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The Impact of Hospice Services on the Quality of Life of Primary Caregivers

Susan C. McMillan and Mary Mahon

Purpose/Objectives: To evaluate the effects of hospice services on the quality of life of primary caregivers and to evaluate the validity and reliability of a new tool. Design: Exploratory, descriptive.

Setting: A nonprofit hospice in Florida; clients are cared for primarily in the home.

Sample: 68 adult primary caregivers of 68 patients with cancer enrolled in hospice care and 62 noncaregiving adults.

Methods: Subjects were recruited on admission to hospice and completed the Caregiver Quality of Life index (CQLI) and the Hospice Quality of Life Index (HQLI) on admission and during week four of hospice care.

Main Research Variables: Caregivers' assessment of their own physical, social, financial, and emotional quality of life; patients' assessment of their physical, psychological, spiritual, social, and financial well-being.

Findings: No significant differences were found in caregiver quality-of-life scores from admission to week four, and no correlations existed between quality-of-life scores and age or education. A significant positive correlation was found between the caregivers' quality of life and their estimate of the patients' quality of life. Evidence exists that the CQU is valid and reliable.

Conclusions: Caregivers of terminally ill people with cancer can maintain their quality of life during the first month of hospice care. The caregiver's perception of the patient's quality of life may affect the caregiver's quality of life.

Implications for Nursing Practice: When offering support to primary caregivers, the hospice team should include the four domains (physical, emotional, social, and financial) and should focus on the interrelatedness of the patient's and caregiver's quality of life.

growing number of Americans are diagnosed with cancer each year. Although many people may be cured and others may live disease-free for a long time, many will die (including more than onehalf million in 1993 alone) (American Cancer Society, 1994). The growing trend toward home care places an increased burden on family members and friends to assist with supportive care of patients who are terminally ill. The feasibility of maintaining the patient at home most often depends on the availability of a primary caregiver (Siegel, Raveis, Houts, & Mor, 1991). This individual may increasingly be responsible for the majority of caregiving tasks as the patient's condition deteriorates. Caregiving tasks may include emotional support, support of activities of daily living, and assistance with other physical aspects of care (Laizner, Yost, Barg, & McCorkle, 1993).

The goal of hospice care is to maintain or improve the quality of life of the patient and caregiver. Although the focus of hospice care is on the patient, the needs of the primary caregiver must not be overlooked. Providing care for a loved one over a period of time produces strain regardless of how motivated the caregiver may be (George & Gwyther, 1986). The caregiver is a critical element in home hospice care for patients who are terminally ill. If the caregiver becomes too stressed by the burden of patient care, the homecare arrangement may collapse. This would necessitate the use of much more expensive and impersonal institutional care (Siegel et al., 1991). Although hospice services are provided to the patient and the caregiver, little attention has been given to studying the quality of life of primary caregivers. This study evaluates the effect of hospice services on the quality of life of primary caregivers and studies the validity and reliability of the newly developed Caregiver Quality of Life Index (CQLI).

Literature Review

Quality of Life

Quality of life has been conceptualized to include four domains: physical, psychological, social, and financial well-being. Each of these domains is essential to the overall quality of life of people who are and people who are not healthy (Feld, 1987; Ferrans & Powers, 1985; Ferrell et al., 1992; Flanagan, 1982). Caregivers of patients in hospice care often are called on to report the quality of life of the patient, but few studies were found that reported the caregivers' quality of life.

The literature suggests that the majority of caregivers are women who, on average, tend to be middle-aged or elderly (Hileman, Lackey, & Hassanein, 1992; Jensen & Given, 1991; Siegel et al., 1991; Stetz, 1987; Wingate & Lackey, 1989).

Susan C. McMillan, PhD, RN, FAAN, is the American Cancer Society professor of oncology nursing in the College of Nursing at the University of South Florida, and, at the time of this study, Mary Mahon, RN, was program director at the Hospice of Hillsborough, Inc., both in Tampa. (Submitted July 1993. Accepted for publication January 17, 1994.)

Hospice Services

Kane, Klein, Bernstein, Rothenberg, and Wales (1985) conducted one of the first studies designed to evaluate the effectiveness of hospice services. Patients who were terminally ill were assigned randomly to either hospice or nonhospice inpatient units. Patients receiving hospice care and their significant others (n = 195) were interviewed weekly. These significant others showed some decrease in anxiety and greater satisfaction with involvement in care than did the significant others of the patients in the nonhospice group.

Effects of Caregiving

Stetz (1987) interviewed 65 spouses of adults with cancer who were terminally ill and were receiving services from a homecare agency. Results suggested that caregivers, who primarily were women ($\overline{X} = 66.4$ years), were confined to the home an average of 23.2 hours per day. Caregiving demands fell into one of four dimensions physical care, psychosocial concerns, role alterations, or financial alterations. Physical demands of care were ranked as most demanding; managing the household and managing finances also were mentioned frequently.

Results from an instrument-development study identified five components of caregiver reaction to caregiving: caregiver esteem, family supportiveness, impact on finances, impact on schedule, and impact on physical health (Given et al., 1992). Investigators found that as patients' needs increase, a corresponding increase occurs in the impact on finances, family supportiveness, and health. They also found that caregiver esteem was negatively associated with caregiver depression. Caregiver depression also was positively associated with a negative impact on finances (r = 0.34), family supportiveness (r = 0.39), health (r = 0.57), and schedule (r = 0.46).

Physical Effects of Caregiving

The physical strain of caregiving is thought to take its toll on caregivers. In a study by Jensen and Given (1991), a sample of 248 caregivers of patients with cancer were assessed for fatigue. Sixty-five percent of the caregivers were women, and 65% were over 50 years of age. Approximately 53% complained of moderate or severe fatigue that was not found to be related to age or the duration of caregiving. Wingate and Lackey (1989) revealed that three of seven identified needs of caregivers centered around the physical aspects of the role (i.e., household management needs, physical needs, and the need for respite).

Support Needs of Caregivers

Primary caregivers often need support from others. Hull (1992) found that caregivers of hospice patients used social support to cope with identified stressors. Included as primary elements of this social support were hospice nurses, family, friends, and neighbors. Stommel and Kingry (1991) reported a study of support patterns for 232 spouse-caregivers of patients with cancer. Results suggested that caregivers are much more likely to receive support when minor children are a part of the household. This information, combined with the information from the literature about the advanced age of caregivers, suggests that most would not have minor children and might be less likely to garner social support.

Patient Needs

The patient's needs affect the caregiver. Siegel et al. (1991) studied 483 people with cancer and their caregivers. They found that when care was associated with a high degree of caregiver burden, the patient was more likely to have unmet needs. A study of family members caring for people receiving chemotherapy found that caregiver burden was predicted by amount of patient dependency (Carey, Oberst, McCubbin, & Hughes, 1991). Hileman et al. (1992) found a significant negative relationship between the patient's level of activity and the caregiver's psychological needs.

In summary, quality of life includes domains of physical, psychological, social, and financial well-being. These domains provide the conceptual framework for the study. The literature supports the idea that caregiving has an impact on or is affected by each of these. Caregiving, which is known to cause physical strain and fatigue, also interferes with mood and results in anxiety and other emotional concerns (Kane et al., 1985; Stetz, 1987). Social support and financial need appear to affect caregiving (Given et al., 1992; Stetz). Thus, the review of literature supports including all of these elements in assessing the quality of life of caregivers of patients with cancer who are terminally ill. Little was found in the literature relating specifically to the study of quality of life of hospice primary caregivers, and no studies were found that addressed the effect of hospice services on the quality of life of the primary caregiver.

- This study addressed the following questions
- What are the effects of hospice services on the primary caregivers' quality of life from admission to week four?
- To what extent is caregiver quality of life related to patient quality of life?

In addition, this study sought to provide data regarding the validity and reliability of the CQLI.

Methods

Setting

This study was conducted in a nonprofit hospice that provides care in one county in Florida. Although most care is given in homes, some patients are admitted from hospitals or nursing homes or may be institutionalized during hospice care. For patients who are institutionalized, the hospice team works with the institution's staff to continue hospice services.

Sample

The caregiver sample consisted of the primary caregivers of 68 adults with cancer who were receiving hospice care. An earlier study (McMillan & Mahon, 1994), which used only patients who were alert and oriented, was seriously biased because it eliminated patients who were unable to self-report (i.e., those who were debilitated or comatose). To avoid bias in the present study, 65% of the sample consisted of primary caregivers who were caring for alert and oriented patients. The other 35% were caring for patients who were debilitated or comatose. If death was imminent when the patient was admitted to hospice, the patient and caregiver were excluded from the study. Selfreporting patients and all caregivers were oriented and able to read and understand English.

An additional sample of 62 apparently healthy noncaregiving adults also was included in the study as a comparison group to study construct validity of the CQLI. Of these, 22 were obtained from a church group, 7 from a retirement apartment community, and 33 from two office settings. None of these adults were involved in caregiving activities for hospice patients, people with cancer, or elderly individuals at the time of the study. Adults with children were not excluded from the sample.

Instruments

This study was part of a larger project that involved study of patients and caregivers. Three instruments were included in the larger study. First, the CQLI, designed by the investigator, was the focus of this study. Second, patient data that is the focus of a separate study was gathered using the Hospice Quality of Life Index (HQLI). However, some descriptive data about patients (from the HQLI) is reported in this study to shed light on caregiver quality of life. Finally, a demographic data tool was used to collect standard demographic data about the patient and caregiver.

Caregiver Ouality of Life Index: The COLI is a brief self-report instrument comprised of four items. Two of the items were taken from an earlier study of quality of life of hospice patients and caregivers (Morris, Suissa, Sherwood, Wright, & Greer, 1986). The first item asks about the caregiver's emotional quality of life; the second asks about social quality of life. Because overall quality of life has been conceptualized to include four critical domains (Feld, 1987: Ferrans & Powers, 1985: Ferrell et al., 1992: Flanagan, 1982), a third item about financial quality of life and a fourth item about physical quality of life were added. All items are 100 mm visual analogue scales with anchors on either end of the line that state "lowest quality" and "highest quality." For each item, lowest and highest quality of life are described briefly (see Figure 1). Scores were summed and averaged to obtain a total score ranging from 0 - 100.

Because the CQLI was a new tool, no data existed about its validity or reliability. Thus, these critical characteristics were studied as part of this project. Prior to its use with the study sample, content validity of the CQLI was assessed by a group of content experts. The items were reviewed by five surviving caregivers of hospice patients who had died more than two years previously. A content validity index (CVI) was calculated for each item. Those CVIs were summed and averaged to generate a CVI for the tool. Construct validity was assessed by comparing the scores of the caregivers with the scores of a group of noncaregiving volunteers. A significant difference in the two sets of scores would provide additional evidence of construct validity. To assess reliability of the CQLI, internal consistency was estimated using Cronbach's alpha.

Hospice Quality of Life Index: The HQLI is a 25-item scale designed by the investigators to elicit information about four domains of the patient's quality of life: physical well-being, psychological and spiritual well-being, social well-being, and financial well-being. Each item is a

visual analogue scale with adjectival anchors on each end and a 100 mm line between the anchors on which the patient is asked to make a single mark. The raw score on the item is obtained by measuring the number of millimeters from the zero to the mark. Each item then is weighted by its importance. The importance dimension is determined by asking the subject to rate, on a four-point scale, whether a given aspect of quality of life (e.g., pain relief, feeling anxious) is "not important," "somewhat important," "important," or "extremely important." This dimension is rated from 0-3. The subject's raw score for each item is multiplied by the weight for that item. Thus, items that the subjects rate as unimportant are effectively dropped out of the scale, and other items are weighted according to their importance to the individual. Resulting scores may range from 0-300, with 0 representing the worst possible and 300 representing the best possible quality of life.

The HQLI was developed based on a careful review of the literature, thus providing beginning evidence of construct validity. In addition, a group of seven experienced hospice nurses evaluated the HQLI for content validity. Resulting CVIs for the items ranged from 0.4-1.0 with an overall CVI for the whole tool of 0.83. Reliability was estimated using Cronbach's alpha (r = 0.87).

Demographic data forms: Caregiver data included age, gender, years of education, and relationship to the patient. Patient data included age, gender, years of education, admission date, and functional status reported as Karnofsky Performance Scale (KPS) scores recorded routinely by the hospice nurses. KPS scores may range from 0 ("dead") to 100 ("normal," "no complaints," "no evidence of disease"). Noncaregivers were asked to record age, gender, and years of education.

Procedures

Following approval by the appropriate review committees, patients and caregivers were identified for the study as they were admitted to hospice care. Within 48 hours of admission, the research assistant and an RN experienced in oncology and medical-surgical nursing visited the patient and caregiver to explain the study and obtain consent. The patient and the caregiver were asked to evaluate *independently* the patient's quality of life using the HQLI. In addition, caregivers were asked to evaluate their own quality of life using the CQLI. During the fourth week of hospice care, the patient and caregiver were asked to complete the forms a second time. This second data collection occurred between 21 and 28 days after admission to hospice. If the patient died in the interim, the caregiver was not asked to complete the forms a second time.

The adults in the noncaregiving comparison group were approached individually and asked to participate. After receiving information about the study and giving written consent, they filled out the CQLI and a brief demographic questionnaire.

Data Analysis

To answer the first question about the effect of hospice services on caregiver quality of life, caregiver scores were tabulated. Mean scores were calculated for admission and week four and compared using a paired t-test. The second research question, about the relationship between patient Directions: Please place a mark on the line under the question at a point that best describes you at the present time (today).

Emotional Quality of Life

Lowest quality applies to someone who is depressed, anxious, insecure, alienated, and lonely. Highest quality applies to someone who is emotionally comfortable with self, others, and environment.

Highest
Quality

Social Quality of Life

Lowest quality applies to someone whose social relationships are unsatisfactory, of poor quality, or few; help from family and friends is not even available occasionally.

Highest quality applies to someone whose social relationships are very satisfactory and extensive; at least one person would assist him or her indefinitely.

Lowest	Highest
Quality	Quality

Financial Quality of Life

Lowest quality describes someone who constantly is worried about medical costs and present and future living expenses. Highest quality describes someone who feels confident of his or her financial status now and in the future.

Lowest	Highest
Quality	 Quality

Physical Quality of Life

Lowest quality describes someone who has no energy or is physically ill and feels unable to maintain normal activities. Highest quality describes someone who is energetic, in good physical health, and is maintaining normal activity levels.

Lowest	Highest
Quality	 Quality

Figure 1. Caregiver Quality of Life Index

and caregiver quality of life, was answered using Pearson correlation coefficients. Validity and reliability questions were answered using the CVI, independent t-test, and Cronbach's alpha.

Results

Sample Characteristics

Sixty-eight patient and caregiver dyads were enrolled in the study. Caregivers were predominantly female (85.3%); their mean age was 57.7 years (range 30–87); and they had an average of 12.3 years of formal education ranging from fourth grade to graduate degrees (see Table 1). Caregivers were wives (44.1%), daughters (19.1%), husbands (10.3%), other relatives (20.7%), or friends (2.9%); two (2.9%) were certified nursing assistants.

The patients predominantly were male (61.7%) and ranged in age from 36 to 90 years ($\overline{X} = 67$) (see Table 1). All but three received care in their own homes. One patient was in a nursing home, one was in a hospital, and one was in the home of a relative. Patients had an average of 11.5 years of formal education ranging from none to graduate degrees (see Table 1). The patients' mean functional status (as measured by the KPS score on admission to hospice) was 47.8 (range 10–80). By week four, the KPS for the 28 subjects who were still living was 43.9 (range 30– 60).

Although 68 patients were admitted to the study sample, only 28 were alive at the second measurement period. The average length of stay for all patients in this hospice was 7.4 weeks during the data collection period. The average length of stay for patients admitted to the study was 8 weeks (range 0.5-37). The noncaregiver subjects of volunteers predominantly were female (77.5%), their mean age was 48.9 years, and they reported an average of 14.7 years of education (range 2–22) (see Table 1).

Hospice Quality of Life

On admission, patient self-reported quality-of-life scores were higher than their caregivers' scores on the HQLI. However, caregiver HQLI scores were closer to patient scores in the fourth week of hospice care. For patients who were unable to self-report, the mean HQLI scores for caregiver-reported patient quality of life were considerably lower (see Table 2). No correlation existed between patient and caregiver scores on admission (r = 0.06) and only a very weak correlation existed by week four (r = 0.22).

Table 1. Selected Demographic Variables

Variable	Caregivers	Patients	Noncaregivers
Age in years			
X	57.7	67.0	48.9
Range	30-87	36-90	21-94
Years of education	1		
X	12.3	11.5	14.7
Range	4-18	0-21	2-22
Gender			
Male (%)	10(14.7)	42 (61.7)	14 (22.5)
Female (%)	58 (85.3)	26 (38.2)	48 (77.5)

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Caregiver Quality of Life

For the 68 caregivers who reported on admission, the mean caregiver quality of life was 61.5 (SD = 21.5) For the 28 caregivers remaining in the study in the fourth week of hospice care, the mean quality-of-life score was 58.7 (SD = 24.2) (see Table 3). A paired t-test revealed no significant difference in CQLI scores from admission to week four for those 28 primary caregivers.

Data were analyzed separately for caregivers of selfreporting patients and caregivers of patients who were too debilitated to self-report. Mean scores for the group of caregivers (n = 44) of patients who were able to respond to the patient questionnaire were similar at the two administrations ($\overline{X} = 61.2$ and 62.1). The mean scores for the group of caregivers (n = 24) of patients who were *not* able to respond were similar to the responder group on admission ($\overline{X} = 61.9$), but much lower ($\overline{X} = 48.4$) during week four (see Table 3).

Further analysis revealed more specific information regarding the four individual CQLI items. Table 4 summarizes scores for social, emotional, physical, and financial quality-of-life domains.

Relationships Among Variables

No relationship was found between caregiver age and total score or between age and the scores on the four items of the CQLI. No correlation existed between the caregivers' years of education and total CQLI scores. A weak positive correlation did exist, however, between caregivers' years of education and their financial quality of life scores (r = 0.31, p < 0.01).

A comparison of means scores between male and female caregivers revealed that females had slightly higher total mean scores and higher scores on emotional and physical quality-of-life items at admission. These scores evened out for the small group of caregivers (n = 28) remaining in the study by week four (see Table 5). Statistical analysis of differences was not feasible because of the small number of males in the primary caregiver sample.

Correlations among the items were weak to moderate ranging from 0.32–0.64 (see Table 6). The strongest correlation was between physical and emotional quality of life. The weakest correlation was between physical and social quality of life. Significant positive correlations were found between the caregivers' estimate of the pa-

Table 2. Hospice Quality of Life Index Scores on Admission and at Week Four

	1	Admission			Week 4		
Group	n	x	SD	n	x	SD	
Patients able to self-report	44	173.1	29.5	16	160.9	22.6	
Caregivers of patients able to self-report	44	164.2	25.6	20	163.6	22.7	
Caregivers of patients unable to self-report	24	144.9	30.2	8	157.4	28.7	

Table 3. Caregiver Quality of Life Scores

Group	n	x	SD
All Caregivers			
Admission	68	61.5	21.5
Week 4	28	58.7	24.2
Caregivers of the			
Responding Patients			
Admission	45	61.2	23.0
Week 4	21	62.1	22.6
Caregivers of the			
Nonresponding Patients			
Admission	23	61.9	18.8
Week 4	7	48.4	27.6
Noncaregivers	62	76.2	21.5

tients' quality of life using the HQLI and the caregivers' estimates of their own quality of life as reported on the CQLI (r = 0.40, p < 0.007). Total score on the HQLI, as reported by the patient, also was positively correlated with the emotional (r = 0.35, p < 0.02), financial (r = 0.44, p < 0.004), and physical (r = 0.35, p < 0.03) domain items on the CQLI. No significant correlation existed with the social domain item (r = 0.11).

Table 4. Caregiver Quality of Life Scale Domain Item Scores^{α}

Item	n	x	SD	t	р
Emotional					
Domain Item					
 Noncaregivers 	62	82.4	18.3		
 Caregivers on 				5.09	< 0.001
admission	68	61.0	27.8		
 Caregivers at 					
Week 4	28	56.0	27.0		
Social					
Domain Item					
 Noncaregivers 	62	86.5	13.7		
Caregivers on				4.14	< 0.001
admission	68	72.0	24.1		
 Caregivers at 					
Week 4	28	69.0	23.9		
Financial					
Domain Item					
 Noncaregivers 	62	63.2	31.0		
 Caregivers on 				1.59	ns
admission	68	54.6	30.3		
 Caregivers at 					
Week 4	28	46.5	31.2		
Physical					
Domain Item					
 Noncaregivers 	62	72.7	26.5		
 Caregivers on 				2.9	< 0.005
admission	68	58.2	30.4		
 Caregivers at 					
Week 4	28	63.1	29.5		

^a Scores may range from 0 to 100.

ns = nonsignificant

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Table 5. Caregiver Quality (of Life	Scores by	/ Gender
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	Female Caregivers			Male	Aale Caregi	
Source	n	x	SD	n	x	SD
Admission						
Emotional Item	57	64.4	27.2	10	47.0	22.4
Social Item	57	72.5	23.8	10	75.6	16.6
Financial Item	57	55.1	31.2	10	57.0	21.7
Physical Item	57	60.0	29.3	10	53.3	33.8
Total score	57	63.1	21.5	10	58.2	13.2
Week Four						
Emotional Item	23	56.0	28.3	4	58.0	26.1
Social Item	23	67.7	25.1	4	78.3	19.9
Financial Item	23	48.0	33.1	4	34.0	20.2
Physical Item	23	63.6	30.8	4	63.5	29.2
Total score	23	58.8	26.5	4	58.4	10.9

Validity and Reliability

CVIs were generated using the ratings of five former primary caregivers. The resulting CVIs for items all were 1.0, which resulted in an overall CVI of 1.0. Based on these findings, revision prior to use in the study was not deemed necessary.

Validity also was studied by comparing the caregivers with the noncaregiver adult volunteers. The mean score for caregivers ($\overline{X} = 61.45$, SD = 21.5) was significantly lower than the mean for noncaregiver adult volunteers ($\overline{X} = 76.19$, SD = 16.3) (t = 4.36, p < 0.000). On every CQLI item, the noncaregiver mean score was higher than the caregivers' mean score, and all differences were statistically significant except for the financial domain item (see Table 4).

The internal consistency reliability of the CQLI was assessed using Cronbach's alpha. At admission (n = 68), the alpha was 0.76, and the average interitem correlation was 0.44. In the fourth week of care (n = 28), the alpha for the CQLI was 0.88.

Discussion

Demographic Variables

 $^{\circ}n = 68$

One goal of hospice services is to improve the primary caregivers' quality of life. Although the caregivers' mean quality of life did not improve significantly, neither did it decrease significantly. The general trend was toward stability. Perhaps during a time of immense crisis and strain, such as the imminent death of a loved one, holding steady is the best one could hope for.

Two types of patients were included in the study-patients who were able to respond and patients who were too

Table 6. Pearson Correlations Among Items of the Caregiver Quality of Life Scale^a

Item	Emotional	Social	Financial	Physical
Emotional	1.00			
Social	0.45	1.00		
Financial	0.47	0.45	1.00	
Physical	0.64	0.32	0.43	1.00

debilitated to respond. Researchers expected that patients who were too debilitated to respond might pose a greater burden and, therefore, have a more negative impact on caregiver quality of life. On admission, this did not appear to be the case because the mean scores for the caregivers of responding and nonresponding patients were similar. After four weeks of hospice care, however, scores dropped for the seven caregivers of nonresponders who survived and remained in the study. This noticeable decrease in quality of life scores might be caused by the patients' excessive debility. In this case, hospice staff should take note of the need to offer greater support to caregivers who must care for debilitated patients for long periods of time. A limitation of the study is the small group of patients who survived for three weeks; only 28 caregivers remained in the study at the second data collection period.

The primary caregivers generally were older women caring for older men, a finding consistent with the other caregiver studies (Siegel et al., 1991; Stetz, 1987). The caregiver's age might be expected to be a factor in quality of life. However, this apparently was not the case. No relationship was found between age and total score or item scores on the CQLI. Thus, caregiving appears to have an impact on caregivers regardless of their age. A weak correlation existed between level of education and the CQLI financial domain item score. This suggests that better educated caregivers tended to have a somewhat better financial quality of life, which is not a surprising finding.

On admission, noticeable differences existed between male and female caregivers; male caregivers reported lower emotional and physical quality of life. This might suggest that males feel less able to be caregivers, a role that traditionally has been ascribed to women. These gender differences are consistent with the findings of earlier research (Carey et al., 1991). These differences no longer were apparent by week four; however, only 28 caregivers (4 of whom were male) remained in the study by this point.

Quality-of-Life Variables

Moderate correlations existed among items on the CQLI. This suggests that the four items assess related, but essentially different, aspects of quality of life. The stronger correlation between physical and emotional quality of life might be expected given the essential relatedness of the physical and psychological aspects of the human being. This result supports those of Given et al. (1992) who found a significant relationship (r = 0.57) between the physical impact of caregiving and caregiver depression.

Conversely, the weaker correlation between social and physical quality of life also was predictable. In some cases, a caregiver's weakened physical state might result in social isolation; in others it might result in increased social support. The amount and types of support would be very individual, depending on the situation. This study was conducted in Florida where many retirees have settled away from their nuclear or extended families. Thus, isolation is a real possibility. However, many of these same retirees have been in Florida long enough to have built up a network of social support that would sustain them through any crisis. The caregiver's social support is an important aspect for the hospice team to assess.

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One interesting finding was the positive correlation between the caregiver's assessment of the patient's quality of life (on the HQLI) and the caregiver's assessment of his or her own quality of life (on the CQLI). Although the correlation was not strong (r = 0.40), it was considerably stronger than the correlation between the patient's score on the HQLI and the caregiver's score on the HQLI (r = 0.06). This result might suggest that the caregivers' perception of the patients' quality of life influences their perception of their own quality of life. Conversely, this result might indicate that the caregivers' own quality of life. This finding supports the idea that the hospice team should focus on the interrelatedness of the patient's and the caregiver's quality of life as care is being planned.

Validity and Reliability of the Caregiver Quality of Life Index

Evidence of validity of the newly developed CQLI was provided in three ways. First, the CQLI was developed based on a careful review of the literature. This provided beginning confidence in its validity. Second, prior to its use in the study, a group of content experts (five caregivers) evaluated the items. The resulting CVI was high (1.0) providing further support for its validity. Third, as part of the study, construct validity was evaluated using the known groups technique. The difference between total scores of the caregivers and the noncaregivers was statistically significant, suggesting that the tool can differentiate between the levels of quality of life of adults who are and are not serving as caregivers. This lends additional evidence for the construct validity of this newly developed instrument. Although the instrument is brief, with items that are fairly global in scope, it is able to discern varying levels of quality of life.

Likewise, the individual items were able to differentiate between the caregivers and the noncaregivers. Each of the four-item means was higher for the noncaregiver group

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than for the caregiver group. This suggests that all four elements included in the caregiver quality of life instrument are affected by caregiving, thus confirming their relevance in the instrument.

The length of the tool was a study limitation. A fouritem tool decreases variability in scores with possible negative implications for reliability. However, the reliability of the CQLI using Cronbach's alpha (r = 0.76 and 0.88) appeared to be good for a new tool, especially one with only four items. Thus, although brief, the CQLI appears to have adequate reliability. This data, although limited, provides beginning evidence for the validity and reliability of the new CQLI. A valid and reliable instrument such as the CQLI potentially is useful in clinical practice as part of an overall assessment of hospice caregivers. Because it is short, it may be more useful in clinical settings than other longer quality-of-life measures. However, further study of the validity and reliability of the CQLI is warranted.

Conclusions

Study results suggest that during a time of strain and crisis, caregivers of patients with cancer who are terminally ill who receive hospice services for three weeks are able to maintain their quality of life. Caregiver quality of life also appears to be related to the caregiver's perception of the patient's quality of life. Hospice staff and other healthcare providers need to focus attention on the specific needs of primary caregivers of patients with cancer who are terminally ill. Assessment, planning, implementation, and evaluation of care for hospice caregivers should address the four domains of quality of life—physical, emotional, social, and financial.

In addition, the study provided evidence of the validity and reliability of a new instrument designed to evaluate quality of life of hospice caregivers. Although the evidence provided is strong, a single study never is sufficient, and further research is needed.

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