**The Role of Spirituality in
Quality of Life at the End of Life**

By

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A Master's Paper submitted to the faculty of
The University of North Carolina at Chapel Hill
In partial fulfillment of the requirements for
The degree of Master in Public Health in
The Public Health Leadership Program.

Chapel Hill

2003

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Abstract

Background:

Quality of life issues have received increased attention in the public health and patient care realms as patient-centered quality indices have gained recognition. With increasingly complex and invasive measures available for care of the seriously ill patient, end-of-life quality of life issues are currently being investigated to help optimize care of the whole person near the end of life. Furthermore, it has been shown that patients generally place greater importance upon spiritual factors in relation to their quality of life than do physicians.

The QUAL-E is a recently developed quality-of-life scale developed to particularly address issues present in the lives of seriously ill patients. Like several scales developed before it, the QUAL-E has incorporated questions that provide information into the patient's spiritual well-being. Analysis of these questions will yield information on how symptoms effects a patient's sense of spiritual peace and on whether there are associations between demographic information and a patient's inclination to place greater information on spiritual factors in peace self-assessment.

Methods:

This project looked at data from the first validation phase of the QUAL-E in which 200 patients with advanced serious illness were asked the original 54 QUAL-E questions. The questions that pertain to the spiritual health and the importance placed upon spiritual peace by the patient were analyzed against reported symptom severity and demographic information. Correlation analysis was conducted among individual symptom responses and symptom summary scores compared to spiritual peace questions in the entire dataset and in symptom subsets. Nonparametric analysis was also conducted to show associations between the presence or degree of particular symptoms and spiritual peace.

Results:

Analysis of the dataset from questionnaires filled out by 200 patients with advanced serious illness revealed no consistent correlations between the presence or severity of symptoms and self-reported sense of peace as indicated by six representative questions. Nonparametric analysis revealed inconsistent associations between certain questions and symptom degree. Analysis of demographic information and reported importance of peace in the quality of life revealed living alone as a factor associated with an increased sense of peace.

Discussion:

This research failed to show associations between self-reported symptom presence or severity and self-reported level of spiritual peace. Further research is necessary to better characterize the factors that may influence a patient's sense of peace and the importance placed upon spiritual factors.

End-of-Life Quality of Life Background:

Advances in the medical treatment of advanced serious illness have concomitantly raised issues concerning the quality of life for the patient at the end of life. Improvements in medical care have led to greater ranges of therapeutic options against advanced disease symptoms. Many advanced disease courses can thereby be prolonged, but patients are expected to die from such diseases eventually. It is under these conditions that optimal end-of-life care concentrates on the quality of life of the patient and family.[1,2] The focus of medical efforts shifts from directly combating the disease in hopes of full recovery towards patient and symptom management in the context of the end-of-life experience. The end-of-life experience has been shown to be subjective and to exhibit great interpersonal variation.[3] Various attempts to quantitatively capture the quality of life construct have been made with mixed results.

Quality of life indices have attempted to integrate responses regarding patient physical symptoms, emotional states, support systems, and overall well-being. Early National Hospice Organization measures incorporated information on pain control, maintenance of daily activities, satisfaction of care, and anxiety levels, using different existing scales to measure each variable.[4] The Spitzer Index comprises assessments of activity, physical independence, well-being, support, and mood. The Spitzer Index and the Uniscale Index were used with the Karnofsky Performance Index for function assessment to assess terminal quality

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of life in a study that collected only caregiver data.[5] It has been shown, however, that third-party assessment of end-of-life quality of life shows lower quality levels than patient self-reports.[6] The McGill Quality of Life index consists of seventeen questions, some novel and some based on the pre-existing Missoula-Vitas Index. These scales were developed specifically for assessment of end-of-life quality of life. The McGill index accentuates the existential domain of quality of life and shows diminished attention to the physical signs domain compared to other measures.[7]

In response to concurrent concerns about poor communication between patient and health care providers, the SUPPORT trials (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) investigated physician perceptions and actual patient therapy preferences. Phase one was a prospective observational study that did show deviations in physician perceptions of patient preferences and actual patient preferences. Phase two was a randomized controlled trial, and nurses were assigned to the intervention group to explicitly assess patient wishes and serve as a liaison to the attending physician.[8] The results did not show a significant benefit from the more extensive physician-patient collaboration, with nearly equal percentages of patients in both groups reporting excellent care. The study did further document that many patients with terminal illnesses receive unwanted care that prolongs their disease states and their suffering. Thus, additional research was warranted to further assess what factors are most important in determining quality of life at the end of life and optimally to develop an instrument to measure such factors.

Development of the QUAL-E Scale:

The deficiency of empirically defensible factors for defining a good death made necessary research to determine the most importance features of optimum end-of-life quality of life. In efforts to improve upon the measure of end-of-life quality of life, a study was begun to utilize responses from patients with advanced serious illness, recently bereaved family members, and health care providers to better identify these characteristics of a good death.[9] The study used focus groups and in-depth interviews to initially assess the common factors deemed important by these populations at the end of life. More than 70 attributes were described that were then consolidated into six domains: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. Spiritual matters were categorized under the completion domain in conjunction with conflict resolution and spending time with loved ones.

Using these focus groups and interviews, a list of 44 attributes were compiled into a survey. The survey consisted of the attributes, and respondents were asked to gauge the importance of each quality according to 5-point Likert scale ranging from strongly disagree to strongly agree. The survey was sent to 2000 individuals drawn equally from pools of terminally ill patients, bereaved family members, physicians, and other care providers. The responses indicated that there were some areas of strong agreement between the respondent groups and other areas of significant dissimilarity. Physicians, expectedly, focused most on the physical symptom management aspects of end-of-life quality of life.

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Patients expressed concern for a wider spectrum of physical, psychological, social, and spiritual factors. Of note, several items that were found to be important among more than 70% of patients and were found significantly less important among physicians included several religious and spiritual factors. These items included a feeling of life completion, coming to peace with God, and the importance of praying. Physicians also less frequently agreed with the importance of meeting with religious representatives compared to both patients and family members.

These two studies were utilized to develop a new assessment tool to measure end-of-life quality of life, the QUAL-E. The six domains of experiences identified from these previous studies were represented in the QUAL-E. These six domains, again, are: pain and symptom management, communication about treatment, preparation for death, completion, contributing to others, and being known as a whole person. To assess symptom affects and management, the QUAL-E asked the patient to identify up to three symptoms he or she experiences, in no particular order. The patient was then asked additional questions about each symptom.

The questionnaire was pretested iteratively with 25 patients to assess readability and interpretability. Participants offered feedback, and revisions were made as necessary.

Along with the 54 item QUAL-E questionnaire, study subjects supplied demographic information that included age, gender, ethnicity, marital status, living situation, education, and illness type.

Responses were assessed with regards to similarity among questions with common themes. Questions within a domain that sought information on one certain theme but had different item phrasings were compared. If the response distributions were sufficiently similar, then some questions would not be used for analysis. There were several questions in the original QUAL-E that sought religious and spiritual importance information by asking about feelings of peace in different realms. Sufficient agreement among these responses led to only one of these questions being used in factor analysis.[10] Spirituality was incorporated into the completion domain that also included items on meaning in life and the ability to interact and feel useful. The completion domain was interpreted as representing various ways by which the patient could transcend his or her illness. Specifically, these six completion questions inquired into the following patient capacities: able to help others, making positive difference for others, ability to say important things to friends and family, sense of meaning in life, ability to share important things with family, and being at peace with oneself.

Spirituality and Medicine:

Given the importance placed upon spirituality by a large percentage of the general population, it is expected that spiritual peace would factor into end-of-life quality of life assessment. In spite of the past connections between medicine and religion, modern scientific medical practice has found no consistent method or utility for assessing a patient's spiritual health. The argument over whether to engage a patient in a discussion about religious and spiritual issues continues in the medical field, with no consensus yet reached as to the optimal approach.

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Some argue that religious belief issues are essentially counter to the nature of medicine and, thus, should not be approached by the physician.[11] Others assert that general inquiries into how and if a patient utilizes faith in coping with their illness should be encouraged.[12] Increased interest in integrating religious awareness into medicine is evidenced by the offering of courses on religion, spirituality, and health in at least thirty US medical schools.[13]

There is good reason, according to recent survey data, for the medical profession to pay attention to patient spiritual issues. In a 1996 US poll of 1000 adults, 79% of the respondents believed that spiritual faith could help patients recover from disease, and 63% believed that physicians should inquire as to the spiritual beliefs of their patients.[14] In a 1994 study, 48% of hospital inpatients expressed a desire for their physicians to pray with them.[15] Furthermore, disparities have been shown to exist between patient spiritual beliefs and physician spiritual beliefs. Whereas 95% of US patients report a belief in God, only 64% of US physicians say they believe in God.[16] While the medical profession is rightly cautious in straying from its evidence-based tenets, many are now advocating that patients receive appropriate attention to their spiritual needs in conjunction with their other medical services.[17] Such spiritual attention need not come directly from a physician or other health care provider, but acknowledging such a need in certain populations would help providers make appropriate referrals.

The argument for approaching the subject of spirituality is more compelling in times of serious illness, when many patients give more attention to

their spiritual state and potentially draw strength from their spiritual and religious beliefs.[18] A recent survey asked patients whether spiritual or religious beliefs would impact their medical decisions if they became gravely ill and whether they would like their physician to inquire about their spiritual or religious beliefs.[19] The study showed that two thirds of the subjects welcomed the physician inquiry into their spiritual or religious beliefs. Patients who agreed that spiritual or religious beliefs would impact their medical decisions were twice as likely to welcome such a physician inquiry. Nearly half of those patients who denied having spiritual or religious beliefs that would effect their medical decisions nonetheless wanted to be asked by their physician about the beliefs. Recommendations have been made about how a physician can best reply to such religious or spiritual concerns made by patients at the end of life.[20]

Given the importance of patient spiritual assessment in advanced illness as indicated above, it is not surprising that QUAL-E analysis has shown significant response variation among questions pertaining to spirituality.[10] This project will look at relationships between patient symptom levels and the QUAL-E completion factors that seek to quantitatively capture a patient's spiritual well-being. This work will attempt to determine whether self-reported degree of spiritual fulfillment impacts the patient's self-reported symptom assessment. Negative associations would suggest a benefit from greater spiritual fulfillment on the quality-of-life symptom components. Relationships between both being at peace and self-reported importance of being at peace and symptom and demographic information will also be explored. Such research may shed light on

potential benefits from addressing elements of spiritual well-being in the patient with advanced serious illness.

Methods:

This project uses data collected during the cross-sectional study that sought to establish the psychometric properties of the QUAL-E questionnaire.[10]

The subjects comprised patients with one of four terminal health conditions: stage IV cancer, congestive heart failure with an ejection fraction of 20% or less, chronic obstructive pulmonary disease with forced expiratory volume in 1 second of 1.0 liter or less, or dialysis-dependent end-stage renal disease. Patients were identified by reviewing rosters for the oncology, heart failure, pulmonary, and dialysis clinics at the Duke University and Durham VA Medical Centers. Patients were randomly assigned recruitment numbers, and as many patients as possible were seen each clinic day. Patients were given the Short Portable Mental Health Status Questionnaire during the visit and were excluded with scores less than 8 out of 10. Patients were recruited until the desired 200 patients were enrolled.

Analysis

Patients reported up to three symptoms and proceeded to answer four questions per symptom regarding frequency, severity, interference with life activities, and associated worry. Rating questions were all on 1-5 Likert scales. Patients were not specifically instructed to rank symptoms in ascending or descending order. For analysis purposes, some means of consolidating symptoms was necessary. For this reason, several well-represented symptom categories

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were developed to encompass the majority of symptoms. Pain, shortness of breath, fatigue, gastrointestinal problems, and anxiety were the most frequently reported symptoms. More than a dozen other symptoms, including dizziness, numbness, and insomnia, were reported fewer than twenty times each among the 200 subjects and were not individually analyzed.

Some patients reported more symptoms than other patients. Developing a composite symptom score for the whole dataset would be difficult without affording considerable weight to the presence of any additional symptom, regardless of overall severity or frequency. A general composite symptom score would have its advantages in capturing overall patient self-reported symptom discomfort. Composite scores for each symptom and composite scores across symptom questions (frequency, severity, interference, and worry) were compiled. Correlation values were computed for each of these composite scores against each of the completion factor questions and the question concerning importance of peace in quality of life.

Separate data subsets for the most heavily represented symptoms were compiled: pain, shortness of breath, fatigue, gastrointestinal problems, and anxiety. The subject numbers in each subset ranged from 29 (anxiety) to 105 (pain). Correlation analysis was then conducted between the composite scores for the subset's symptom and the completion factors and the importance of peace in quality of life question. Fourteen of the 105 subjects reporting pain had pain as more than one of their reported symptoms. For example, one patient may report post-surgical leg pain as symptom one and chest pain as symptom two. Analysis

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was performed on the entire subset of 105 subjects reporting pain, which would bias towards those with multiple pain symptoms, as well on a subset of 91 subjects reporting pain as only one of their symptoms.

Analysis was conducted on the entire dataset to determine whether any associations exist between the presence of particular symptoms and responses to the completion factor questions. To this end, Mann-Whitney tests were performed grouped by the presence or absence of each of the five most commonly reported symptoms.

Data subsets representing each of the five most commonly reported symptoms were then analyzed by Mann-Whitney tests grouped by the intensity of the particular symptom. The symptom severity and frequency sum was calculated within each subset, with the scores ranging from two to ten. This method would increase the chances of finding a significant relationship if any exists. A summation score of seven or greater would indicate that the patient reported a more than moderate severity or frequency of the symptom. A score of six or lower indicates that at most both severity and frequency are moderate, and a slightly higher severity would be paired with lower frequency. Thus, this method of division would best separate the patients into the desired two groups. Subjects with symptom sums below seven were labeled with a zero, and those with sums of seven or above were labeled with a one. This method divided the subsets into approximate halves that could then be tested with the Mann-Whitney method. The fatigue subset was most evenly divided into those with sums below eight and

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those with sums of eight or above, thus Mann-Whitney tests were performed on this subset with the cutoff at seven and then with the cutoff at eight.

While not included in the final QUAL-E questionnaire based upon previously published analysis, an item in the original 54-question tool inquired into the impact of being at peace on the overall quality of life.[10] Precisely, this question asks, "How much does your level of being at peace affect your quality of life?" Using Mann-Whitney tests and ANOVA as appropriate, demographic items were analyzed to determine whether such information could assist providers in anticipating patients who might place greater importance on spiritual factors. These demographic factors included gender, whether or not they live alone, race, education, marital status, and primary diagnosis. The entire dataset was also divided by age over or below 60 years and analyzed by the Mann-Whitney test. Similar analysis was conducted to show associations between these demographic factors and the self-reported overall quality of life.

All analysis was conducted using S-PLUS statistical software (Statistical Sciences, Inc., Seattle, Washington).

Results:

The first set of analyses was conducted on the full data set to determine whether any significant correlations between any of the six completion factors and symptom scores exist. A range of symptom scores from the four associated symptom questions were included in the correlation table so as to decrease the chances of overlooking possible correlations. Individual symptom questions, individual symptom sums, symptom experience sums, symptom severity sums,

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symptom enjoyment sums, symptom worry sums, and a composite sum across all responses were included for correlation analysis. No positive or negative correlation coefficients were found. The greatest correlation coefficients were seen between feeling at peace and each of the symptom score factors, but these range from only -0.12 and -0.22.

Correlation analysis was also performed on the symptom subsets for pain, shortness of breath, fatigue, gastrointestinal distress, and anxiety. Two individual symptom scores were created, one including the symptom question about worry and the other excluding the question. As symptom worry related more to potential for future symptom-related discomfort than to current discomfort, correlating against both cases would decrease the chance of overlooking a potential relationship. No correlations were found above 0.4. Correlation coefficients between the completion factors and the symptom scores were somewhat higher in the fatigue subset, but the greatest coefficient was nonetheless only -0.38.

Since no correlations were found within the entire dataset or within individual symptom subsets, further formal multifactorial regression efforts were not conducted. Analyses were conducted in efforts to control for some of the demographic information for the full dataset and for each subset, but no significant correlations were apparent.

Furthermore, nonparametric analysis was conducted to determine whether relationships exist between groups reporting a certain symptom versus those not reporting the symptom and between groups within a symptom subset who

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reported high discomfort versus those reporting lower discomfort. Such bivariate nonparametric analysis would, given the lack of results from direct correlations described above, increase the chance of seeing any correlation between higher completion factor responses and lower symptom related discomfort.

Using the entire dataset and grouping by symptom, none of the Mann-Whitney tests provided evidence that a population reporting a particular symptom had a significantly different median of completion factor question responses compared to a population without that symptom. The Mann-Whitney tests between each symptom and importance of peace in quality of life revealed one significant negative correlation between pain and the importance of peace ($p=0.03$), indicating that the median importance attributed to being at peace was greater in a population not reporting pain as a symptom.

Mann-Whitney tests within symptom subsets grouped by symptom severity and frequency scores turned up several significant findings. Within the pain subset, the population reporting less pain reported more success in the completion factor pertaining to saying important things to loved ones ($p=0.02$). Within the fatigue subset, the population reporting more fatigue reported greater success in making a difference in the lives of others ($p=0.047$). In the anxiety subset, the population reporting more anxiety displayed a higher median for feeling at peace ($p=0.047$).

Mann-Whitney and ANOVA tests were used to determine whether certain demographic information were associated with subjects feeling at peace and with reported importance of feeling at peace within the context of quality of life. The

population of subjects living alone had a higher median value for being at peace compared to those who did not live alone (p=0.03). No associations were found between being at peace and age, race, education, marital status, age and primary diagnosis. When comparing the same demographic information against reported importance of feeling at peace, only marital status revealed a significant relationship (p=0.02).

Discussion:

As medical advances continue to prolong the final stages of life through more efficacious treatment of terminal illnesses, it will become increasingly important to understand the complexities of end-of-life quality of life. Developing a method to adequately measure quality of life in terminally ill patients is an important step towards determining how to improve quality of life. In efforts to attract attention to this issue and to encourage scientific study into end-of-life quality of life, the American Medical Association and the Institute of Medicine have proposed objectives in improving end-of-life care.[21,22] Previous research has already recognized the importance of spiritual factors in the assessment of quality of life at the end of life.[18-20] This research has attempted to elucidate relationships between patient-reported symptom magnitude and spirituality levels. Furthermore, relationships between patient-reported importance placed upon spirituality factors and symptom and demographic information were investigated.

There are several possible explanations for the lack of significant associations between spirituality-related questions, also known as the completion

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factors from the QUAL-E questionnaire, and symptom severity measures. A single set of questions inquiring into overall symptom-related discomfort from all symptoms would have allowed for easier analysis. While sums of most symptom factor combinations were included in correlation analysis, a uniform symptom score was not achievable. Furthermore, the completion factor response distributions were skewed to the left, with each of the six questions having medians of four or five. The vast majority of the subjects reported high levels of peace. It is possible that the Likert scale failed to fully capture subject variation. The difference between five and four may be interpreted by subjects as dramatically dissimilar to the difference between four and three.

Lack of subject variation and potential weaknesses in the Likert scale to properly delineate subjects were conceivably addressed by the nonparametric analyses. Still, there were no consistent results to indicate that increased symptom severity impacted upon the level of a patient's spiritual peace. Even the significant results varied heavily between subject subsets. While subjects with low pain symptom scores revealed significantly increased success in saying important thing to loved ones, such associations within the entire dataset and within other subsets did not approach significance. Some of the results were in fact counterintuitive. Why would patients reporting increased fatigue also report greater ability to make a positive difference in others' lives? How can one explain why patients reporting higher levels of anxiety also describe significantly heightened senses of being at peace?

As previously mentioned, spiritual factors have been established as important by both patients and care providers. It would potentially be helpful if there were some recognizable features of a patient that characterize him or her into a group more likely to respond favorably to addressing the QUAL-E completion factors. There were no indications from this analysis that age, race, education level, or primary diagnosis played any role in a patient's level of peace or in whether a patient placed importance in being at peace. Whether a patient lived alone or not was positively associated with increased peace levels, perhaps calling into question the role of caregivers at home in contributing to a patient's level of spiritual peace. Perhaps this is a result of a heightened conscious importance attributed by patients who live alone to their spiritual health. Further investigation into whether religious denomination and frequency of religious service attendance influence these peace and importance of peace factors is necessary to help address these questions. Recent research conducted in a population with advanced cancer found that most of the relationship between spiritual well-being and quality of life was attributable to the meaning and peace portion as opposed to the faith portion.[23] Such analysis will help inform clinicians about where to concentrate efforts to improve this aspect of patient quality of life. Continued research addressing the issues raised above is needed to appropriately incorporate spiritual and peace factors into the scientific study of end-of-life quality of life. Such research will assist the health care system in improving the overall quality of care provided to people with advanced serious illnesses.

REFERENCES

1. American Geriatrics Society. The care of dying patients: A position statement for the American Geriatrics Society. J Am Geriatr Soc, 1995; 43:577-578.

2. Field MJ, Cassell C. Approach Death: Improving Care at the End of Life, Institute of Medicine. Washington, DC; National Academy Press, 1997.

3. Cohen S, Mount B. Quality-of-life assessment in terminal illness: Defining and measuring subjective well-being in the dying. J Palliat Care, 1992; 8:40-45.

4. Kane RL, Wales J, Bernstein L, Kaplan S. A Randomized Controlled Trial of Hospice Care. The Lancet. April 1984.

5. Morris JN et al. Last Days: A Study of the Quality of Life of Terminally Ill Cancer Patients. J Chron Dis; 39(1), 1986.

6. Magaziner J, et al. Patient-Proxy Response Comparability on Measures of Patient Health and Functional Status. J Clin Epi, 1988.

7. Cohen SR, Mount BM, Strobel MG, Bue F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. Palliat Med, 9, 1995.

8. Connors AF et al. A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). JAMA, 247(20), 1995.

9. Steinhauser KE, et al. In Search of a Good Death: Observations of Patients, Families, and Providers. Ann Inter Med, 2000; 132(10), 825-832.

10. Steinhauser KE et al. Initial Assessment of a New Instrument to Measure Quality of Life at the End of Life. J Palliat Med, 2002;5(6).

11. Sloan R, Bagiella E, VandeCeek L, et al. Should physicians prescribe religious activities? N Engl J Med, 2000;342:1913-1916.

12. Matthew DA, McCullough ME, Larson DB, Koenig HG, Swyers JP, Milano MG. Religious commitment and health status. Arch Fam Med, 1998;7:118-124.

13. Levin JS, Larson DN, Puchalski CM. Religion and spirituality in medicine: research and education. JAMA, 1997;278:792-793.

14. McNichol T. The new faith in medicine. USA Today. April 7, 1996:4.

15. King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith healing and prayer. J Fam Pract, 1994;39:349-352.

16. Gallup G. Religion in America. Princeton, NJ: Princeton Religious Research Center; 1990.

17. Astrow AB, Puchalski CM, Sulmasy DP. Religion, Spirituality, and Health Care: Social, Ethical, and Practical Considerations. Am J Med, 2001;110.

18. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA, 2000;284:2476-2482.

19. Ehman JW, et al. Do Patients Want Physicians to Inquire About Their Spiritual or Religious Beliefs if They Become Gravely Ill? Arch Int Med, 1999; 159.
20. Lo B, et al. Discussing Religious and Spiritual Issues at the End of Life: A Practical Guide for Physicians. JAMA, 2002;287.
21. Council on Scientific Affairs, American Medical Association. Good care of the dying patient. JAMA. 1996;275, 474-478.
22. Field M, Cassel C. Approaching Death. Washington, DC: Institute of Medicine; 1997.
23. Fisch M, et al. Assessment of Quality of Life in Outpatients with Advanced Cancer. J Clin Onc. 2003;21(14), 2754-2759.