

Quality of Life in Hospice Patients With Terminal Illness

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To better understand quality of life (QOL) and its important correlates among patients with terminal illness, a cross-sectional correlational design was used in a study based on Stewart, Teno, Patrick, and Lynn's conceptual model of factors affecting QOL of dying patients and their families. Sixty participants were recruited from two local hospice programs in the midwestern region of the United States. Data were collected at the participants' homes. The participants had an above average QOL. Living with the caregiver, spirituality, pain intensity, physical performance status, and social support as a set explained 38% of the variance in their QOL. Among these five predictors, living with the caregiver, spirituality, and social support statistically were significant predictors of the QOL of these participants. Participants who did not live with their caregivers experienced less pain intensity, perceived higher spirituality, had more social support, and had a significantly better QOL. Important contributions of these findings are discussed.

Keywords: *patients with terminal illness; quality of life; spirituality*

Death and dying are inevitable events in a human's life. Although no one can escape this experience, death rarely receives attention from scientists and society as a whole. By 2020, 2.5 million persons will die annually in the United States (Brock & Foley, 1998). Advanced technology and modern medicine have increased the length of life; however, quality of life (QOL) at the end of life remains relatively unexplored.

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RESEARCH ON END OF LIFE

Although hospice care is believed to foster QOL while dying, little research has assessed QOL in hospice patients. Only a few studies in the United States have evaluated hospice care outcomes (Kane, Klein, Bernstein, Rothenberg, & Wales, 1985; Kane, Wales, Bernstein, Leibowitz, & Kaplan, 1984; Kidder, 1992; Mor, Greer, & Kastenbaum, 1988; Morris et al. 1986; Wallston, Burger, Smith, & Baugher, 1988), and most of these have concentrated on cost-effectiveness. Although Mor et al. (1998) measured QOL as one of the important hospice outcomes, their study used the family caregivers' proxy measure of the patients' QOL. Others have found a discrepancy between patients' rating of their QOL and proxy measures and caution against using such proxy measures (Bretscher et al., 1999; Brunelli et al., 1998; Clipp & George, 1992; Ganzini, Johnston, & Hoffman, 1999; Hardy, Edmonds, Turner, Rees, & A'Hern, 1999; Higginson & McCarthy, 1993; Maguire, Walsh, Jeacock, & Kingston, 1999; McMillan, 1996; Weitzner, Meyers, Steinbruecker, Saleeba, & Sandifer, 1997). Still other studies either focused on physical and psychological symptoms or on satisfaction with care, failing to capture all of the domains of QOL for patients with terminal illness (e.g., Kane et al., 1984, 1985; Peruselli, Paci, Franceschi, Legori, & Mannucci, 1997).

QOL

QOL is believed to be the most important outcome of care at the end of life (Stewart, Teno, Patrick, & Lynn, 1999). QOL has been conceptualized in two ways: global QOL and health-related QOL (HRQOL). Global QOL is defined as an individual's subjective well-being (Cella, 1994; Cohen, Hassan, Lapointe, & Mount, 1996; Cohen & Mount, 1992; Cohen, Mount, & MacDonald, 1996), or a global evaluation of satisfaction with one's life (Cooley, 1998; Nuamah, Cooley, Fawcett, & McCorkle, 1999). HRQOL, on the other hand, is "a more focused concept related to the impact of a medical condition or the impact of specific medical interventions on a person's physical, psychological, and social well-being" (Skeel, 1998, p. 876). HRQOL is relevant for patients receiving active treatment for disease (Choe, Padilla, Chae, & Kim, 2001). For individuals at the end of life, however, when the focus of treatment changes from curing disease to preserving QOL, global QOL becomes more relevant (Clinch, Dudgeon, & Schipper, 1998; Cohen et al., 1996; Houck, Avis, Gallant, Fuller, & Goodman, 1999; Lynn, 1997; McMillan, 1996; Stewart et al., 1999).

In general, there are several domains that contribute to an individual's global QOL. These are physical, psychological, social, and existential well-being (Cohen, Hassan, et al., 1996; Ferrell, 1995; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Physical well-being captures the individuals' perceptions of their physical condition including symptoms; psychological well-being taps emotional responses, such as depression and anxiety; existential well-being embodies the individual's ability to find meaning and purpose in life and to transcend difficult life circumstances; and social well-being focuses on individuals' perceptions of their support from others. Because QOL is considered to be one of the most important outcomes for end-of-life care, surprisingly few studies have examined important correlates of global QOL for a patient with terminal illness.

Stewart et al. (1999) presented a conceptual framework for evaluating quality of care for patients who were seriously ill and dying and their families. This framework is based on Donabedian's (1992) formulation of structure, process, and outcomes. The structure (e.g., access to hospice, provider skills) and process (e.g., physical care, attention to emotional needs) of care influence desired outcomes, including global QOL. Being mindful of the response burden for hospice patients, four key variables (i.e., spirituality, pain, physical performance, social support) were selected from Stewart et al.'s (1999) conceptual framework for investigation.

Spirituality, Pain, Physical Performance, and Social Support

Spirituality is the interconnectedness between self, others, nature, and Ultimate Other (God) (Clark & Heidenreich, 1995; Floriani, 1999; Hood Morris, 1996; Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1996). Spirituality provides a sense of meaning and purpose, enables transcendence, and empowers individuals to be whole and to live life fully. Spirituality has two components, religious well-being (i.e., a relationship with God or Higher Being) and existential well-being (i.e., a sense of purpose and meaning in life; Moberg, 1979). Reed (1987) found that adults with terminal illness have greater religiousness when compared to other adults and that these adults' spirituality was positively correlated with psychological well-being. At this point, little is known about the relationship between spirituality and other aspects of QOL, such as physical and social well-being.

Pain is the most debilitating and frequently reported symptom of patients with terminal illness (Dahl, 1996; Hall, Schroder, & Weaver, 2002). Pain interferes with psychological and existential well-being and diminishes social relationships (Easley & Elliott, 2001; Ferrell, Rhiner, Cohen, &

Grant, 1991). Although the relationship between physical pain and QOL has been empirically demonstrated (Ferrell et al., 1991), relatively little research has evaluated the relationship of pain to all aspects of QOL in a hospice setting, where there often is greater attention to pain management.

According to Stewart et al.'s (1999) framework, physical performance status is another factor that influences patients' QOL. Many patients are completely dependent in activities of daily living before death (McCarthy, 1990; Peruselli et al., 1997). Researchers and clinicians often place emphasis on the physical domain of QOL, assuming one's QOL decreases as disease and physical disability progress. Some researchers, however, have documented that other aspects of QOL gain importance as one approaches death. For example, the existential domain has been demonstrated to increase in importance as one approaches death and becomes increasingly physically debilitated (Cohen, Mount, Tomas, & Mount, 1996). The interplay between physical performance status and other factors on QOL at the end of life remains unclear.

Social support is a key element in how people manage and cope with illness (Lamendola & Newman, 1994; Smith, Fernengel, Holcroft, Gerald, & Marien, 1994). Focusing on the patients with terminal illness, Stewart et al. (1999) identified emotional and tangible support as important to QOL. Hospice, by the very nature of its focus, offers emotional and tangible support to patients who are dying. Social support has been found to have a significant relationship with QOL for patients with terminal illness (Cohen, Hassan, et al., 1996), to be associated with less distress due to pain (Rosenfeld et al., 1996), and to have a positive relationship with spirituality (Reed, 1994). The relationship of social support to QOL in a hospice population also warrants further investigation.

PURPOSE

The purpose of the present study was to fill the gaps in current end-of-life research by examining important correlates of QOL of participants. The following research question was addressed: What is the relationship among spirituality, pain, physical performance status, social support, and QOL of patients receiving hospice care?

DESIGN

To study the relationship between these important factors and QOL of participants among those who receive in-home hospice care, a cross-sectional, correlational design with a convenience sample was used.

SAMPLE

A convenience sample ($N = 60$) of participants was obtained through two local hospice programs. During the 4-month period of data collection, 95 participants received invitation letters from the directors of the hospice programs. Nine patients died, and one moved to a nursing home setting before the follow-up phone call. Among the 85 potential participants, 63 agreed to participate in the study, and 60 participants completed the questionnaires. The effective response rate for the present study was 71%.

Participants' mean age was 73 years ($SD = 11$). The median length of stay (LOS) in a hospice program until data collection day was 28.8 days. The majority of the participants were Caucasian (95%), 55% were married (32% widowed, 10% divorced, and one each were single or separated), and 43% were men. More than one half (63%) of the participants indicated their religious affiliation as Protestant, 20% were Catholic, and 8% each indicated either "other" or "none." Of the participants, 25 (42%) had more than 12 years of education, and 22% did not complete high school. All participants lived in a home setting; the majority cohabited with a caregiver (78%). Most (82%) had a cancer diagnosis, especially lung cancer (23%). Of the participants, 39 (65%) had agreed to forgo cardiopulmonary resuscitation (CPR). The mortality rate during the data collection period was 53%. For those who died during the data collection process, 91% of the participants died at their homes with family members present. In addition, one participant died in a nursing home during a respite care period, and two others died in the hospital after receiving CPR.

MEASURES

For this investigation, five instruments, each measuring one study variable, were used. Psychometric properties for each questionnaire are described.

McGill Quality of Life Questionnaire (MQOL)

QOL of participants was measured using Cohen, Hassan, et al.'s (1996), Cohen, Mount, Tomas, et al.'s (1996), and Cohen et al.'s (1997) 16-item MQOL (plus one single-item global measure of QOL-SIS). There are five subscales within this instrument: Physical Symptoms, Physical Well-Being, Psychological Symptoms, Existential Well-Being, and Social Well-Being. Each MQOL item is scored ranging from 0 to 10, 0 = *the worst situation* and 10 = *the best*. The MQOL total score is the mean of the scores of the five subscales.

Reliability as estimated by Cronbach's alpha ranged from .83 to .89. Convergent and construct validity has been supported in a comparison study on cancer patients (Cohen, Mount, Tomas, et al., 1996).

Spiritual Well-Being Scale (SWBS)

The spirituality of participants was measured using Paloutzian and Ellison's (1982) 20-item SWBS. There are two subscales within the SWBS: Religious and Existential Well-Being. Higher scores represent higher levels of spirituality. National norms were obtained on this instrument across a variety of samples (Bufford, Paloutzian, & Ellison, 1991). Reliability, as measured by Cronbach's alpha, ranged from .82 to .86. Construct validity was supported by its positive relationship with self-transcendence (Walton, Schultz, Beck, & Walls, 1991), religiousness and hope (Mickley, Soeken, & Belcher, 1992), mental health, and QOL (Riley et al., 1998); and its negative relationship with loneliness (Walton et al., 1991) and demands of illness (Fernsler, Klemm, & Miller, 1999).

American Pain Society Patient Outcome Questionnaire (APS-POQ)

The APS-POQ was developed by the American Pain Society Quality of Care Committee (McNeill, Sherwood, Starck, & Thompson, 1998). Because pain intensity was our major interest and we wanted to reduce response burden on participants, only the Pain Intensity subscale of APS-POQ was used in the present study. First, participants were asked if they have had any pain in the last 24 hr. Those who indicated that they were in pain rated how much discomfort or pain they were having at that time on a scale ranging from 0 (*no pain*) to 10 (*worst pain possible*). They also indicated the worst pain and

the average level of pain they have had in the last 24 hr. Internal consistency reliability was .75 for the Pain Intensity subscale (McNeill et al., 1998).

Eastern Cooperative Oncology Group Performance Status Rating (ECOG-PSR)

The ECOG-PSR (Zubrod et al., 1960) is a single-item measure of physical performance status that indicates overall physical status and ambulatory ability. The total score of ECOG-PSR ranges from 0 (*fully active*) to 4 (*completely disabled*). Because ECOG-PSR is a single-item instrument, internal consistency reliability cannot be assessed. Concurrent validity of the ECOG-PSR was demonstrated by correlating the ECOG-PSR score with the total Edmonton Functional Assessment Tool (Kaasa, Loomis, Gillis, Bruera, & Hanson, 1997) score ($r = .85, p < .0001$).

The Medical Outcomes Study Social Support Survey (MOS-SS)

The MOS-SS was developed by Sherbourne and Stewart (1991) to measure multidimensional aspects of social support. There are five subscales within this instrument: Emotional, Informational, Tangible, Positive Social Interaction, and Affectionate Social Support. Respondents are asked to indicate how often each kind of support is available to them if they need it. For the purpose of this investigation, we used only the Emotional, Informational, and Affectionate Support subscales to measure the participants' social support to reduce participant burden and because they receive tangible support from their caregivers. Internal consistency reliability was reported as .97 for the total score of MOS-SS (Sherbourne & Stewart, 1991). Construct validity was supported by its negative relationship with loneliness ($r = -.67$), and positive relationships with family functioning ($r = .53$), marital functioning ($r = .56$), mental health ($r = .45$), and current health ($r = .22$) (Sherbourne & Stewart, 1991).

Procedure

Participants' approvals were obtained prior to data collection. All data were collected at participants' homes by the first author. Times to meet with

participants were arranged for their convenience. After explaining the purpose of the present study and obtaining informed consent, each question was read verbatim to the participants, and responses were immediately recorded. Although this procedure might have resulted in more socially acceptable responses, it was necessary to limit respondent burden.

Data Analysis

To examine the relationship between the independent variables and the dependent variable, Pearson correlations and regression analysis were conducted. Because of the exploratory nature of the present study, in addition to the independent variables addressed in the research question, demographic and health care utilization information were evaluated to determine if they might be relevant to include or control in the regression analysis.

RESULTS

In the present study, spirituality, pain, physical performance status, and social support were the independent variables used to predict the dependent variable—patients' QOL. The means and standard deviations of the study variables, including total scores and subscales, are presented in Table 1. The three most frequent complaints of troublesome symptoms were pain (55.7%), fatigue (47.5%), and shortness of breath (26.2%).

Living with the caregiver was the only demographic variable associated with QOL. Those who lived with their caregiver had a lower QOL than those who did not live with their caregiver (6.28 vs. 7.69, $t = 3.34$, $p < .01$). This variable, therefore, was included in the regression equation for participants' QOL.

Correlation coefficients among the study variables are presented in Table 2. Participants' QOL correlated significantly with pain intensity ($r = -.31$), spirituality ($r = .42$), and social support ($r = .34$). In the present study, physical performance status did not have a significant correlation with participants' QOL ($r = -.06$, $p = .32$).

Results of the multiple regression analysis showed that the five independent variables entered as a set were significantly related to participants' QOL, $R^2 = .38$, $F(5, 54) = 6.66$, $p = .001$ (see Table 3). The unstandardized regression coefficients (b weight) indicated that living with the caregiver ($b = -1.13$, $t = -2.6$, $p = .01$), spirituality ($b = .02$, $t = 2.6$, $p = .01$), and social

TABLE 1: Means and Standard Deviations of Study Variables (N = 60)

<i>Study Variables (Possible Range)</i>	<i>M (SD)</i>
Dependent variable	
Quality-of-life total score (0 – 10)	6.7 (1.3)
Social well-being (0 – 10)	8.3 (1.5)
Psychological well-being (0 – 10)	6.8 (2.4)
Existential well-being (0 – 10)	6.5 (2.1)
Physical symptoms (0 – 10)	6.3 (2.1)
Physical well-being (0 – 10)	5.3 (2.2)
Independent variables	
Spirituality total score (20 – 120)	95.8 (18.0)
Religious well-being (10 – 60)	51.0 (9.1)
Existential well-being (10 – 60)	44.8 (9.7)
Pain intensity (0 – 10)	4.2 (1.8)
63.9% had pain	
Physical performance (0 – 4)	2.9 (.83)
Social support	
Emotional support (4 – 20)	16.8 (3.2)
Informational support (4 – 20)	16.5 (3.1)
Affectionate support (3 – 15)	13.1 (2.6)

NOTE: Quality of life was measured with the McGill Quality of Life Questionnaire (Cohen et al., 1997); spirituality was measured with the Spiritual Well-Being Scale (Paloutzian & Ellison, 1982); pain was measured with the Pain Intensity subscale of the American Pain Society Patient Outcome Questionnaire (McNeill, Sherwood, Starck, & Thompson, 1998); physical performance was measured with the Eastern Cooperative Oncology Group Performance Status Rating (Zubrod et al., 1960); social support was measured with the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991).

support ($b = .04, t = 2.1, p = .04$) were statistically significant contributors to participants' QOL.

DISCUSSION

The hospice patients in the present study had an above average QOL. When compared to national norms on the SWBS (Bufford et al., 1991), participants in the present study had a moderate level of spirituality, a very positive view of their relationship with God, and a moderate level of life satisfaction and purpose. Patients with terminal illness who select hospice care may have greater spiritual and existential well-being than those who do not seek or accept hospice care. Acceptance of hospice care may reflect a greater acknowledgement of their approaching death. When patients accept

TABLE 2: Correlations Among Independent and Dependent Variables (N = 60)

Variable	1	2	3	4	5
1. Quality of life	1.00	-.31**	-.06	.42***	.34**
2. Pain intensity		1.00	-.17	-.15	-.15
3. Physical performance			1.00	.01	.13
4. Spirituality				1.00	.24*
5. Social support					1.00

NOTE: Quality of life was measured with the McGill Quality of Life Questionnaire (Cohen et al., 1997); spirituality was measured with the Spiritual Well-Being Scale (Paloutzian & Ellison, 1982); pain was measured with the Pain Intensity subscale of the American Pain Society Patient Outcome Questionnaire (McNeill, Sherwood, Starck, & Thompson, 1998); physical performance was measured with the Eastern Cooperative Oncology Group Performance Status Rating (Zubrod et al., 1960); social support was measured with the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991).

* $p < .05$. ** $p < .01$. *** $p < .001$.

TABLE 3: Results of Multiple Regression Analysis for Quality of Life of Patients with Terminal Illness (N = 60)

Variable	b	SE	t	Total R ²	F
Living with the caregiver	-1.13	.43	-2.61**		
Pain intensity	-.10	.07	-1.47		
Physical performance	-.002	.21	-.01	.38	6.66***
Spirituality	.02	.01	2.64**		
Social support	.04	.02	2.07*		

NOTE: Quality of life was measured with the McGill Quality of Life Questionnaire (Cohen et al., 1997); spirituality was measured with the Spiritual Well-Being Scale (Paloutzian & Ellison, 1982); pain was measured with the Pain Intensity subscale of the American Pain Society Patient Outcome Questionnaire (McNeill, Sherwood, Starck, & Thompson, 1998); physical performance was measured with the Eastern Cooperative Oncology Group Performance Status Rating (Zubrod et al., 1960); social support was measured with the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991).

* $p < .05$. ** $p < .01$. *** $p < .001$.

approaching death, they tend to re-evaluate their purpose and meaning of life. The high QOL in this sample may be because of their higher spiritual and existential well-being. Whether this is because of hospice care, or a function of pre-existing beliefs that led to selecting hospice care, cannot be determined from the present study. The high correlation between religious and existential well-being ($r = .79$), however, coupled with the fact that only

8% ($n = 5$) did not identify with a religion, suggests there were high pre-existing beliefs among this sample. Although some researchers have suggested that individuals do not have to practice or believe in a particular religion to have spiritual well-being (Hatch, Burg, Naberhaus, & Hellmich, 1998; Thomas & Retsas, 1999), others have suggested that individuals who have a strong religious belief are more likely to have strong psychological and spiritual well-being (Bufford et al., 1991; Hermann, 2001; Mickley & Soeken, 1993). Spiritual well-being may support patients selecting hospice care and thus account for their having greater QOL than those who do not seek or accept hospice care.

Although others (Cohen, Mount, & MacDonald, 1996; Ferrell et al., 1991; Ganzini et al., 1999; Houck et al., 1999; Riley et al., 1998; Skevington, 1998; Zacharias, Gilg, & Foxall, 1994) have found spirituality and social support to be important predictors of QOL in patients with terminal illness, this is the first study to look at this relationship in a hospice population. In addition to relatively high spirituality, the majority of the participants in the present study also reported a high level of social support. Most indicated that their support came from their primary caregivers or other family members. Some patients who lived alone referred to their pets (e.g., cat, dog, bird) as the source of their social support, which raises an interesting issue on the value of pets for social support of patients with terminal illness. Other sources of contact, such as hospice personnel, may also be important for those patients who lived alone, thus contributing to their QOL through this enhanced social support.

According to findings from an independent t test and the regression analysis, participants who lived alone had a significantly better QOL than those who lived with their caregivers. This was somewhat surprising. Of the 47 participants who lived with their caregivers, 10 (21%) needed to move to the caregivers' houses. Change in living environment (i.e., having to move to the caregiver's home) and fear of becoming a burden may have contributed to this unexpected finding. Besides existing stress from the challenge of death and dying, change in the living environment may be a tremendous adjustment process for patients with terminal illness and may become an important factor that hinders their QOL. That patients who live with their caregivers fear becoming a burden to their caregivers was also evident from numerous comments by participants. For example, patients said, "All I want to do is die. I want to end this as soon as possible because I don't want to see my family suffer with me. I don't want to become a burden on them." "If the Lord wants me, please just take me as soon as possible. I don't want to wear them out." That being afraid to be a burden is one of the major concerns for

patients with terminal illness has been identified by others (Singer, Martin, & Kelner, 1999; Steinhauer et al., 2000).

Pain intensity was not a significant predictor of QOL, which also was a surprising finding. According to the literature, researchers found that QOL is relatively unimpaired when patients have mild pain (Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995). Of participants in the present study, 63% experienced only mild pain in the last 24 hr, providing supporting evidence for the common belief that hospice care may provide better pain management. All patients in the present study were in hospice care. The QOL of the patients in the present study may not be altered by their pain intensity, not only because of their lower levels of pain but also because of the concomitant reduced variability in pain in the present study.

Participants' physical performance status also did not have a significant relationship with their QOL. Elderly people with a terminal illness may value different aspects of their life. For example, participants may value spiritual well-being more than their functional ability in activities of daily living as they face the challenge of death and dying. On the other hand, there may not have been sufficient variation in this indicator to detect a significant influence on participants' QOL. The majority (77%) of patients in the present study had ECOG-PSR scores of 3 or 4.

A major strength of the present study was the collection of QOL data directly from participants through in-home visits. The method of data collection also resulted in little missing data. There were some limitations, however, that may have affected the results of the study. The strength of collecting data directly from participants also meant that this sample was limited to those who were well enough to be interviewed. Most participants were White, and all came from two local hospice programs in a single metropolitan area. Findings, therefore, may not be generalizable across different cultural and ethnic groups, to the entire hospice population, or across different care settings. As one of the first studies to focus on end of life among hospice patients, and to gather data directly from patients with terminal illness, the present study makes an important contribution to better understanding hospice patients and their needs and concerns.

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