

Confirmation of the “disability paradox” among hospice patients: Preservation of quality of life despite physical ailments and psychosocial concerns

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ABSTRACT

Objective: The purpose of this study was to describe quality of life (QOL) and psychosocial and spiritual issues among patients receiving hospice care.

Methods: A questionnaire addressing QOL, spirituality, optimism, loss, fears about the terminal process and death anxiety was administered to 66 adults receiving care from 14 hospices. The physical components of QOL (physical symptoms and physical well-being) were rated lower than the psychosocial and spiritual aspects (support, existential well-being, psychological symptoms).

Results: Respondents had a strong spiritual connection and a strong sense of hope. Although these individuals did not express anxiety or fear about death, there were concerns about the dying process itself. Also, although most felt at ease with their current situation, respondents were concerned about how their illness was affecting their family. Financial and legal issues did not concern most of these individuals.

Significance of results: There were few significant associations between patient characteristics and the QOL or other psychosocial or spiritual issues addressed. Among this older terminally ill population receiving hospice care, whose functional status was fair and for whom physical symptoms were troublesome, QOL persisted and a positive outlook prevailed.

KEYWORDS: Quality of life, Hospice, Palliative care, Spirituality, Psychological stress

INTRODUCTION

For patients and families who are confronting the end of life, psychosocial and spiritual issues may be

more important than disease-specific concerns. Patients and families want relationships with health care providers that affirm this more encompassing view (Kutner et al., 1999; Steinhauser et al., 2000*b*). Hospice care, which developed as a holistic approach to treatment of the dying, has been championed as a system for delivering competent, compassionate, person-centered end-of-life care. Optimizing quality of life for patients and their caregivers and

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relieving suffering are the primary goals of hospice care (Greer & Mor, 1986; Greer et al., 1986; Reese & Brown, 1997; Bretscher et al., 1999; Carr et al., 2001; Kaasa, 2001). The critically important clinical challenges in providing excellent hospice care include preventing and controlling severe physical symptoms, responding to psychological or emotional needs, and fostering spiritual well-being. Inattention to fundamental psychosocial or spiritual needs contributes to patient and caregiver distress (Kutner et al., 1999; Guo et al., 2001).

It is appropriate to evaluate the success of hospice and palliative care via patients' subjective assessment of physical symptoms, psychological distress, and quality of life (Thorson & Powell, 1992; Skevington et al., 2001; Cohen & Leis, 2002). Quality of life is a multidimensional, dynamic, and subjective concept that is difficult to define and measure (Donnelley, 2000). In the hospice and palliative care setting, quality of life is best conceptualized as "subjective well-being," defined as individuals' perceptions of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns (Cohen & Mount, 2000; Donnelley, 2000; Skevington et al., 2001). Quality of life consists of physical, emotional, social, cognitive, and spiritual components and appears to be a function of the gap between an individuals' hopes and expectations and their actual experience (Bretscher et al., 1999; Donnelley, 2000; Emanuel et al., 2001).

The provision of spiritual care is widely believed to be important at the end of life, particularly in the hospice setting (Millison & Dudley, 1992; Hermann, 2001). Terminally ill patients have indicated a need for coming to peace with God and praying, and cancer survivors describe spiritual coping strategies as useful (Steinhauser et al., 2000a; Thomson, 2000). How an individual is faring spiritually appears to affect that person's physical, psychological, and interpersonal states, all of which contribute to overall quality of life, or sense of well-being (Hermann, 2001; Sulmasy, 2001). Although clinical opinion supports the notion that spirituality is important in the individual's ability to cope with advanced disease, few data are available regarding the role of spirituality and its influence on quality of life or subjective well-being, particularly in the hospice setting (Donnelley, 2000; Thomson, 2000; Hermann, 2001).

Despite general consensus that quality of life, in its broad definition as subjective well-being, is and should be a primary outcome measure in the hospice and palliative care setting, few studies have described the experience of dying from the patient's point of view (Bretscher et al., 1999; Lo et al., 2002).

Indeed, despite the evaluation and care provided by interdisciplinary teams in hospice and palliative care settings, few data describe the frequency or severity of psychosocial or spiritual issues or their relationship to care (Reese & Brown, 1997; Tierney et al., 1998; Emanuel et al., 2001; Skevington et al., 2001; Lo et al., 2002).

Given the lack of data regarding hospice patients' subjective experience of quality of life and its components, we sought to describe and evaluate quality of life and psychosocial and spiritual issues among patients receiving hospice care. The specific aims of the study were to describe the prevalence and types of psychosocial and spiritual issues experienced by hospice patients and to explore relationships between quality of life, psychosocial and spiritual issues, and patient characteristics such as diagnosis, functional status, and duration and location of hospice care.

METHODS

Study Design

Ours was a cross-sectional study using an interviewer-administered questionnaire.

Study Setting

The study was set in the Population-based Palliative Care Research Network (PoPCRN), a research network of organizations that provide hospice/palliative care, based at the University of Colorado Health Sciences Center in the Division of General Internal Medicine (Kutner et al., 2001). At the time of this study, PoPCRN consisted of 41 hospices from three U.S. states and one Canadian province. Study participation is on a study-by-study basis; 14 hospices participated in this study. Patients cared for by these participating hospice organizations received care in their homes (59%), nursing homes (26%), and freestanding facilities (10%) in both rural and urban locales. Average daily census ranged from 1 to over 200 patients; 81% of patients were age 60 or older, 53% were female, and 77% were non-Hispanic white. Fifty-two percent of patients cared for by these organizations had a cancer diagnosis. Each participating hospice/palliative care organization identified one primary contact person, used standardized data collection procedures, and allowed collected data to be analyzed and distributed in ways consistent with confidentiality requirements. This study was approved by the Colorado Multiple Institutional Review Board (COMIRB).

Study Subjects

Study participants were English-speaking adults (age ≥ 18 years) who received care from the participating hospices during the study period (January 1–September 30, 2000) and who consented and were able to participate. All participants provided informed consent in compliance with COMIRB requirements. The study instrument included the Short Portable Mental Status Questionnaire (SPMSQ), an evaluation of cognitive ability (Pfeiffer, 1975). If a potential participant did not pass the cognitive screen (≥ 5 errors), he or she was excluded from study participation.

Data Collection

A designated hospice staff member from each participating site selected study patients, obtained informed consent, conducted the interviews, and collected data. Each hospice was provided with a study notebook containing detailed instructions and five copies of the study instrument. Site coordinators completed and returned the study instruments in preaddressed stamped envelopes, at which time they were sent an additional five study instruments. Site coordinators enrolled patients throughout the study period. PoPCRN researchers assisted participating hospices in the Denver and Colorado Springs areas with enrolling and interviewing patients whenever possible.

Measurement

A template for instrument domains was developed from the literature and the investigators' experience (Kutner et al., 1999; Bryant et al., 2001). This template was refined to produce the final study instrument through several steps: (1) focus groups with hospice staff ($n = 4$ focus groups) to clarify the domains; (2) one-on-one interviews with hospice patients ($n = 8$) to validate the domains; (3) finalization of the instrument domains based on analysis of focus group and interview data; and (4) item construction, using previously validated instruments whenever possible.

The focus groups and individual patient interviews, which were conducted at four Colorado hospices, identified 10 key psychological, social, and spiritual domains, similar to those identified in other studies of the palliative care population (Cohen & Leis, 2002): abstractions, spiritual/religious, social position/role, self and intimate others, negative emotions, tasks of dying, positive emotions, external issues, loss, and terminal process. Study instrument items that addressed these domains

were selected from the following preexisting scales: the McGill Quality of Life Questionnaire (MQOL; Cohen et al., 1997), the Spiritual Involvement and Beliefs Scale–Revised (SIBS-R; Hatch et al., 1998), the Herth Hope Index (Herth, 1992), the Revised Death Anxiety Scale (Thorson & Powell, 1992), and CRISYS (Shalowitz et al., 1998). In addition, investigator-initiated questions were added to address the remaining key issues identified in the focus groups and interviews: (1) wondering “why me?”; (2) loss of appearance, privacy, health, confidence, dreams, hope, loved ones, usual role in family, and usual role outside family; and (3) communication. The study instrument also included basic demographic questions about the patient (gender, age, race/ethnicity, marital status, referral source, date of admission, diagnoses, and treatment setting) and a measure of functional status (Karnofsky Performance Scale; Mor et al., 1984).

The instrument was pilot tested to evaluate ease of use, respondent burden, and content validity and was revised significantly. Scales were modified by eliminating duplicate questions and questions outside the identified key domains. As a result of pilot testing and subsequent revisions, the study instrument was shortened to 91 items. The MQOL was the only preexisting scale that was left intact in its original form. Response categories for all other questions were simplified to “agree,” “neutral,” and “disagree” to accommodate difficulty expressed by this frail population in completing study instruments with multiple response options. The final study instrument took, on average, 30 min to administer.

Analysis

Descriptive statistics were generated for each variable in the study. Frequency tables were constructed for each ordinal and nominal variable. The MQOL, the only scale that was used in its original form, was scored according to MQOL validation studies (Cohen et al., 1997). All other items were selected from previously validated instruments or written by the investigators, thus precluding use of the parent scales' original scoring algorithms. Patient characteristics, including age, gender, marital status, duration and location of hospice care, diagnosis, and functional status were tested for relationships with the MQOL and the individual questionnaire items using analysis of variance, *t* tests, or chi-square tests as appropriate.

RESULTS

Sixty-six patients from 14 hospices participated in this study. As Table 1 shows, study participants had

Table 1. Participant characteristics
(*n* = 66; 14 hospices)

| Characteristic | <i>N</i> (%) |
|--|----------------|
| Gender, female | 37 (56) |
| Race, non-Hispanic white | 59 (89) |
| Currently married | 22 (33) |
| Participant location | |
| Home | 26 (39) |
| Hospice facility | 30 (46) |
| Nursing home | 9 (14) |
| Diagnoses* | |
| Cancer | 35 (53) |
| Pulmonary disease | 19 (29) |
| Cardiac disease | 16 (24) |
| Neurologic disease | 4 (6) |
| Global geriatric decline | 3 (5) |
| | Median (range) |
| Age, years | 76 (28–99) |
| Karnofsky score | 50 (17–90) |
| Short Portable Mental Status Questionnaire adjusted score | 2 (0–4) |
| Education, years | 12 (1–18) |
| Time between hospice enrollment and interview, days | 49 (2–368) |

*Total for diagnoses >100% as individuals could have up to four diagnoses listed.

been receiving hospice care for more than 1 month prior to the study interview (median duration of hospice care at time of interview = 49 days, mean =

91 days) and had fairly well-preserved functional status given that they were sampled from a hospice population (median Karnofsky score = 50). Participants had, on average, 12 (range 1–90) close social contacts monthly. Twenty one percent (*n* = 13) indicated that they were currently suffering and, despite being enrolled in hospice, 20% (*n* = 12) thought that their illness was going to get better. Seventy-three percent (*n* = 48) were very satisfied with the hospice care they were receiving.

Quality of Life

Respondents rated the physical components of quality of life (physical symptoms and physical well-being) lower than the psychosocial and spiritual aspects (support, existential well-being, psychological symptoms) on the McGill Quality of Life (MQOL) questionnaire (response range 0 = bad to 10 = good; Figure 1). They rated their overall quality of life as “average” (mean Single Item Score = 6.4; mean MQOL Total Score = 7.1) and Support as “good” (mean Support subscale score = 8.6), but single symptom troublesomeness as “bad” (mean Single symptom score = 6.7) (Cohen & Mount, 2000). There were no significant associations between age, marital status, gender or duration of hospice care, and any of the MQOL scores. Worse functional status (Karnofsky score < 50) was associated with worse existential well-being (6.9 vs. 7.9 for Karnofsky score ≥ 50, *p* = .017), whereas a cancer diagnosis was associated with greater existential well-being

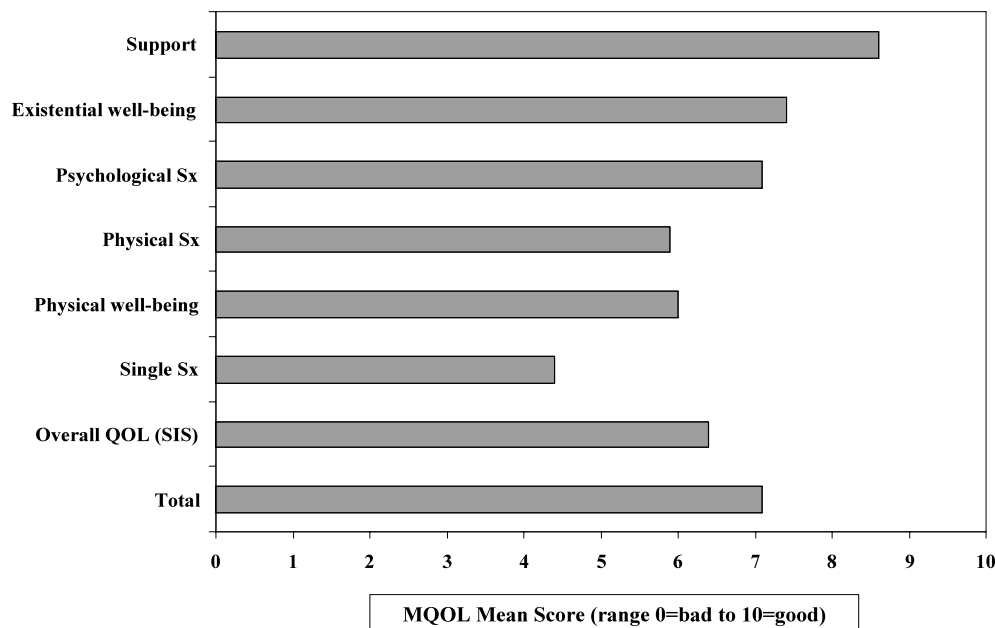


Fig. 1. McGill quality of life mean scores.

(7.8 vs. 6.9 for other diagnoses, $p = .047$). Being cared for at home and having a cancer diagnosis were each associated with a greater sense of support (9.2 vs. 8.2 for other care locations, $p = .005$; 9.0 vs. 8.1 for other diagnoses, $p = .042$).

Spiritual Issues

Respondents had strong spiritual connections, scoring on average 5 on a 1–7 scale (1 = least; 7 = most) in response to the question, “How spiritual a person do you consider yourself?” Eighty-five percent ($n = 52$) indicated that they had a personal relationship with a power greater than themselves; 82% ($n = 50$) agreed that spiritual health contributes to physical health; 79% ($n = 49$) indicated that they had a faith that gave them comfort; 77% ($n = 47$) thought that a spiritual force influences the events in their life; 75% ($n = 46$) depended on a higher power; and only 16% ($n = 10$) rarely felt connected to something greater than themselves.

Hope

Respondents also expressed a strong sense of hope. Ninety percent ($n = 56$) believed that life has value and worth; 87% ($n = 54$) believed that each day has potential; 82% ($n = 51$) had a positive outlook on life, and 58% ($n = 36$) had specific short- or long-range goals.

Processes of Dying and Death

Respondents did not express significant anxiety or fear about death itself, perhaps because a high percentage of respondents seemed to believe in life after death: 72% ($n = 44$) indicated that they are looking forward to a new life after they died and only 3% ($n = 2$) were worried about what happens to them after they die. More than one-fifth of participants did, however, have concerns about the dying process. Despite being enrolled in hospice, 33% ($n = 20$) were afraid of a long, slow dying; 33% ($n = 20$) worried about being helpless; 28% ($n = 17$) feared dying a painful death; 25% ($n = 15$) were frightened by the pain involved in dying; and 20% ($n = 12$) were scared about the future.

Social Issues

Respondents were not particularly bothered or concerned about social stressors, except how burdensome their illness was on their family. While 63% ($n = 39$) felt at ease with their current situation, 68% ($n = 42$) were concerned about how their illness was affecting their family. Perhaps in an effort

to decrease this potential burden, 67% ($n = 41$) planned to leave careful instructions about how things should be done after they are gone. Although most respondents (76%, $n = 47$) were bothered by their loss of health, only a minority were bothered by loss of their usual role in the family (27%, $n = 17$) or outside the family (25%, $n = 15$). Financial and legal issues did not, for the most part, concern these individuals (27%, $n = 17$, and 18%, $n = 11$, expressed concern, respectively).

There were few significant relationships between patient characteristics and responses to the psychosocial or spiritual items. Persons with end-stage heart disease were less likely than those with other diagnoses to worry about being helpless or to be bothered by the loss of their usual role in the family (7% vs. 43%, $p = .011$, and 7% vs. 35%, $p = .046$, respectively). Older respondents (age >79 years) were less likely than younger participants to be concerned about how their illness was affecting their family (age >79 years: 46% agree; 70–79 years: 83% agree; <70 years, 79% agree; $p = .016$).

DISCUSSION

Among this older, terminally ill population receiving hospice care, functional status was fair, physical symptoms were troublesome, and concerns were expressed about the effect of the illness on the individual and the family and about the dying process. Despite this, overall quality of life was preserved and a positive outlook prevailed. The MQOL scores reported by this study population correspond to “good” or “average” days according to previous research describing how home palliative care patients perceived the clinical significance of changes in MQOL scores (Cohen & Mount, 2000). These findings are consistent with previous studies that have found that quality of life is preserved despite deteriorating physical condition, a finding dubbed the “disability paradox” (Bretscher et al., 1999; Donnelly, 2000; Carr et al., 2001; Lo et al., 2002). The participants in our study had relatively preserved quality of life, strong spiritual connections, and had, on average, been receiving hospice care for more than 1 month at the time of the study. Nonetheless, study participants had a number of significant psychosocial concerns, particularly fearing the dying process and being bothered by losses and the effect of the illness on their families. Thus, it is possible that addressing these other significant concerns could have further improved these patients’ quality of life, assuming that such issues are amenable to intervention.

That these patients had relatively preserved quality of life may reflect benefits from hospice care

prior to the study interview. If one assumes that quality of life is determined by the extent to which hopes and ambitions are matched by actual experience, the perceived discrepancy between expectations and actual experience is the critical feature (Carr & Higginson, 2001; Carr et al., 2001). Thus, patients who are receiving hospice care may experience improved quality of life as they adjust their expectations and adapt to their changing clinical status. In addition, when physical symptoms are properly palliated, patients and families may be better able to address the critical psychosocial and spiritual issues that they face at the end of life (Steinhauser et al., 2000b). Improvements in quality of life within 1 or 2 weeks following admission to hospice or palliative care programs have been demonstrated (Cohen et al., 2001; Guo et al., 2001; Lo et al., 2002). Thomson, in a small study of hospice patients, found that spiritual well-being was among the most important domains on quality of life evaluations (Thomson, 2000). Cohen, in a study of patients in a palliative care home setting, identified relationships, functional status, physical symptoms, psychologic status, and, especially, existential issues to be the most important contributors to quality of life (Cohen & Mount, 2000). Our findings are particularly interesting given previous studies that have found, as would be expected, a positive association between symptom distress, particularly pain, and quality of life, with worse symptom distress associated with worse quality of life (Tierney et al., 1998; Guo et al., 2001; Lo et al., 2002; Redinbaugh et al., 2002).

The strengths of this study are the inclusion of hospice patients from multiple community-based sites and the collection of data from patients themselves, rather than proxies. Potential limitations of this study relate to patient selection and characteristics of the study population itself. As is common in studies undertaken in this setting, these results may represent the “best” hospice patients, those who are physically and cognitively able to participate in the study interview (Bretscher et al., 1999; Cohen et al., 2001). In addition, study patients had been receiving hospice care for longer than the U.S. national average hospice length of service. This selection bias limits the generalizability of these study findings to hospice patients who have relatively preserved functional and cognitive status who have been receiving hospice care for some time.

Terminally ill patients receiving hospice care appear to have relatively preserved quality of life, although their quality of life is significantly influenced by distress due to physical symptoms. Preserved overall quality of life, at least as currently measured, may mask significant distress due to

other psychosocial issues, particularly fears about dying, concern about burden on family, and a sense of loss. Personal spirituality or existential well-being may mediate these other areas of distress. Assessing and acknowledging the presence and complexity of the myriad psychosocial and spiritual needs of terminally ill patients and addressing those that are amenable to intervention, particularly physical symptoms, may further the palliative care goals of maximizing quality of life at the end of life.

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REFERENCES

- Bretscher, M., Rummans, T., Sloan, J., et al. (1999). Quality of life in hospice patients: A pilot study. *Psychosomatics*, *40*, 309–313.
- Bryant, L.L., Corbett, K.K., & Kutner, J.S. (2001). In their own words: A model of healthy aging. *Social Science and Medicine*, *53*, 927–941.
- Carr, A.J., Gibson, B., & Robinson, P.G. (2001). Is quality of life determined by expectations or experience? *BMJ (London)*, *322*, 1240–1243.
- Carr, A.J. & Higginson, I.J. (2001). Are quality of life measures patient-centered? *BMJ (London)*, *322*, 1357–1360.
- Cohen, S.R., Boston, P., Mount, B.M., et al. (2001). Changes in quality of life following admission to palliative care units. *Palliative Medicine*, *15*, 363–371.
- Cohen, S.R. & Leis, A. (2002). What determines the quality of life of terminally ill cancer patients from their perspective? *Journal of Palliative Care*, *18*, 48–58.
- Cohen, S.R. & Mount, B.M. (2000). Living with cancer: “Good” days and “bad” days—what produces them? *Cancer*, *89*, 1854–1865.
- Cohen, S.R., Mount, B.M., Bruera, E., et al. (1997). Validity of the McGill quality of life questionnaire in the palliative care setting: A multi-centre Canadian study demonstrating the importance of the existential domain. *Palliative Medicine*, *11*, 3–20.
- Donnelley, S. (2000). Quality-of-life assessment in advanced cancer. *Current Oncology Reports*, *2*, 338–342.
- Emanuel, L.L., Alpert, H.R., & Emanuel, E.J. (2001). Concise screening questions for clinical assessments of terminal care: The needs near the end-of-life care screening tool. *Journal of Palliative Medicine*, *4*, 465–474.
- Greer, D.S. & Mor, V. (1986). An overview of national hospice study findings. *Journal of Chronic Diseases*, *39*, 5–7.

- Greer, D.S., Mor, V., Morris, J.N., et al. (1986). An alternative in terminal care: Results of the national hospice study. *Journal of Chronic Diseases*, 39, 9–26.
- Guo, H., Fine, P.G., Mendoza, T.R., et al. (2001). A preliminary study of the utility of the brief hospice inventory. *Journal of Pain and Symptom Management*, 22, 637–648.
- Hatch, R.L., Burg, M.A., Naberhaus, D.S., et al. (1998). The spiritual involvement and beliefs scale. Development and testing of a new instrument. *Journal of Family Practice*, 46, 476–486.
- Hermann, C.P. (2001). Spiritual needs of dying patients: A qualitative study. *Oncology Nursing Forum*, 28, 67–72.
- Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing*, 17, 1251–1259.
- Kaasa, S. (2001). Assessment of quality of life in palliative care. *Journal of Palliative Medicine*, 4, 413–416.
- Kutner, J.S., Kassner, C.T., & Nowels, D.E. (2001). Symptom burden at the end of life: Hospice providers' perceptions. *Journal of Pain & Symptom Management*, 21, 473–480.
- Kutner, J.S., Steiner, J.F., Corbett, K.K., et al. (1999). Information needs in terminal illness. *Social Science and Medicine*, 48, 1341–1352.
- Lo, R.S.K., Woo, J., Zhoc, K.C.H., et al. (2002). Quality of life of palliative care patients in the last two weeks of life. *Journal of Pain and Symptom Management*, 24, 388–397.
- Millison, M.B. & Dudley, J.R. (1992). Providing spiritual support: A job for all hospice professionals. *Hospice Journal*, 8, 49–66.
- Mor, V., Laliberte, L., Morris, J.N., et al. (1984). The Karnofsky performance status scale. An examination of its reliability and validity in a research setting. *Cancer*, 53, 2002–2007.
- Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*, 23, 433–441.
- Redinbaugh, E.M., Baum, A., DeMoss, C., et al. (2002). Factors associated with the accuracy of family caregiver estimates of patient pain. *Journal of Pain & Symptom Management*, 23, 31–38.
- Reese, D.J. & Brown, D.R. (1997). Psychosocial and spiritual care in hospice: Differences between nursing, social work, and clergy. *Hospice Journal*, 21, 29–41.
- Shalowitz, M.U., Berry, C.A., Rasinski, K.A., et al. (1998). A new measure of contemporary life stress: Development, validation, and reliability of the CRISYS. *Health Services Research*, 33, 1381–1402.
- Skevington, S.M., Carse, M.S., & Williams, A.C.C. (2001). Validation of the WHOQOL-100: Pain management improves quality of life for chronic pain patients. *Clinical Journal of Pain*, 17, 264–275.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., et al. (2000a). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, 284, 2476–2482.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., et al. (2000b). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132, 825–832.
- Sulmasy, D.P. (2001). Addressing the religious and spiritual needs of dying patients. *Western Journal of Medicine*, 175, 251–254.
- Thomson, J.E. (2000). The place of spiritual well-being in hospice patients' overall quality of life. *Hospice Journal*, 15, 13–27.
- Thorson, J.A. & Powell, F.C. (1992). A revised death anxiety scale. *Death Studies*, 16, 507–521.
- Tierney, R.M., Horton, S.M., Hannan, T.J., et al. (1998). Relationships between symptom relief, quality of life, and satisfaction with hospice care. *Palliative Medicine*, 12, 333–344.