Original Article

The Influence of Awareness of Terminal Condition on Spiritual Well-Being in Terminal Cancer Patients

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Abstract
We developed a Spirituality Transcendence Measure (STM) and studied whether awareness of terminal illness affects spiritual well-being in terminal cancer patients. Three sources of spiritual transcendence—the situational, the moral and biographical, and the religious aspect—were assessed in the STM. Cronbach's α of the STM was 0.95, and the principle axis factor analysis extracted only one factor. Thirty-seven terminal cancer patients with male predominance (59.5%) were studied. Awareness of terminal illness was associated with a higher total STM score ($Z = -2.21$, $P = 0.027$), along with the individual scores for each of the three transcendences ($Z = -2.39$, $P = 0.017$; $Z = -2.71$, $P = 0.007$; and $Z = -1.96$, $P = 0.050$). Acceptance of death was associated with a higher situational score ($Z = 2.01$, $P = 0.046$) and a higher religious score ($Z = -2.27$, $P = 0.023$). Announcement of testament was associated with a higher situational score ($Z = -2.30$, $P = 0.021$). We conclude that awareness of terminal illness is associated with spiritual well-being. Telling the complete truth is necessary even when dealing with terminal conditions. J Pain Symptom Manage 2006;31:449–456.

Key Words
Truth disclosure, spirituality, life quality, terminal care

Introduction

Truth disclosure to cancer patients has been advocated and practiced in Western countries for many years. However, most cancer patients in non-Western countries are unaware of their cancer diagnosis and prognosis.[1] In Asia, ethical principles of nonmaleficence and beneficence are usually placed above the principle of respect for patients' autonomy.[2,3] In such societies, family members have a legitimate and superior claim to decision-making authority and responsibility to protect patients even though they are fully competent.[4] It is often

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believed that knowing the diagnosis of cancer might cause patients to lose hope and hasten their death.[5,6] As a result, family members and physicians often conceal the cancer diagnosis and prognosis from the patient even until the terminal stage.[7] With the hospice movement and death education in Taiwan since the 1990s, physicians have become more willing to communicate the cancer diagnosis to their patients. However, truth disclosure is incomplete and prognosis of a terminally ill condition is usually not disclosed to retain hope for the patients.[8]

From the overall perspective of Asian cancer patients, there is a strong preference to be informed by their physicians about their condition.[8,9] Moreover, withholding the cancer diagnosis may not prevent patients from knowing the truth. Many patients can guess their diagnosis from the treatment process, unresolved symptoms, change in body figure, and the change of body function. Our concerns about telling the truth to cancer patients have not been based on reliable evidence. To the contrary, research has indicated that awareness of cancer diagnosis is not related to psychiatric disorders,[10] and understanding the diagnosis indirectly can lead to more psychiatric disturbance.[11] However, we also lack reliable evidence to support truth-telling, especially in the disclosure of terminal illness to cancer patients.

For terminal patients who face death, spiritual and religious comfort may be even more important than physical and psychological health. Spirituality is defined as a universal connection to the transcendent and the search for meaning in life that may or may not be linked to a divine figure.[12] Religiosity is conceptualized as an organized set of beliefs, rituals, and practices engaged in with the goal of connecting to a higher power, such as God.[13] However, the above definitions of spirituality and religiosity are too simplified and vague. Based on the above definitions, health care workers have difficulties in understanding and identifying with patients' spiritual needs and to effectively intervene. Kellehear,[14] in his theoretical model of spiritual needs in palliative care, provided a framework in understanding spirituality and religiosity. In Kellehear's model, spiritual meaning is built on three sources of transcendence: the situational, the moral and biographical, including also the religious aspect. Situational needs arise from personal and social experiences in a context of illness. People need to find meaning, purpose, and hope in light of the experience of illness, looking for experiences of mutuality, connectedness, and situational transcendence. Moral and biographical needs include finding peace and reconciliation, resolution of past and present dilemmas, reunion with others, moral and social analysis, and looking for forgiveness and closure. Religious needs include religious reconciliation, divine forgiveness and support, religious rites, religious visitation and literature, discussion about God, eternal life and hope.[14] In Chinese culture, Confucian philosophy emphasizes balance and harmony. The unity of nature and human beings is the final goal and the highest level of spiritual existence. Unity requires harmony throughout the entire system. To reach this goal, one must start from the pursuit of harmony inside oneself, then with the surrounding environment, and finally toward nature and God. Taking cultural compatibility into consideration, we found that Kellehear's transcendence model is the only available model that can be best fit into the harmonic philosophy of Chinese culture.

To understand the relationship between terminal illness awareness and spirituality, it is important to conduct sound research and delineate practical implications. In research, we need to explore the relationship between terminal illness awareness and a patient's spiritual well-being. Knowledge of the above relationship will encourage further study into the deeper understanding of spirituality. Furthermore, a multidimensional approach to spirituality may assist us in elucidating which aspects of spiritual needs are more related to a patient's perception of illness. For clinical practice, we need evidence to prove that the practice of ethical principles of nonmaleficence and beneficence is of benefit to patients. Hopefully, understanding the spiritual consequences of illness disclosure may encourage physicians to communicate disease prognosis to the patients and overcome the family barrier of truth-telling. To our knowledge, to date there has been no other research reporting the relationship between patients' awareness of terminal illness and spiritual well-being.

Spirituality and religiosity are defined and assessed in different ways in the literature. There is a paucity of quality instruments, which should be specially designed to measure spiritual well-being and have a sound theoretical base. The Spiritual Well-being Scale was devised by Paloutzian and Ellison in 1982,[15] but the validity and reliability of this scale is questionable.[16] The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) scale is a part of the large FACIT measurement for the assessment of quality of life in cancer therapy.[17] It comprises two subscales measuring a sense of meaning and peace and the role of faith in illness. However, the theoretical base of the FACIT-Sp has not been reported, and some of the questionnaire items mix the concept of faith and spirituality together. In this study, we developed a structured questionnaire to assess the spiritual well-being of terminal cancer patients based on Kellehear's three dimensional model of spiritual needs, evaluating whether awareness of terminal illness, acceptance of death, issuance of a testament and treatment expectations affect cancer patients' spiritual well-being.

Methods

Participants

The subjects in this study were terminal cancer patients who were consecutively admitted to three hospices in Taipei, Taiwan from January, 2004 to July, 2004. In the palliative care units, patients were taken care of by multidisciplinary hospice care teams, including chaplains. We informed the patients and family members of the aim of our study and asked for their oral consent to participate. Patients who died of their cancers during the study period were included in the final analysis. Information collected included demographic data on patients and one main family caregiver who was responsible for taking care of the patient at home and during hospitalization, including administration of patients' awareness of terminal illness, acceptance of death, treatment expectations, and announcement of testament. Patients' spiritual well-being was rated by the major family caregiver using the Spirituality Transcendence Measure (STM) after the death of the patient.

Instrument

Based on Kellehear's model of spiritual needs, a STM (Appendix) was developed to measure spiritual well-being in this study. Items in the STM were derived from the collection of past experiences of our research team and pertinent research in the literature. The entire questionnaire has 22 items (6 for situational transcendence, 10 for moral transcendence, and 6 for religious transcendence). Responses to the STM are based upon a 5-point Likert scale ranging from 5 (highly satisfied) to 1 (highly unsatisfied). Higher values reflected a higher level of spiritual well-being.

Patients' awareness of terminal illness, acceptance of death, treatment expectation for hospice admission, and announcement of testament were determined after detailed and tactful interviews with patients and families during the admission process. Awareness of terminal illness was rated "aware" if patients understood that they had an incurable cancer, death was unavoidable, and their lifespan was very limited; "unaware" was assessed if patients knew nothing about the disease or if the patients only knew the cancer diagnosis, but were unaware of the terminal condition. Acceptance of death was rated "fully accepted" if patients understood that death is the destiny of life's journey and the patients felt that they could die without regret; "partially accepted" if patients understood that they were going to die, but still hoped to live longer; and "denied" if a patient could not accept death. Treatment expectations for hospice admission were rated as "curative," "symptom control," "long-term care," or "a place to die." In Taiwanese society, people usually give a nuncupative statement rather than a written testament. In this study, a testament was rated "completed" if a patient had made a written will or a detailed oral directive to his or her family; "partial" if an incomplete oral directive had been given; and "not at all" if no directive had been given by the patient.

Data Analysis

We used SPSS/PC version 11.0 in statistical analysis. Descriptive statistics were computed to describe the demographic characteristics and variables, including patient's awareness of illness, acceptance of death, issuance of

a testament, treatment expectations, and spiritual well-being. We applied internal reliability tests and factor analysis to assess the psychometric properties of the STM. Since our data did not follow a normal distribution, nonparametric analysis was applied to examine the data. We used a Mann-Whitney test for the comparison of variables with two independent categories and a Kruskal-Wallis test for the comparison of three or more categories. Relationships between age and spiritual well-being were examined by Spearman's correlation.

Results

Demographics and Demographic Effects on Spiritual Well-Being

Thirty-seven consecutive eligible patients who were admitted and died in the hospices of three hospitals during the study period were included in this study. All main family caregivers of the deceased patients completed the STM after the death of their relatives. Most of our patients were elderly men with secondary and college education levels, along with Buddhist religious affiliation. Family caregivers were mostly middle-aged wives with higher education levels and with similar religious affiliations as their deceased relatives (Table 1). Spiritual well-being rated by the STM did not differ by age, gender, educational level, or religious affiliation of the patients and their family caregivers.

Table 1
Demographics of Deceased Cancer Patients and Their Family Caregivers

	Patients	Caregivers
Gender		
Men	22 (59.5)	13 (35.1)
Women	15 (40.5)	24 (64.9)
Age (years)		
<40	3 (8.1)	6 (16.2)
40∼64	17 (45.9)	25 (67.6)
≥65	17 (45.9)	6 (16.2)
Education		
Illiteracy	4 (10.8)	4 (10.8)
Primary	10 (27.0)	4 (10.8)
Secondary	10 (27.0)	13 (35.1)
College	13 (35.1)	16 (43.2)
Religion		
None	2 (5.4)	6 (16.2)
Buddhists	28 (75.7)	26 (70.3)
Others	7 (18.9)	5 (13.5)
Relationship between patient and caregiver		
Spouse	15 (40.5)	
Child	11 (29.8)	
Sibling	3 (8.1)	
Others	8 (21.6)	

Psychometric Properties of the STM

Item mean scores of the STM ranged from 4.08 to 4.73; standard deviations ranged from 0.45 to 0.90; and skewness ranged from −0.34 to −1.59. The Cronbach's coefficient α of this data set was 0.95. Item-total correlations ranged from 0.51 to 0.83. Sampling adequacy for the STM revealed a KMO value of 0.63 and a significant Bartlett's test of sphericity ($\chi^2_{231} = 679.57$; $P = 0.0001$), which indicated factor analysis is ordinarily appropriate. Principle axis factoring with oblimin rotation was applied. Scree plot and parallel analysis suggested only one principle factor. Due to the original three transcendence structures, three oblique factors were extracted (Table 2). In the three-factor solution, items from the situational transcendence and the moral transcendence scattered into the first and the last factors. Five of the six items of the religious transcendence grouped into the second factor. Inter-factor correlations ranged from 0.36 to 0.60.

Relationship Among Awareness of Terminal Illness, Acceptance of Death, Treatment Expectations, and Announcement of Testament

All patients in this study acknowledged their cancer diagnoses. However, 12 patients (32.4%) were unaware that they were terminally ill. For acceptance of death, 19 patients (51.4%) fully accepted, 13 patients (35.1%) partially accepted, and five patients (13.5%) denied. Twenty-four patients (64.9%) expected to receive palliative care and symptom control during admission, eight patients (21.6%) expected curative therapy, one patient prepared to die in the hospice, and four patients gave no answers. Nineteen patients (51.4%) issued a written testament or a complete nuncupative will, seven patients (18.9%) delivered an incomplete nuncupative will, and 11 patients (29.7%) had not made their will. Patients aware of their terminal condition had a higher proportion of making a dying will ($\chi^2 = 9.40$, $df = 2$, $P = 0.009$) and had greater acceptance of death ($\chi^2 = 7.78$, $df = 2$, $P = 0.02$) than those who were unaware of their terminal condition.

Table 2
Factor Analysis of the Spirituality Transcendence Measure

Items	Factor 1	Factor 2	Factor 3
Self-satisfaction in life review (M)	**0.934**	−0.110	−0.139
Respect from family and friends (S)	**0.808**		
Fulfill last wishes (S)	**0.727**		
Ready to face death (M)	**0.682**	0.179	
Solve unresolved issues (M)	**0.666**		0.116
Compensate for all regrets (M)	**0.646**		0.233
Open another direction of life (M)	**0.625**	0.186	
Issue advance directives (M)	**0.587**		
Understand death is nature (S)	**0.556**		0.295
Has control to do what one wants to do. (S)	**0.543**		0.179
Believe in an afterlife (R)	**0.462**	0.374	
Peaceful in dying process (M)	**0.381**	0.298	0.214
Reward from religious practice (R)		**0.946**	
Peaceful from religious practice (R)		**0.878**	
Receive help from clergy (R)		**0.635**	0.111
Believe in an afterlife (R)	0.303	**0.565**	0.214
Religious rites (R)	0.207	**0.353**	0.211
Access to spiritual support (M)		−0.119	**0.944**
Resolve confusion and anxiety about dying (S)			**0.817**
Put down spiritual burdens (M)	−0.114	0.237	**0.791**
Support from family (S)	0.201		**0.776**
Say goodbye before death (M)	0.326		**0.369**
Inter-factor correlations			
Factor 2	0.489		
Factor 3	0.602	0.355	

Principle axis factoring with oblimin rotation and Kaiser normalization.
S = situational dimension; M = moral and biographical dimension; and R = religious dimension.

Factors Related to Patients' Spiritual Well-Being

Patients who were aware of their terminal illness had a significantly higher score in the three dimensions of the STM and the STM as a whole than those who were unaware of their terminal illness. Patients who had full acceptance of death had a significantly higher score in the situational and religious dimensions of the STM than those who partially accepted or could not accept their death. Patients who announced a complete testament had a significantly higher score only in the situation dimension of the STM than in those who had announced an incomplete nuncupative testament or no testament at all (Table 3).

Discussion

Our study may be the first report that empirically demonstrates the relationship between awareness of terminal illness and spiritual well-being at the end of life. We used Kellehear's model of spiritual needs as the conceptual framework of spiritually and developed a structured scale to evaluate the three sources of transcendence: the situational, the moral and biographical, along with religious aspects. Kellehear's model has the advantages of clear separation of religiosity from other spiritual dimensions, a sound theoretical base, and a multidimensional approach to the complex conceptualization of spirituality. From clinical experience, terminally ill patients have many different kinds of needs at different points of their illness course and have individual differences in spiritual needs. Kellehear's model of needs can provide a framework for palliative care professionals to understand the complex nature of spiritual needs and how to meet those needs.

Psychometric analysis of the STM revealed promising results in this study. Internal consistency reliability (Cronbach's coefficient) was satisfactory. Factor analysis using principle axis factoring revealed only one major factor. When we limited the number of factors to three to reproduce the conceptual structure of Kellehear's model, we found that only religious transcendence can be separated from the other two factors. This demonstrated that religiosity is a distinct dimension from the other two spiritual transcendences. From the item mean scores of the STM, we found that

Table 3
Spiritual Well-Being and Awareness of Terminal Illness

	Awareness of terminal illness		Mann-Whitney *U* test	
Spiritual well-being	Aware Mean (SD)	Unaware Mean (SD)	*Z*	*P* (two tailed)
Whole scale	95.54 (9.91)	88.56 (6.82)	−2.21	0.027
Situational	32.44 (3.39)	30.00 (3.32)	−2.39	0.017
Moral	41.25 (4.36)	37.33 (3.39)	−2.71	0.007
Religious	26.28 (3.36)	23.18 (3.38)	−1.96	0.050
	Acceptance of death			
	Accepted Mean (SD)	Partial/unaccepted Mean (SD)		
Whole scale	96.39 (8.37)	90.33 (10.21)	−1.88	0.062
Situational	46.33 (4.39)	42.94 (5.54)	−2.01	0.046
Moral	23.42 (2.01)	22.65 (2.42)	−0.77	0.471
Religious	26.68 (2.47)	23.53 (4.85)	−2.27	0.023
	Testament			
	Given Mean (SD)	Partial/not given Mean (SD)		
Whole scale	95.89 (9.33)	90.93 (9.52)	−1.69	0.093
Situational	46.16 (5.01)	42.93 (4.98)	−2.30	0.021
Moral	23.67 (1.94)	22.44 (2.36)	−1.83	0.085
Religious	25.74 (3.83)	24.59 (4.33)	−0.85	0.415

the surrogate responses were skewed to one end. This homogenous set of response to the STM items may affect the results in factor analysis so that principle axis factoring produced only one major factor.

Why awareness of terminal illness affects spiritual well-being is a difficult question to answer. Faced with imminent death, people may redirect and reevaluate their lives and turn their attention from bodily needs to spiritual needs. One previous study revealed that terminally ill adults have increased spirituality over nonterminally ill or healthy adults.[15] Hope is an essential need for human beings. Understanding one's life expectancy may allow people to refocus their hope on "being" rather than "doing," to emphasize relationships with others and with God and to explore the belief regarding life after death. When patients begin to think about and bring up their spiritual issues, they may have the chance to explore and finally resolve them. Thus, awareness of terminal illness may become a turning point, which people set forth to deal with their spiritual needs and reach a better level of spiritual well-being. On the other hand, for patients whose lives have no pleasure, death becomes a release from suffering. Awareness of terminal illness becomes a comfort because people know that death is close at hand.

Although the three spiritual transcendences were highly correlated with each other, different patient characteristics affected spiritual transcendences differently. Patients who accepted death had better spiritual well-being in situational and religious dimensions but not in a moral dimension. The explanation of the relationship between acceptance of death and religiosity is more apparent. People who face death may seek a relationship with God or some divine figure and may give serious consideration their existence after death. However, the lack of a relationship between acceptance of death and moral transcendence needs further study. We also found that patients who have announced a complete testament had a higher score only in the situational dimension of the STM. In Taiwan, people usually give their wills to their family members orally. The nuncupative will commonly includes funeral and property arrangements, and wishes regarding assets given to family members. The interpersonal and social context of the testament may account for the association with the situational transcendence of spiritual well-being.

Awareness of terminal illness, acceptance of death, and announcement of testament were highly associated with each other and were associated with spirituality. The relationship

among these variables and the relationship between each variable and spiritual well-being under the control of other variables requires further studies with larger samples.

Major limitations of our study are as follows: First, we used surrogate responses instead of direct interviews with terminal cancer patients to obtain information about spiritual well-being. The questionnaire interview with terminal cancer patients is very difficult, especially for patients in Taiwan who receive hospice care at a very terminal stage. A previous study reported that for more than 80% of patients, the length of hospice admission was within 30 days and by the end, more than 60% of the patients died.[7] At this stage, patients are usually too weak or have intractable symptoms that may prevent them from doing a questionnaire interview. Moreover, patients' family members may be reluctant to see their sick relatives disturbed. As a result, we used each family's main caregiver as a surrogate for the cancer patients. In our study, about 80% of family caregivers were the spouse and children. Similar results were observed in a previous study in Taiwan.[18] With the exception of the patients themselves, family caregivers can best understand patients' perspectives. However, surrogates may have difficulty in representing the patients for those things that cannot be directly observed, such as patients' attitudes or values.

Second, patients included in this study were not a representative sample of terminal cancer patients. It is possible that patients who had good spiritual well-being and were satisfied with the hospice care were more likely to be included in this study. Moreover, this study had a small sample size and homogeneity of responses to the STM. These deficiencies may affect the psychometric testing of the STM, especially in factor analysis. Further studies involving larger sample sizes and a heterogeneous group of patients are needed.

Third, possible confounding factors existed in the relationship between truth-telling and spiritual well-being. Truth-telling may be easier for patients who were more likely to accept death and be prepared for the bad news. Patients with the above characteristics are also more likely to perceive spiritual well-being. These confounding factors should be elucidated in future studies. With all the limitations and possible biases, the results in this study should be interpreted with caution.

Nevertheless, our findings have pointed out some important clinical implications and directions for future studies. Pertinent to our beliefs about truth-telling, health care professionals who take care of terminal cancer patients should be educated and informed about the benefits of complete truth disclosure. Patients not only need to know the diagnosis, but also need to know when to prepare to go. Knowing that religious belief is an important part of spiritual well-being and the powerful effects of spiritual well-being on end-of-life despair,[19,20] the role of a hospital chaplain in the hospice care team should be emphasized, especially for patients at terminal stages.

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Appendix
Spirituality Transcendence Measure

Situational
- Resolve the confusion and anxiety about dying
- Support from family
- Fulfill last wishes with the assistance of family or professional caregivers
- Have control to do what one wants to do
- Respect from family and friends
- Understand death is a part of natural life

Moral and biographical
- Access to spiritual support
- Solve unresolved issues
- Put down spiritual burdens
- Open another direction of life
- Able to issue advance directives
- Self-satisfaction in life review
- Compensate or confess for all regrets
- Peaceful in the dying process
- Say goodbye before death
- Ready to face death

Religious
- Believe in an afterlife
- Receive help from clergy
- Believe in an afterlife reducing anxiety toward death
- Religious rites
- Reward from religious practice
- Peace from religious practice