | -1.6 |
| 8 | Terminal cancer patients know the purpose of a 'hospice' is to help them prepare for death. | -1.8 |
| 30 | Hospice service providers remind me of the imminence of death. | -2.0 |

Table 10. Meaning of Hospice Factor E: Religious

| No. | Statement | Z |
|-----|--|------|
| 25 | More facilities should be established to provide wider access to hospice care. | 2.1 |
| 27 | Hospice service providers should have rigorous hospice training. | 2.1 |
| 14 | The service of a hospice is a blessing from God. | 1.1 |
| 1 | They help terminal patients and their families prepare for death and make the rest of their lives comfortable. | 1.1 |
| 17 | Hospice workers understand the significance of death. | 1.1 |
| 30 | Hospice service providers remind me of the imminence of death. | -1.0 |
| 10 | Hospice should focus on the physical and emotional needs rather than religion. | -1.1 |
| 3 | A hospice mainly provides relief for symptoms and pain. | -1.4 |
| 28 | I don't know the meaning of 'hospice,' as it is mainly used in Western culture. | -1.8 |
| 15 | A hospice is responsible for funeral arrangements when a patient dies. | -2.0 |

Consensus on the meaning of hospice

Among the five hospice factors there were 9 consensus statements (see Table 11). The highest positive consensus item was “Hospice care should include a close relationship with the terminal patient’s family” (21). The most negative item was “Hospice service providers remind me of the imminence of death” (30). Other significant consensus statements receiving negative responses were: “A hospice is responsible for funeral arrangements when a patient dies” (15); and “I don’t know the meaning of ‘hospice,’ as it is mainly used in Western culture” (28).

Table 11. Meaning of Hospice: Consensus Items

| No. | Statement | Z | Range |
|-----|--|-------|-------|
| 21 | Hospice care should include a close relationship with the terminal patient’s family. | 0.55 | 0.9 |
| 24 | Hospice costs should be covered by Medicare. | 0.35 | 0.9 |
| 26 | We are all mortal and should be prepared for our death through hospice training. | 0.34 | 0.9 |
| 22 | Hospice care should be available to every terminal patient. | 0.18 | 0.8 |
| | | | |
| 23 | Caring for patients in a hospice is a selfless and uplifting experience. | -0.64 | 1.0 |
| 20 | Hospice care is only for patients who know they are dying. | -0.93 | 0.8 |
| 28 | I don’t know the meaning of ‘hospice,’ as it is mainly used in Western culture. | -1.51 | 0.8 |
| 15 | A hospice is responsible for funeral arrangements when a patient dies. | -1.53 | 1.0 |
| 30 | Hospice service providers remind me of the imminence of death. | -1.59 | 1.0 |

Relationship between Cancer and Hospice Viewpoints

Three of the respondents who associated cancer with death (Factor 1) understood hospice care on a theoretical level, though they may not have had practical experience (Factor D). Those who approached cancer in a positive-coping way (Factor 2) tended either to have personal experience with hospice (Factor A) or strong beliefs about hospice based on Christian religious training (Factor E). The six loaders on Factor 3 who approached cancer with intense fear and anxiety as a harbinger of painful death tended to view hospice care as the work of guardian angels who would reassure them and ease their pain (Factor B). They were uncertain about its other aspects, because they had neither practical experience nor formal background in the

theory of hospice. Factor 4 (Escaping) saw cancer as a frightening disease that anyone could get. If a miraculous cure was not possible, they hoped for merciful death. Those individuals having practical experience in hospice roles saw hospice as improving physical comfort and providing an opportunity to prepare psychologically and spiritually for death (Factor 1). The two loaders on Factor C (Ambiguous) without training about hospice thought only of nursing care to help patients die more comfortably, and had a negative view of any religious role.

In this study, the participants who were hospice professionals tended to have positive attitudes about cancer and meeting the needs of cancer patients. Participants who held more positive attitudes about cancer had a greater tendency to be involved with hospice care. Those who approached the disease with fear and anxiety as a certain painful death had mixed feelings about hospice. While they were inclined to work in hospice themselves, they viewed hospice professionals as having special talent to serve as guardian angels. Participants in this study expected the fear of pain would cause many complications for patients and families, and ultimately interfere with acceptance and access to hospice care. Positive thinking about cancer treatment and a strong religious background were success predictors for patients who participate and derive most benefit from hospice care.

Discussion and Conclusions

There have been numerous studies of the significance of cancer and hospice. The purpose of this study was to identify the structure of the underlying subjectivity. Professionals, non-professionals, and volunteers performed two Q sorts yielding information about ways in which they react intellectually and emotionally to *cancer* and *hospice* and how their views of these two concepts are related.

Four distinct subjective factors were found in the responses to the Q sort on the meaning of cancer: 1) Those who associate cancer with death considered that once diagnosed with cancer a patient should prepare for death, because cancer is incurable. 2) Positive-coping individuals indicated that cancer patients should be informed about their diagnosis and needed active treatment to alleviate pain. They also felt that patients and their families should accept the situation and try to provide comfort for the patient and for each other. 3) The pain-fearing factor was comprised of a group of respondents who viewed cancer with such fear and anxiety as a painful way to die that they did not want to talk or even think about it. More than in any other factor, there was the feeling that people with cancer should not be informed of the diagnosis to avoid psychological trauma. 4) An escapist Factor 4 felt that although they might prefer to escape the mental trauma, cancer patients needed to be told about their condition so they could

prepare for a less painful death. They wanted to believe in miracle cures, but indicated that sometimes mercy killing is justified.

Five subjective factors were found in the Q sort on the hospice Q sort:

1) Individuals on Factor A were experienced in the concept and believed hospice could help cancer patients and their families spiritually to accept death. Hospice service was recognized as a special calling that only a few can perform. 2) Factor B looked on hospice as a way to help cancer patients and their families enhance the quality of life remaining. They acknowledged that the work is especially difficult because the word *hospice* reminds many of death and dying, and felt that these service providers were guardian angels. 3) Factor C felt that the emphasis of hospice was nursing care to help prepare terminal patients for death, leaving out any consideration of religion. They seemed somewhat ambiguous, perhaps because they had little or no knowledge about either theoretical or practical aspects of hospice care. 4) Respondents on Factor D were trained in the theoretical aspects of hospice and felt that care providers should have an appreciation of the value of death and receive rigorous training. They saw *hospice* as a cue to induce them to take stock of their own lives. 5) The last group (Factor E) considered hospice more suitable for religion professionals. Most people involved in this group were Christians, and they voiced strong Christian values in their approach to hospice.

The result of this study has shown that individuals who approach cancer positively and are not hindered by overwhelming fear and anxiety seemed to be more able to participate in roles as hospice care providers. They can help people who are suffering from cancer to be prepared for death and to establish better quality for the remainder of their lives. Individuals who are afraid of cancer and try to escape from the painful reality seemed to not know the meaning of hospice or to want to learn. Those fearful individuals would just observe and offer physical assistance to cancer patients and their families.

Health care professionals, non-professionals, and volunteers will need to establish an educational program to encourage understanding of the concepts of cancer and hospice and improve coping skills. The results of this study will be useful in development of hospice policy and a systematic educational program for hospice and cancer patients.

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Appendix I

Demographic characteristics and factor weights of P-sample

A. Meaning of Cancer

| Factor | Factor Weight | Gender | Age | Religion | Occupation |
|---------------|----------------------|---------------|------------|-----------------|--------------------------|
| 1(n=10) | 2.5096 | F | 30 | none | postgraduate student |
| | 1.4348 | F | 32 | none | postgraduate student |
| | 1.1961 | F | 27 | Catholic | postgraduate student |
| | 0.9410 | F | 46 | none | voluntary service course |
| | 0.8984 | F | 48 | Christian | researcher |
| | 0.8765 | F | 48 | Christian | chief nurse |
| | 0.8411 | F | 28 | none | postgraduate student |
| | 0.7233 | F | 50 | Catholic | voluntary service course |
| | 0.6789 | F | 53 | Christian | voluntary service course |
| | 0.5557 | F | 27 | Christian | postgraduate student |
| 2(n=11) | 2.0875 | F | 52 | Christian | nurse director |
| | 1.8986 | F | 47 | Christian | nursing professor |
| | 1.7531 | F | 45 | Christian | voluntary service course |
| | 1.5998 | F | 50 | Christian | nursing professor |
| | 1.5718 | M | 55 | Christian | doctor |
| | 1.2506 | F | 53 | Christian | nursing professor |
| | 0.8066 | F | 29 | Christian | postgraduate student |
| | 0.7916 | F | 48 | Christian | voluntary server |
| | 0.7716 | F | 48 | Christian | voluntary server |
| | 0.7469 | M | 28 | none | postgraduate student |
| | 0.4988 | F | 51 | Christian | voluntary service course |
| 3(n=6) | 1.5792 | F | 47 | Catholic | voluntary server |
| | 1.2238 | M | 47 | Catholic | voluntary server |
| | 1.0099 | F | 47 | none | nurse |
| | 0.9843 | F | 48 | Catholic | voluntary service course |
| | 0.5607 | F | 36 | Buddhist | nursing professor |
| | 0.4943 | F | 65 | Christian | voluntary server |
| 4(n=6) | 1.1876 | F | 33 | none | nursing professor |
| | 0.9178 | M | 28 | none | postgraduate student |
| | 0.8864 | F | 47 | none | chief nurse |
| | 0.8128 | M | 27 | Catholic | postgraduate student |
| | 0.7991 | F | 28 | Buddhist | postgraduate student |
| | 0.6309 | F | 26 | Catholic | postgraduate student |

*Demographic characteristics and factor weights of P-sample**B. Meaning of Hospice*

| Factor | Factor Weight | Gender | Age | Religion | Occupation |
|---------------|----------------------|---------------|------------|-----------------|--------------------------|
| A(n=13) | 1.6108 | F | 48 | Christian | researcher |
| | 1.5132 | F | 51 | Christian | voluntary service course |
| | 1.3959 | F | 33 | none | nursing professor |
| | 1.4447 | F | 65 | Christian | voluntary server |
| | 1.3775 | F | 45 | Christian | voluntary service course |
| | 1.2185 | F | 48 | Christian | voluntary service course |
| | 1.1198 | F | 53 | Christian | nursing professor |
| | 1.1196 | F | 50 | Christian | nursing professor |
| | 0.9310 | F | 52 | Christian | nurse director |
| | 0.8974 | F | 26 | Catholic | postgraduate student |
| | 0.8437 | F | 51 | Christian | voluntary service course |
| | 0.8014 | F | 27 | Christian | postgraduate student |
| | 0.7728 | F | 47 | Christian | nursing professor |
| B(n=5) | 0.9647 | F | 47 | none | chief nurse |
| | 0.9531 | F | 47 | Catholic | voluntary server |
| | 0.9369 | F | 47 | none | nurse |
| | 0.7483 | F | 48 | Christian | voluntary server |
| | 0.5001 | M | 47 | Catholic | voluntary server |
| C(n=8) | 2.1723 | F | 50 | Catholic | voluntary service course |
| | 1.3390 | F | 46 | none | voluntary service course |
| | 1.1202 | M | 28 | none | postgraduate student |
| | 1.0947 | M | 27 | Catholic | postgraduate student |
| | 1.0597 | F | 28 | Buddhist | postgraduate student |
| | 0.8836 | M | 28 | none | postgraduate student |
| | 0.8172 | F | 42 | none | voluntary service course |
| | 0.6002 | F | 48 | Christian | chief nurse |
| D(n=5) | 1.0461 | F | 28 | none | postgraduate student |
| | 0.7157 | F | 27 | Christian | postgraduate student |
| | 0.6623 | F | 30 | none | postgraduate student |
| | 0.6106 | F | 32 | none | postgraduate student |
| | 0.6025 | F | 38 | catholic | voluntary server |
| E(n=4) | 1.6747 | F | 48 | Christian | voluntary server |
| | 0.6880 | F | 53 | Christian | voluntary server |
| | 0.6675 | M | 55 | Christian | doctor |
| | 0.6485 | F | 29 | Christian | postgraduate student |

Appendix II

Factor Scores[†] A. Meaning of Cancer

| No. | Statement | Factor (N) | | | |
|-----|--|------------|--------|-------|-------|
| | | 1 (10) | 2 (11) | 3 (6) | 4 (6) |
| | | Z | | | |
| 1. | Cancer is incurable. | -0.5 | -1.4 | -1.0 | -0.4 |
| 2. | The word 'cancer' reminds me of death. | 0.1 | -0.5 | -0.1 | -0.1 |
| 3. | Treatment is so expensive that it causes loss of property. | 0.9 | 0.6 | 0.6 | 0.1 |
| 4. | It is a curse from God and punishment for sin. | -1.8 | -1.9 | -2.1 | -2.1 |
| 5. | I don't want to think or talk about cancer. | -0.4 | -0.7 | 1.8 | -0.8 |
| 6. | A cancer diagnosis causes great mental stress, even if it is not life-threatening. | 1.6 | 0.5 | 1.4 | 1.5 |
| 7. | Medical professionals have difficulty telling patients they have cancer. | 0.2 | 0.7 | 0.5 | 0.2 |
| 8. | Cancer cannot be cured completely. | -0.1 | -1.2 | -1.5 | -1.2 |
| 9. | It is not much different from other diseases, because it can be cured by modern medicine. | -1.3 | -0.2 | 0.2 | -0.3 |
| 10. | It is best to prevent cancer by maintaining a healthy lifestyle. | 1.4 | 1.2 | 1.3 | 1.5 |
| 11. | Anyone, even I, can get cancer. | 1.5 | 1.3 | 1.4 | 0.3 |
| 12. | Cancer therapy must continue for the rest of the patient's life. | -1.0 | 0.5 | 0.5 | -0.2 |
| 13. | In terminal cancer, both patient and family should be notified so they can prepare for death. | 1.4 | 1.6 | 0.5 | 1.4 |
| 14. | When a cancer diagnosis is reached, the first priority is to notify the patient and family. | 1.5 | 1.5 | 0.3 | 0.8 |
| 15. | Hospital treatment does not cure cancer, it can only relieve symptoms. | 0.2 | -0.7 | -0.9 | -0.4 |
| 16. | Cancer causes much pain and anxiety. | 0.8 | 0.2 | 1.7 | 1.3 |
| 17. | Neither patients nor professionals want to mention the word 'cancer.' | 0.3 | -0.1 | -0.1 | -0.4 |
| 18. | Medical professionals find cancer more stressful to treat than other diseases. | 0.8 | 0.0 | 0.1 | 0.0 |
| 19. | In some cases of terminal cancer, mercy killing is justified. | -0.2 | -1.2 | -0.8 | 0.6 |
| 20. | If I were a terminal cancer patient, I would want to tell my family and prepare them for my death. | 1.5 | 1.8 | 0.0 | 1.0 |

[†] Statements amended for translation clarity.

Factor Scores[†] A. Meaning of Cancer (continued)

| No. | Statement | Factor (N) | | | |
|---------------------|---|------------|--------|-------|-------|
| | | 1 (10) | 2 (11) | 3 (6) | 4 (6) |
| | | Z | | | |
| 21. | I think about my own health when I see a cancer patient. | 1.1 | 0.8 | 1.0 | 0.9 |
| 22. | Telling a patient he has terminal cancer destroys hope. | -0.7 | -1.1 | -0.9 | -0.9 |
| 23. | It is a frightening disease that robs patients of everything. | -0.6 | -0.7 | -0.9 | 1.2 |
| 24. | It may be a blessing from God, although it is very painful. | -0.7 | 0.7 | -1.0 | -1.4 |
| 25. | I would want to deal with cancer in my own way, without any hospital treatment. | -1.0 | -1.4 | -1.0 | -1.0 |
| 26. | Medical professionals should be the ones to tell the patient and family about a cancer diagnosis. | 0.4 | 1.3 | 0.4 | 1.1 |
| 27. | Cancer can be cured, although people may have a preconception that it is always fatal. | -0.3 | 0.7 | 0.0 | -0.1 |
| 28. | Miracle cures happen, even in the last stage of cancer. | -1.1 | 0.5 | -0.2 | 0.6 |
| 29. | Modern medicine can cure some cancers if they are detected in an early or intermediate stage. | -0.5 | 0.5 | 0.9 | 0.8 |
| 30. | This disease occurs in naïve people and those who cannot express themselves easily. [‡] | -1.1 | -0.6 | -0.4 | -1.7 |
| 31. | I don't want to get near a cancer patient, because I might get it. | -1.8 | -1.2 | -1.5 | -2.0 |
| 32. | Folk remedies are more effective for cancer than are modern medicines. | -1.1 | -0.9 | -1.2 | -0.8 |
| 33. | Most people think cancer causes painful death. | 0.7 | -0.7 | 1.0 | 0.3 |
| Eigenvalue | | 15.28 | 1.97 | 1.68 | 1.20 |
| Explained Variance | | 0.46 | 0.06 | 0.05 | 0.04 |
| Cumulative variance | | 0.46 | 0.52 | 0.57 | 0.61 |

[†] Statements amended for translation clarity.

[‡] The reference here is to people who do not have medical knowledge and are unquestioningly trustful and obedient with medical professionals.

Factor Scores[†] B. Meaning of Hospice

| No. | Statement | Factor (N) | | | | |
|----------|--|------------|-------|-------|-------|-------|
| | | A (13) | B (5) | C (8) | D (5) | E (4) |
| Z | | | | | | |
| 1. | They help terminal patients and their families prepare for death and make the rest of their lives comfortable. | 1.6 | 2.2 | 1.8 | 0.2 | 1.1 |
| 2. | 'Hospice' is a reminder of 'death' or 'dying.' | -1.9 | 0.0 | -0.6 | -1.1 | -0.7 |
| 3. | A hospice mainly provides relief for symptoms and pain. | -0.5 | 0.1 | -0.5 | -0.4 | -1.4 |
| 4. | They emphasize companionship to keep patients from feeling they are alone. | 0.4 | -0.1 | 1.2 | 0.0 | -0.7 |
| 5. | They enhance the quality of life for terminal patients and their families. | 1.4 | 1.5 | 0.6 | 0.8 | -0.3 |
| 6. | They do their best to ease the physical and mental stresses associated with terminal cancer. | 1.1 | 0.4 | 0.8 | 0.7 | -0.5 |
| 7. | They have professional nurses specially trained to help terminal patients and their families. | 0.4 | 1.1 | 1.3 | 1.4 | -0.8 |
| 8. | Terminal cancer patients know the purpose of a 'hospice' is to help them prepare for death. | -1.7 | -0.4 | -1.2 | -1.8 | -0.2 |
| 9. | They are very important in helping dying patients make spiritual preparations. | 1.3 | 1.7 | 0.1 | 0.2 | 0.1 |
| 10. | Hospice should focus on the physical and emotional needs rather than religion. | -0.7 | -0.6 | 0.9 | 0.8 | -1.1 |
| 11. | They should leave spiritual matters to specially trained religious leaders. | -0.8 | -1.7 | -1.5 | -1.6 | 0.6 |
| 12. | Hospice workers are sent from God. | -0.3 | 1.3 | -1.2 | 0.1 | 0.4 |
| 13. | Hospice care is a special service calling that only a few people are able to perform. | 0.4 | -0.5 | -1.1 | -0.9 | -0.4 |
| 14. | The service of a hospice is a blessing from God. | 0.2 | 0.7 | -0.5 | 0.0 | 1.1 |
| 15. | A hospice is responsible for funeral arrangements when a patient dies. | -1.5 | -1.9 | -1.2 | -1.0 | -2.0 |
| 16. | Hospice includes caring for the family after a patient's death. | 0.8 | -1.0 | 0.1 | 1.4 | -0.6 |
| 17. | Hospice workers understand the significance of death. | 0.6 | -0.0 | 0.4 | 1.3 | 1.1 |
| 18. | The term 'hospice' causes me to reflect on my own life. | -0.1 | 0.6 | 0.0 | 1.2 | 0.8 |

[†] Statements amended for translation clarity.

Factor Scores[†] B. Meaning of Hospice (continued)

| No. | Statement | Factor (N) | | | | |
|---------------------|--|------------|-------|-------|-------|-------|
| | | A (13) | B (5) | C (8) | D (5) | E (4) |
| <i>Z</i> | | | | | | |
| 19. | The process of dying is also a blessing from God. | 0.3 | -0.5 | -1.3 | 0.3 | 0.6 |
| 20. | Hospice care is only for patients who know they are dying. | -1.1 | -1.1 | -0.4 | -1.2 | -0.8 |
| 21. | Hospice care should include a close relationship with the terminal patient's family. | 0.9 | 0.0 | 0.7 | 0.3 | 0.8 |
| 22. | Hospice care should be available to every terminal patient. | 0.3 | -0.3 | 0.2 | 0.2 | 0.5 |
| 23. | Caring for patients in a hospice is a selfless and uplifting experience. | -0.4 | -1.2 | -0.6 | -0.8 | -0.2 |
| 24. | Hospice costs should be covered by Medicare. | 0.0 | 0.0 | 0.9 | 0.3 | 0.6 |
| 25. | More facilities should be established to provide wider access to hospice care. | 0.5 | 1.1 | 1.4 | 0.6 | 2.1 |
| 26. | We are all mortal and should be prepared for our death through hospice training. | 0.8 | 0.1 | 0.5 | -0.1 | 0.4 |
| 27. | Hospice service providers should have rigorous hospice training. | 0.8 | 0.4 | 1.4 | 1.2 | 2.1 |
| 28. | I don't know the meaning of 'hospice,' as it is mainly used in Western culture. | -1.7 | -1.0 | -1.5 | -1.6 | -1.8 |
| 29. | They can nurse not only last phase cancer patients but all people who are dying. | 0.9 | 0.4 | 0.8 | 1.3 | 0.2 |
| 30. | Hospice service providers remind me of the imminence of death. | -1.7 | -1.6 | -1.6 | -2.0 | -1.0 |
| Eigenvalue | | 16.83 | 2.39 | 2.04 | 1.24 | 1.03 |
| Explained Variance | | 0.47 | 0.07 | 0.06 | 0.03 | 0.03 |
| Cumulative variance | | 0.47 | 0.53 | 0.59 | 0.62 | 0.65 |

[†] Statements amended for translation clarity.