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## Informal Hospice Caregiving: The Toll on Quality of Life

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According to the National Hospice and Palliative Care Organization's Standards of Practice for Hospice Programs, a primary goal of hospice care is to enhance the quality of life of individuals and their families during the final stages of illness, the dying process, and the bereavement period (National Hospice and Palliative Care Organization, 2000). Notably, the dyad of patient and family is the focus of care in these standards rather than the patient alone. These services, provided to terminally ill patients who are expected to live less than six months and their families, are considered the gold standard for end-of-life care (Eues, 2007). The professionals who provide hospice care are members of an interdisciplinary hospice team, comprised of physicians, nurses, social workers, chaplains, and others. Together, they aim to address the patient's physical symptoms as well as the emotional and spiritual concerns of the patient and family (Janda et al., 2007; McMillan & Mahon, 1994; Moody & McMillan, 2003).

However, the provision of hospice care increasingly relies on the ability of a non-hospice professional to perform caregiving tasks at the patient's home. These "informal caregivers" are frequently spouses/partners or adult children but may also be siblings, parents, other relations, or friends. Informal caregivers take on such tasks as medication administration, symptom evaluation, personal care and other activities of daily living. Additional tasks may include emotional support for the patient and legal and financial assistance. In many cases, caregivers may have jobs or other caregiving responsibilities to simultaneously maintain. (McMillan & Mahon, 1994; Weitzner, McMillan, & Jacobsen, 1999). It has been suggested that caregivers additionally act as a buffer for patients by taking on responsibilities related to the coordination of services and providers—a task that can be frustrating, complex, and taxing if there is not good communication among all parties (Fleming et al., 2006). All of these responsibilities must be managed while simultaneously witnessing and coping with the impending death of a loved one.

If no one is able to fulfill this role or a caregiver becomes unable to perform the required activities, there may be tangible consequences for the patient. Patients may receive suboptimal quality of care and have unmet needs, or the arrangement for care at home may completely collapse (Carter, Lewin, Rashid, Adams, & Clover, 2007). Patients may thus become unable to conclude the dying process at home as may be desired, and they likely will require transfer to a nursing home or other care facility. Such a move frequently leads to less personalized care, disruption of care continuity, and additional expense (Stewart, Teno, Patrick, & Lynn, 1999; Weitzner et al., 1999). Because informal caregivers are so necessary, and because the aforementioned goals of hospice care include attention to patients' families, hospice providers need to be concerned about the quality of life consequences of caregiving for caregivers. Understanding and addressing the needs of informal caregivers throughout the dying process and bereavement period is essential if hospice is to achieve its stated objectives.

### Quality of Life: Theory and Background

The concept of quality of life may be defined as including at least four domains: physical, psychological, social, and financial well-being (Edwards & Ung, 2002; McMillan & Mahon, 1994). Though these domains are interrelated in that one domain may affect quality of life in

another area, each is a unique contributor to overall quality of life (Bocchi & Angelo, 2008). An essential feature of the construct of quality of life is also that it is a subjective judgment of well-being rather than an externally imposed measure (Bernhard, Lowy, Mathys, Herrmann, & Hurny, 2003).

A significant influence on quality of life is the availability of resources. Such resources include the sociodemographic, medical, psychosocial, and physical factors that allow an individual to meet internal and external demands. According to Lazarus' coping theory, if perceived demands exceed perceived resources, decreased quality of life may be one of the consequences of poor coping (Kim & Given, 2008; Lazarus, 1993). If on the other hand caregivers can mobilize their resources to handle the stress of caregiving, quality of life may not suffer (Van Puymbroeck & Rittman, 2005). Thus, quality of life is an outcome that results from a variety of internal and external factors (e.g. resources) and processes (e.g. coping).

As the importance of the informal caregiver has become more widely recognized, research has begun to document the difficulties and burdens associated with this role including its effect on quality of life. Caregivers of cancer patients, for example, have been a topic of recent research and have been found to exhibit problems in each of the four domains. With respect to social well being, caregivers of cancer patients may have few opportunities to socialize, have disrupted schedules, lack sufficient support by friends and family for caregiving activities, and feel isolated or trapped at home. Psychological and emotional difficulties include distress about the patient's condition and increased depression and anxiety. The financial cost of caregiving can also be overwhelming due to the cost of healthcare, lost time at work or changing jobs, or even needing to move to another location to provide care. Physically, many caregivers experience sleep disturbances, severe fatigue, and poorer physical health; they may also be less likely to resolve existing medical problems (Carter et al., 2007; Edwards & Ung, 2002; Grunfeld et al., 2004; Hanratty, Holland, Jacoby, & Whitehead, 2007; McMillan & Mahon, 1994; Weitzner et al., 1999). For caregivers of patients with AIDS, symptoms of worrying, feeling sad, pain, difficulty sleeping, and irritability have also been found (Sherman et al., 2007). In a sample of terminal patients who were veterans, caregivers had significant unmet concrete and psychosocial needs (Cheng et al., 1994). Overall, informal caregiver quality of life has been shown to be lower than the general population in multiple settings. However, there is evidence that if caregivers are adequately supported, a decrease in quality of life may not simply be inevitable (Chentsova-Dutton et al., 2000; Janda et al., 2007; Pinguart & Sorensen, 2007; Sorrell, 2007).

It is unclear how demographic variables may affect caregiver quality of life since the results of past studies have been mixed. Various studies have found combinations of the following caregiver characteristics to be predictors of quality of life for cancer caregivers: relationship to the patient, gender, age, marital status, and education (Moody & McMillan, 2003). Carter et al (2007) found that better quality of life was correlated with caregivers who were married to the patient, male, older, and had at least a high school education. However in a study conducted by Sherman et al (2007), caregivers who were married to the patient had increased psychological symptoms, implying poorer psychological quality of life. Yet another study found that coping strategies of older caregivers were fewer and less effective (Raleigh, Robinson, Marold, & Jamison, 2006). Using a meta-analysis of previous work, researchers found that female caregivers had poorer well being than male caregivers and greater stress and depression were found in older spouses as compared to adult children. However, a complicating finding was that regardless of relationship to the patient, there was more depression in older caregivers but more stress in younger caregivers. This was thought to be due to fewer coping resources for older caregivers but more competing roles (e.g. jobs, other caregiving responsibilities) for younger caregivers (Pinguart & Sorensen, 2007). Interestingly, the status and characteristics of the patient may too have predictive value for better caregiver quality of

life, such as the patient being married, older, with a high school education or higher, and currently feeling well or having less symptom distress (Awadalla et al., 2007).

Returning to the concept of treating the patient and caregiver as a dyad, or unit of care, past research has shown that the quality of life of patient and caregiver is often linked directly or indirectly. Overall quality of life for brain tumor patients and their caregivers has been found to be correlated (Janda et al., 2007), while caregivers' impressions of cancer patients' quality of life, for example, can also predict patient and caregiver quality of life. (Awadalla et al., 2007; McMillan & Mahon, 1994). In a study of terminal cancer patients, mental health of patients was specifically linked to the mental health of caregivers (Fleming et al., 2006). Caregiver quality of life in another study of cancer patients was found to be correlated with but worse than patient quality of life (Carter et al., 2007), and it has been noted that family members of dying patients need just as much or possibly more support than the patient (Stewart et al., 1999). Thus, attention to caregiver quality of life is important for both the caregivers themselves and the patients under their care.

Despite increasing attention to the caregiver component of the patient-caregiver dyad in general, only a subset of research to this point focuses on caregivers of terminal patients receiving hospice care. Several studies have focused on caregivers of cancer patients who are in stable condition (Awadalla et al., 2007) or patients who are in recovery, e.g. from a stroke (Van Puymbroeck & Rittman, 2005). However, a cross-sectional study that did directly compare family caregivers of terminal cancer patients receiving hospice care with family caregivers of cancer patients receiving active treatment found that the former had significantly worse quality of life, greater impairment in physical function, poorer general and physical health, and less vitality. This was attributed to patients' poorer performance status (Weitzner et al., 1999), which has been linked to poorer quality of life for caregivers in other research as well (Janda et al., 2007).

Most of the studies that focus on caregivers in end-of-life situations have been of cross-sectional design and thus unable to describe the caregiver experience longitudinally over time. The few studies that have looked at caregivers longitudinally provide evidence that cancer caregiver quality of life decreases near patient end of life (Grunfeld et al., 2004) as does quality of life for caregivers of ALS patients (Gauthier et al., 2006). However, no difference was found in a small study (n=28) which measured hospice caregivers of cancer patients at admission and after four weeks of hospice stay (McMillan & Mahon, 1994). Two countering conceptual models of the long-term effects of caregiving have thus been used to describe trends in the caregiving experience. The wear-and-tear model posits that the stress of caregiving over time erodes physical, psychological, and social coping such that a decrease in quality of life results, whereas the adaptational model theorizes that role accommodation can occur and negative effects will not necessarily result over time if effective coping strategies are utilized. Evidence thus far is equivocal as to which model is a better fit or, more specifically, for which caregivers under what circumstances each trajectory is likely (Gauthier et al., 2006; Kim & Given, 2008; Raleigh et al., 2006).

Research in palliative care, particularly in the hospice setting, is distinctively difficult due to recruitment issues, attrition due to patient death, and ethical considerations in approaching caregivers of dying patients, yet a better understanding of quality of life issues over the course of hospice stay is essential to learning how to provide adequate support to caregivers. It is also important to understand the experience of all hospice caregivers rather than only those who care for cancer patients, who represent a large but decreasing percentage of hospice patients (National Hospice and Palliative Care Organization, 2008). In at least one population of caregivers for AIDS and cancer patients, no significant differences were found in either symptom experiences or changes in quality of life between the two groups over a three-month

period (Sherman, Ye, Calabrese, & Gatto, 2006; Sherman et al., 2007), but more research is needed.

The purpose of the present study is to determine the quality of life experienced by informal hospice caregivers when hospice services are initiated. Furthermore, we aim to describe the trajectory of quality of life after one month of hospice services. Our intention is to improve current understanding of the informal hospice caregiver experience and provide a basis for developing clinical interventions and future studies. The research questions informing this study are: (1) Upon patients' admission to hospice services, how do informal caregivers self-evaluate their emotional, social, financial, and physical quality of life? (2) How does perceived quality of life in these domains change after one month in the role of informal hospice caregiver?

## Methods

### Participant recruitment

Informal caregivers (n=76) and the patients they cared for (n=72) were recruited from two small hospices in the Midwestern United States as part of two separate studies focusing on psychosocial needs of hospice patients and their caregivers. Both studies were approved by the supporting university's Institutional Review Board and participating hospices' research review boards. The slightly greater number of caregivers as compared to patients reflects four cases in which two caregivers of a single patient were identified and included. Inclusion criteria for patient and caregiver participants were: a) over the age of 18 years, b) access to a standard telephone line, c) without functional hearing loss or with a hearing aid that allowed the participant to conduct phone conversations, d) intact mental status as demonstrated by having a score greater than or equal to seven on the Short Portable Mental Status Questionnaire (Pfeiffer, 1975) as assessed by the hospice registered nurse.

Upon admission to hospice services, all patients/caregivers who met the inclusion criteria were notified that the hospice was involved in a research study to improve patient/family services and were asked for consent to a visit by a Research Project Coordinator (RPC) for more information. If consent was granted, the patients/caregivers were referred to the RPC for actual recruitment to the study. Once patients/caregivers consented to participation in the study, the RPC enrolled them and initiated the study plan.

### Measures and administration

Caregiver quality of life was measured using the Caregiver Quality of Life Index-Revised (CQLI-R). The CQLI was developed by McMillan and Mahon (1994), and it was later revised and re-validated for use as an interview instrument (Courtney, Demiris, Oliver, & Porock, 2005). The CQLI-R consists of self-reported quality of life for the following four items: emotional, social, financial, and physical. Each item is a scale from 0–10 with anchor descriptions of characteristics of someone who epitomizes the lowest (i.e. 0) and highest (i.e. 10) quality of life for the given item. This instrument has been found to have strong psychometric criteria for reliability, and it has been recommended in published reviews of caregiver quality of life instruments for its brevity, reliability, and validity (Edwards & Ung, 2002).

Upon enrollment, each caregiver completed an initial CQLI-R during an interview with the RPC. Demographic information about the patient and caregiver was also collected at this time. The CQLI-R was subsequently administered by phone interview at one month following enrollment.

## Statistical analysis

Demographic information was characterized using frequencies and percentages. A total CQLI-R score was calculated for caregivers' total quality of life by summing the four subscale scores for a total score out of 40 points. Means were then calculated for each of the four subscales as well as total quality of life. For the subsample (n=45) of caregivers who were able to provide one-month CQLI-R responses, the Wilcoxon signed-rank test was then used to compare the mean scores for caregivers on each subscale as well as total quality of life between initial CQLI-R (study enrollment) and CQLI-R at one month. Attrition rate, median days between admission and enrollment, and median days between initial and one-month CQLI-R completion were also calculated. ANOVA was also performed to evaluate any differences in initial caregiver quality of life and in change in caregiver quality of life across the following caregiver and patient demographic variables: gender, ethnicity, other caregiving responsibilities, employment status, marital status, residence, education level, relationship to patient, and patient primary diagnosis. Data were analyzed with SPSS software.

## Results

The demographics of caregivers and the patients they cared for are listed in Tables 1 and 2. The average age of caregivers in this sample was 59 years (range: 22–87 years). The majority of them were female (82.9%), white (96.1%), married (73%), and had an education level of some college or higher (73.5%). Two-thirds of caregivers were living with the patient (66.7%) and without employment outside the home (66.7%). More than half did not have other caregiving responsibilities (58%). Relationship to the patient was frequently adult child (40.8%) or spouse (35.5%), with the remainder being parent, sibling, or other. The average age of patients in this sample was 75 years (range: 43–101 years). The majority of patients were white (97.2%) and resided at home (86.1%), but there were a similar number of males and females. Cancer was the primary diagnosis in 50% of patients.

Results of the CQLI-R assessments are summarized in Table 3. At initial CQLI-R assessment for the entire sample, quality of life was regarded as being the highest in the social domain (7.91). Emotional quality of life was the next highest (7.71), followed by financial (7.00), with physical quality of life being the lowest (6.80). Median number of days from patient hospice admission to initial CQLI-R completion was 10.5 days.

At one month following study enrollment, 45 caregivers of 43 patients remained in the study and completed the one-month CQLI-R. Thus, one-month CQLI-R was not obtained from 31 caregivers—an attrition rate of 41% within approximately 30 days of study enrollment. The primary reason for discontinuation with the study prior to data collection of the one-month CQLI-R was patient death, as was the case for 27 caregivers of 25 patients in this sample; four caregivers withdrew from the study.

For the subsample of caregivers who completed a one-month CQLI-R, the median number of days from initial CQLI-R to one-month CQLI-R was 32 days. Analysis with the Wilcoxon signed-rank test revealed that caregiver total quality of life significantly decreased an average of 3.85 points approximately one month after patient enrollment in hospice ( $p < 0.01$ ). Analysis of the subscales showed a significant decrease of 1.27 points in caregivers' emotional quality of life ( $p < 0.01$ ) and a significant decrease of 1.98 points in caregivers' social quality of life ( $p < 0.01$ ). Physical quality of life decreased an average of 0.53 points but did not reach statistical significance. Financial quality of life was the most stable, decreasing by only 0.07 points. Finally, ANOVA revealed no statistically significant differences in either initial caregiver quality of life or change in caregiver quality of life across any of the demographic variables analyzed.

## Discussion

The purpose of this study was to describe the well being of informal caregivers at hospice enrollment and one month later in terms of social, emotional, financial and physical quality of life. With regard to the first research question, caregivers self-reported that their social quality of life was the highest and physical quality of life was the lowest at the point that hospice services had been recently initiated. However, the range in mean scores for the four subscales was not extremely broad, spanning from 6.80 to 7.91 on a 0–10 scale. Although a control sample was not part of this research design, these responses would point to an overall medium-high perceived quality of life in all four domains. This may reflect cases in which participants had not yet been very negatively affected by the caregiver role, cases in which participants had largely adjusted to the caregiver role, or it could reflect having recently gained the support of hospice professionals. High social quality of life may especially reflect initially strong support from hospice staff as well as friends and family upon patient's admission to hospice services. Physical quality of life being ranked lowest could relate to the age of the caregivers as well as to the physical demands of caregiving to that point.

For the second research question, our hypothesis that caregiver quality of life would decrease was partially confirmed. There was a significant decrease in social, emotional, and total quality of life. Physical quality of life also decreased but the change did not reach statistical significance. Meanwhile, financial quality of life was quite stable.

It is notable that social quality of life started as the highest reported quality of life domain but became the lowest reported quality of life domain after one month. This change may result from the perception of waning support from one's social network or from inadequate seeking or accepting of help from others when needed. Our results provide strong support for efforts by hospices to continue to develop and improve interventions that help caregivers utilize coping strategies, such as seeking social support to help maintain their quality of life, a technique that is useful for caregivers of non-terminal and terminal patients alike (Bocchi & Angelo, 2008; Raleigh et al., 2006).

Decreased emotional quality of life is likely partially attributable to impending loss of a loved one and the probable deteriorating condition of the patient. To some extent, this may be an unavoidable part of the grieving process that begins at patient's diagnosis with a terminal prognosis; providing emotional support to the patient has also been reported to be one of the most difficult caregiving tasks. However, it has been argued that health care may have greater power to moderate quality of life at the end-of-life than at any other time (Stewart et al., 1999). Thus emotional quality of life is another area of focus for hospice providers that may not be receiving as much attention and support as could be helpful during the dying process and bereavement period.

Implications of the social and emotional quality of life findings are relevant to the work of the entire hospice team but are unquestionably important for social workers. According to the National Hospice and Palliative Care Organization (2008), hospice social workers are responsible for providing services to an average caseload of 23.4 patients and families, compared to 9.5 for home health aides and 11.2 for nurse case managers. These numbers may point to a structural lack of support for social workers to have the time needed to thoroughly address social and emotional needs of caregivers as well as patients. However, it is a positive finding that hospice caregivers in a previous study identified hospice nurses, aides, and social workers as contributing significantly to their support system; this demonstrates the important role that hospice workers already have in helping caregivers adapt and implies an opportunity for even further influence (Raleigh et al., 2006). Bereavement counselors and others who provide a bridge between pre and post-bereavement periods with caregivers must also be aware

of pre-bereavement symptomatology and levels of social support, which have been found to be predictive of post-bereavement depression (Kurtz, Kurtz, Given, & Given, 1997).

The stability of financial quality of life may reflect the fact that the majority of caregivers in our sample were not currently employed and were not placing a source of income at risk by taking on caregiving responsibilities. Stable financial quality of life may also be a sign that Medicare (for patients 65 years and older) and private insurance coverage of hospice services are providing caregivers some relief from the documented financial strain of medical care and caregiving in the United States—especially as compared to more aggressive and often fruitless end-of-life options. As both a humane way to provide a dignified death and a cost-saving option for end-of-life care, future policy should continue strive to improve funding for and access to hospice services (Carlson, Morrison, & Bradley, 2008). Low socioeconomic, rural, minority, and older patients are unfortunately underrepresented in hospice utilization (Ahmed et al., 2004; Casey, Moscovice, Virnig, & Durham, 2005; Kwak, Haley, & Chiriboga, 2008), and only 25% of patients overall who qualify for hospice care actually enroll (Eues, 2007).

Finally, physical quality of life remains an area worthy of investigation. Although we did not find a statistically significant decline, this domain was the lowest-ranked at initiation of hospice services and did slightly decrease after one month. Hospice staff can work to improve physical quality of life by checking that caregivers are seeking medical attention for ongoing issues and simply being alert to physical signs in caregivers as opposed to patients alone. This finding may also suggest the value of a formal physical assessment of caregivers to determine if their perception of physical decline is correlated to actual physical decline due to caregiving. It should be noted that as life expectancy continues to lengthen and the population ages, more and more caregivers are likely to be elderly; this may affect the physical ability of more and more possible caregivers to provide patient care.

The demographics of our sample are similar to those found in previous research in that most hospice caregivers are female and middle-aged or elderly (Janda et al., 2007; McMillan & Mahon, 1994; Moody & McMillan, 2003). Past studies have reported variable findings as to the difference that demographic variables may make in caregiver quality of life. We were unable to make any of these distinctions in this sample at initial CQLI-R assessment, which may be attributable to insufficient heterogeneity within a small sample. However, further research will hopefully provide clarification as to what characteristics may predict vulnerable quality of life for caregivers. Such findings would be clinically valuable for early initiation of supportive interventions for caregivers at increased risk.

Recognized limitations of the present study include small sample size and recruitment and attrition issues, well-documented and challenging problems in palliative care research (McMillan & Mahon, 1994; Sherman et al., 2005; Sherman et al., 2007). Patient death was by far the most frequent reason for withdrawal from the study prior to one-month data collection, and we suggest more frequent assessment in future research. Difficulties in recruitment of this sample, e.g. delay in enrollment following admission, were compounded by a natural disaster that occurred in the region of one of the involved hospices. Also, we cannot rule out the effect that self-selection may have had in determining participation. It is quite possible that caregivers with a lower quality of life were less willing or interested in becoming involved in such a project, especially at a time of increased stress. Those who withdrew may have done so for reasons that could be associated with decreased quality of life. Our inclusion criteria also ruled out caregivers who had functional hearing loss, those without access to a phone line, and those who cared for patients without intact mental status; the latter of these criteria is particularly known to be an arduous task that results in diminished quality of life for caregivers and frequent patient institutionalization (Argimon, Limon, Vila, & Cabezas, 2005; Mausbach et al., 2006;

Pinquart & Sorensen, 2007). Another limitation was lack of a control sample for our first research question.

In addition, we did not administer a measure of the patient's relative caregiving requirements. It was not known, for example, how many hours per day were spent caregiving or the physical strength needed to perform tasks. Some patients require more constant care and are less able to perform tasks such as bathing or toileting on their own; such differences are likely to be reflected in caregiver quality of life. Some patients are also closer to dying at the point they enter hospice services and/or are at different stages of illnesses with different trajectories (McMillan & Mahon, 1994). The length of time between patient diagnosis and hospice admission and/or the length of time a caregiver has been performing caregiving duties prior to hospice admission are other potentially important factors that were not measured in this study. Another limitation in instrumentation is that the CQLI-R is ideal for its brevity but conversely lacks the detailed information of a more elaborate measure. It is similarly noted that our calculation of total quality of life assumes that the four domains are the only contributors and equal contributors to global quality of life. As we did not separately ask for a global quality of life self-rating to be interpreted by the caregivers themselves, nor did we ask caregivers how important each domain was to them, our analysis is somewhat limited. Indeed, there is some evidence that quality-of-life as it relates to health may not be a constant construct, with different domains becoming more or less important at various points (Bernhard et al., 2003). More research is needed to understand how the relative importance of these domains and others, such as spiritual and cultural, play into hospice caregiver quality of life specifically.

## Implications and Conclusions

Despite recognized limitations and difficulties, our findings are a valuable addition to the current literature available on informal hospice caregivers' quality of life. We found that physical quality of life was the lowest of the four domains near hospice admission while emotional, social, and total quality of life significantly declined over the first month of hospice care. These are areas of particular concern to the interdisciplinary hospice team, especially those who focus on supporting caregiver emotional and social quality of life, such as social workers, chaplains, and counselors.

Hospice providers, and social workers in particular, should pay increased attention to assessing and proactively addressing caregiver needs in these domains. Currently, much of this assessment is informal. Any discussion of psychosocial needs of caregivers may be overshadowed by attention to the physical symptoms of patients in hospice interdisciplinary team meetings (Parker Oliver et al., in press). Although quality of life is a stated focus of palliative and hospice care, quality of life data has not been uniformly collected in clinical practice due in part to logistics (Morris, Perez, & McNoe, 1998). Furthermore, the median length of service for hospice patients is just under three weeks, which grants only a narrow window of opportunity to intervene with many caregivers prior to patient death (National Hospice and Palliative Care Organization, 2008). However, it would likely be feasible to incorporate a formal, perhaps weekly, brief measure of caregiver quality of life status such as the CQLI-R into standard evaluation within the hospice setting. Use of other standardized assessment tools, such as the Social Work Assessment Tool (SWAT), would further assist in providing an understanding of issues facing informal hospice caregivers (Reese et al., 2006). This would help hospice providers, especially social workers, quantitatively describe to the hospice team and identify for intervention those caregivers who are experiencing poor quality of life. Since hospice services are frequently provided at patients' homes rather than at a central location, the ability to complete a brief interview by phone, as was done here, or via Internet would limit the amount of additional time and resources such screening would require from hospice providers and informal caregivers. More research is needed to aid professional



providers in clarifying how to predict who may be most susceptible to deteriorating quality of life related to caregiving responsibilities as well as which interventions are most effective. Suggestions for possible interventions include caregiver education, respite services, referral to psychological counseling, support groups, and measures to improve communication—some of which have already shown promise (Chentsova-Dutton et al., 2000; Demir, Oliver, Courtney, & Day, 2007; Hudson, Hayman-White, Aranda, & Kristjanson, 2006). Meanwhile, the assurance that hospice is doing its best to relieve a loved one's suffering is also critical in treating the patient-family unit and may do much to decrease the stress felt by caregivers (Eues, 2007).

We conclude that caregiving for a dying loved one is a uniquely demanding task. The informal caregiver role is both necessary for the provision of gold standard end-of-life care as well as an important target for support within the hospice philosophy. It is exceedingly important for the following to occur: 1) future policy should address issues such as overall access to hospice services and lack of adequate structure of services to address psychosocial needs, 2) hospice teams must strive to continually improve their clinical services with regard to caregivers' quality of life, especially in the emotional and social domains, and 3) future research needs to further investigate the complexities of caregivers' needs and offer effective, clinically-proven interventions. In this way, hospices can reach their goal of supporting and honoring the needs and wishes of patients and their caregivers throughout the end of life.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**  
Demographics of Caregivers

Characteristic	n (%) <sup>a</sup>
Gender	
Male	13 (17.1)
Female	63 (82.9)
Age	
20–29	1 (1.6)
30–39	5 (7.8)
40–49	10 (15.6)
50–59	17 (26.6)
60–69	13 (20.3)
70–79	13 (20.3)
80–89	5 (7.8)
Missing values	12
Ethnicity	
Caucasian	73 (96.1)
African American	2 (2.6)
Asian	1 (1.3)
Residence	
Lives with patient	50 (66.7)
Does not live with patient	25 (33.3)
Missing values	1
Marital Status	
Never married	5 (6.8)
Widowed	4 (5.4)
Divorced/Separated	11 (14.9)
Married	54 (73.0)
Missing values	2
Other caregiving responsibilities	
Yes	29 (42.0)
No	40 (58.0)
Missing values	7
Employment	
None outside the home	46 (66.7)
Part-time employment	3 (4.3)
Full-time employment	17 (24.6)
Volunteer work	3 (4.3)
Missing values	7
Education	
Less than high school	4 (5.9)
High School	14 (20.6)
Some college	29 (42.6)
Undergraduate degree	10 (14.7)

Characteristic	n (%) <sup>a</sup>
Graduate degree	11 (16.2)
Missing values	8
Relationship to patient	
Spouse/partner	27 (35.5)
Adult child	31 (40.8)
Parent	1 (1.3)
Sibling	3 (3.9)
Other	14 (18.4)

<sup>a</sup>Percentage of valid cases is reported.

**Table 2**  
Demographics of Patients

Characteristic	n (%) <sup>a</sup>
Gender	
Male	33 (45.8)
Female	39 (54.2)
Age	
40–49	5 (7.4)
50–59	5 (7.4)
60–69	15 (22.1)
70–79	14 (20.6)
80–89	22 (32.4)
90–99	10 (14.7)
100+	1 (1.5)
Missing values	4
Ethnicity	
Caucasian	70 (97.2)
African American	1 (1.4)
Asian	1 (1.4)
Residence	
Home	62 (86.1)
Long-Term Care Facility	10 (13.9)
Primary Diagnosis	
Cancer	36 (50.0)
Heart	9 (12.5)
Lung	12 (16.7)
Diabetes	1 (1.4)
ALS	1 (1.4)
Failure to thrive	6 (8.3)
Stroke	1 (1.4)
Other	6 (8.3)

<sup>a</sup>Percentage of valid cases is reported.

**Table 3**

Average Quality of Life for Informal Hospice Caregivers

Observation	Quality of Life Domain					Total
	Emotional	Social	Financial	Physical		
Initial CQLI-R (n=76) <sup>a</sup>	7.71	7.91	7.00	6.80		29.42
Initial CQLI-R (n=45) <sup>b</sup>	7.71	7.96	6.71	6.71		29.09
1 month CQLI-R (n=45) <sup>b</sup>	6.44	5.98	6.64	6.18		25.24
Mean Difference from initial to 1 month CQLI-R (n=45) <sup>b</sup>	-1.27**	-1.98**	-0.07	-0.53		-3.85**

\*\*\*  
p<0.01

<sup>a</sup>Represents data from total sample;

<sup>b</sup>Represents data from subsample