

Reciprocal Suffering: The Need to Improve Family Caregivers' Quality of Life through Palliative Care

DEBORAH WITT SHERMAN, Ph.D., R.N., ANP, CS

ABSTRACT

There is growing recognition of the reciprocity of suffering by patients and families experiencing terminal illness and the need to improve the quality of their lives as the patient's illness progresses. Research is presented that addresses the importance of a dyadic perspective in recognizing patients' and families' stress and adjustment and the related physical, emotional, social, spiritual and financial needs at the end-of-life. These aspects of quality of life are specifically addressed by palliative care. The philosophy and goals of palliative care are described, as is its role in promoting the best possible quality of life for patients and their families experiencing terminal illness. This article addresses the importance of assessing the dynamics of the family caregiving system and potential palliative care interventions to enhance the quality of life of family caregivers. Implications for research are also discussed.

A PERSON'S FAMILY is often the primary source of physical and emotional support in times of distress. At no time is there any greater stress than when a person is diagnosed with a terminal illness, which engenders myriad complex physical, emotional, social, and spiritual needs. Yet, recent changes in the health care system have often led to a patient's early discharge from hospital to home with both acute and chronic conditions and with limited or no home care assistance. Many terminally ill patients also are expressing a desire to return home, and end-of-life care at home is again becoming a part of our social norm.¹ Home care attempts to provide a sense of normalcy for the patient and to provide an environment that sustains relationships without the technological stressors inherent in a hospital environment.²

With this has come the expectation that family members accept the physical and emotional

responsibility of being direct care providers. However, most family members are unprepared to deal with the physical and emotional needs of their loved ones and the intense demands inherent to the caregiver role. Suffering, in the form of physical, emotional, social, and spiritual distress, that accompanies terminal illness thus becomes an experience not only of the patient, but of their family caregivers. As the patient's illness progresses, the needs of the family also intensify and change, with both patients and family caregivers potentially experiencing a significant compromise in the quality of their lives.

Health care professionals are now realizing that family caregivers are indeed "second-order patients" who are in need of care and support.³ Although family caregivers serve as members of the caregiving team, they too must be recipients of palliative care. Palliative care,

as a philosophy of care, provides a combination of active and compassionate therapies intended to comfort and support patients and families who are living with life-threatening illness.⁴ This article will therefore address the reciprocal suffering of family caregivers, specifically their physical, emotional, and social needs and issues in caring for terminally ill family members, as well as the associated changes in their quality of life and the opportunities for health care professionals to improve family caregivers' quality of life through palliative care and related research.

RECIPROCAL SUFFERING: THE STRESS OF FAMILY CAREGIVERS

Suffering is an innate component of incurable and terminal illness as people struggle with discomfort, disability, and the impending loss of all they have been and all they imagined they will be.⁵ Suffering has been described by Saunders⁶ as "total pain" which involves various physical, emotional, existential, and social factors that contribute to the experience. According to Cherney and colleagues, suffering is an aversive experience that undermines the quality of life.⁷ Chapman and Gavrin⁸ characterized suffering as the perceived physical and psychological threat to the integrity of self, negative affective quality, sense of perceived helplessness, and perceived loss. In more recent history, there has been a recognition of the intimate reciprocity of suffering by patients and families experiencing terminal illness. Their suffering is inextricably interrelated as the suffering of one amplifies the distress of the other.⁷ Ferrell⁹ also believes that the experience of suffering entails two related processes: one that is intrapersonal, involving the individual's attempt to cope with suffering, and the second that is interpersonal, involving the caring of others. Although family members may express the rewards of caring for terminally ill relatives, such care can have major psychosocial and physical effects, including heightened symptoms of depression, anxiety, psychosomatic symptoms, restrictions of roles and activities, strain in relationships, and poor physical health.¹⁰ This suffering has been acknowledged

by patients who report that their greatest concern is not their own pain, death, or other physical symptoms, but rather the impact of the disease on their families.¹¹

Like patients with a terminal illness, family members are in transition from living with the disease to anticipating the death of their loved one from the disease.² As a result of the illness, all members of the family, including the patient, face major changes in their lives that necessitate both internal and external adjustments in coping with the multiple aspects of loss. With the fear that death will occur in their absence, family caregivers may refuse to leave the patient's side for even a moment and can have a strong compulsion to attend to the patient's every need with disregard for their own needs.¹² However, if they do tend to their own needs, they are often wrought with a sense of guilt regarding their own health and their desire to live life.¹¹

In the face of the patient's pain and suffering, family caregivers also may experience a sense of powerlessness and are often frightened and confused by the dramatic physical and emotional changes they perceive in their loved one as the disease progresses.¹¹ There may be additional stress for family caregivers from having strangers in the home, physical changes to the home, and time away from work and friends. Disruptions in the family member's social life and the overall loss of social mobility, as well as social abandonment by friends, may negatively effect their quality of life.³ As a result of these stressors, family caregivers are subject to feelings of anger, jealousy, and an increase in their own needs because of their own heightened psychological distress.

The results of several studies have identified the stress on family caregivers when a member is seriously or terminally ill. Hays,¹³ in a descriptive study of 50 patients and caregivers in a hospice program, reported that family caregivers exhibited increased anxiety and fatigue in response to uncontrolled patient symptoms in the 10 days before the patient's death. Based on a sample of 77 adults with terminal cancer and their relatives, Hinton¹⁴ also found that relatives suffered grief and their own strain and ill health with serious depression and anxiety in the later stages of illness.

Beeney, Butow, and Dunn¹⁵ further reported that the spouse of a person with cancer is subject to many conflicting emotions and adjustment tasks, including conflict among feelings of loss, sadness, guilt, difficulty in knowing how to talk with the person who has cancer, worry about the possibility of death, and difficulty adjusting to the bodily changes of the partner. The participants stated that there is often pressure to be strong and supportive for the patient, which comes from health professionals who expect that the family will automatically provide such support. Several studies also have shown that the spouse of a cancer patient experiences levels of distress at least as severe as that of his or her partner when the disease is advancing.¹⁶⁻¹⁸ The results of qualitative studies further indicate that compared with the comments by patients, relatively few family caregivers describe terminal illness as a growth-promoting experience.¹⁹ This may indicate that caregivers are at even greater risk for distress that would affect their quality of life. As such, health care costs may be inadvertently increased if a large proportion of caregivers need psychosocial interventions in the face of their own burden and suffering.

As additional stressors, the family caregiver must adapt to changes in family roles and responsibilities by filling in for or delegating the role and responsibilities of the ill family member, while attempting to meet the increased emotional needs of other family members and performing standard family functions.²⁰ Blanchard, Albrecht, and Ruckdeschel²¹ noted that cancer causes changes in the family's identity, roles, and daily functioning, with 20% to 30% of partners suffering from psychological impairment and mood disturbance as a result of a spouse's cancer. Factors that predicted high levels of spousal distress included disease stage, emotional adjustment of the patient, gender, age, marital adjustment and family functioning.

Family members, as key providers of patient care, also have informational needs because they share the responsibility for decision making and for addressing the ongoing and often intimate daily needs of the patient. The financial burden on families is also significant because 25% of caregivers lose their jobs due to

caregiver responsibilities and nearly one third of families lose their major source of income or their savings.³ The results of a national population-based investigation of people who die from cancer support both of these propositions. The study found that 81% of the sample were cared for by relatives and that more than half of the relatives were unable to obtain the information they wanted from physicians. Over 25% of relatives reported the need for greater financial support, as well as help with domestic chores.²²

When facing the terminal illness of a relative, the suffering extends to every member of the family as a unit in some way. Family members often spend considerable time reviewing painful aspects of the past with feelings of regret for disagreements, conflicts, or failures and a wish that relationships with the patient and with each other were somehow different. With each family member's unique experience of the stress, families may find it difficult to pull together to effectively cope with the imposed life changes. In families where communication is indirect, little agreement about the nature of the problem may exist, and roles may be rigidly entrenched, resulting in conflict with regard to the delegation of the role responsibilities formally assumed by the ill family member. The dynamics of families in times of crisis may exacerbate a lack of tolerance for differences in opinion. Additional conflict also may occur when family members differ in their preferences for the location of care. Certain family members may prefer to care for their relative at home, while others may be reluctant or refuse to provide such care, given their perceived limitations in coping with the physical and emotional stress and the fears related to such a responsibility. The success of home care is therefore dependent on the availability of an able and willing caregiver, comprehensive and reliable home care resources, the patient's physical condition, and a suitable home care environment.²³

Indeed, coping with a terminal illness requires many life changes for both patients and their family members. Through a qualitative study, Davies, Reimer, and Marten²³ identified the experience of transition in families with terminal illness. The transition begins when fam-

ily members make significant attempts to re-define their life situation in terms of how they view themselves, the patient, and each other. Although both family caregivers and patients may acknowledge the extra responsibilities and burdens of care, there is often a mutual offering of support and reassurance to alleviate the sadness and depression that may accompany role changes. Contending with change also includes attaining or maintaining meaningful relationships as both patients and family members recognize the limited time they have together, and both grieve the loss of their social connections with others. Like the patient, family members struggle with the paradox of living with and dying from the illness with the conflicting desires to fight and keep going versus the desire to give up. In their search for meaning, patients and families affirm spiritual values, change life priorities, and examine how the experience of illness has contributed to their personal growth. Importantly, like their dying loved one, they live day to day to make the most of the present as they prepare for death on practical, cognitive, and emotional levels.

In caring for a terminally ill family member, Byock⁵ hopes that both patients and family members can transcend their reciprocal suffering and experience growth through the recognition of each other's love, completion of their relationships, acceptance of the finality of death, and achievement of a new sense of self. With this comes the possibility that both will experience dying as a process that can be as precious as it was painful.

RECIPROCAL SUFFERING AND ITS EFFECT ON QUALITY OF LIFE: A DYADIC PERSPECTIVE

The quality of life of patients and families is important across all stages of the illness trajectory, but most importantly during the final phases of an illness.^{24,25} Although quality of life can mean different things to different people, it generally refers to such factors as happiness or unhappiness and satisfaction or dissatisfaction with life.²⁶ In examining quality of life from the patient's perspective, one group of researchers described it as the impact of sickness

and health care on a person's daily activities and sense of well-being.²⁷ Patients' perceptions of their quality of life relates to their personal, subjective evaluation of their life experiences and their ability to control all aspects of their lives and of their illness.²⁸

Beyond a global definition of quality of life, investigators are now interested in the measurement of the dimensions of quality of life, which includes physical well-being, emotional well-being, social well-being, health and functioning, spirituality, and treatment satisfaction.²⁹⁻³¹ In fact, King et al.³² suggested that social support, access to the primary care provider, socioeconomic status, and the delivery of health services be measured as additional dimensions of quality of life in the context of serious illness. All of these dimensions of the patient's quality of life of the patient are also relevant to the quality of life of family caregivers. Some researchers emphasize the need to address the financial burden on the family, as well as bereavement and grief resolutions as added dimensions of quality of life of the family.³³

From the dyadic perspective of patients and family caregivers facing terminal illness, quality of life is an important outcome variable.¹¹ A dyadic perspective allows for an analysis of the patterns of perceiving and coping by terminally ill patients and their families and recognition of the changes in their quality of life as the disease advances. In a study of Kruse³⁴ of 50 patient-caregiver dyads in the terminal phase of illness, it was found that patients' and caregivers' forms of perceiving and coping with the end stage of life were significantly related. Other researchers report that the quality of life of family members revolves around meeting the patient's needs,^{35,36} and that the reciprocal suffering associated with terminal illness often has extremely deleterious effects not only on the patients' but the family caregivers' quality of life.³⁷

The importance of congruence in patient-caregiver perceptions was noted by Miaskowski et al.,³⁸ who found that differences in the perception of pain between patients and their family caregivers were associated with deleterious outcomes for both. Based on a sample of 78 patient-caregiver dyads, it was reported

that in noncongruent dyads with regard to pain perception, caregivers had significantly higher caregiver strain and patients reported significantly more mood disturbance and lower quality of life than dyads who reported congruence in pain perception.

Based on a longitudinal study, reciprocity of suffering was noted by Ell et al.,³⁹ who reported that caregivers of terminally ill family members experienced distress 1 year after diagnosis with 30% reporting a decline in their mental health. More recently, Hodgson et al.⁴⁰ found that 32% of caregivers experienced severe anxiety at the time of referral to home care for their terminally ill family member and that 26% remained severely anxious during the last week of life. The investigators concluded that the health care needs of family caregivers are heightened during terminal illness and that addressing the needs of the caregiver is important to the well-being of the patient.

In another study of family members of patients during the terminal phase of illness, it was concluded that patients' quality of life scores were moderately correlated with family members' health during the palliative care phase ($r = -0.38, p < 0.05$). Furthermore, family members' scores on the health index (symptoms of stress scale) were significantly lower than normative scores based on a healthy population.⁴¹

A study of the quality of life and coping of patients with gynecologic cancer ($n = 40$) and their spouses also confirmed that patients and spouses recorded similar responses with regard to overall quality of life and its domains, and that the family domain was the most important domain in both groups.⁴² In a study by Wicks et al.,⁴³ the quality of life and the level of subjective burden on family caregivers of patients with end-stage renal disease was examined. Based on a sample of 96 caregivers and their relatives, it was found that caregiver quality of life was related to caregiver burden ($r = -0.40, p < 0.0001$), and caregiver self-rated health ($r = 0.67, p < 0.0001$).

Dunn et al.,⁴⁴ examined the quality of life for spouses of patients receiving continuous ambulatory peritoneal dialysis. Based on 38 patient-spouse dyads, it was found that marital adjustment was the best predictor of quality of

life for the spouse, with income the next best predictor. The quality of life of patient and spouses was similar, except for lower spouse scores in the family domain. It was concluded that understanding the effect of a chronic or terminal illness on the spouse will help health care professionals to provide quality care for both the patient and spouse.

PALLIATIVE CARE: ALLEVIATING RECIPROCAL SUFFERING

Important aspects of the quality of life as death approaches include physical concerns (pain and symptoms), psychological distress (depression and existential anxiety), functioning (physical, emotional, and social), spiritual well-being, social support, planning for preferences in care, and the health care provider-patient relationship.⁴⁵ In a longitudinal study of 68 patients with life expectancy of less than 6 months, changes in the patients' quality of life were negatively correlated with the number of symptoms and perceived symptom distress.⁴⁶ Understandably, as their symptoms worsened, patients' physical and functional well-being deteriorated and psychological distress intensified. The changing needs of patients and the increase in the patient's physical and emotional distress significantly contributes to the distress of the family as they attempt to meet the patient's needs and maintain the functioning of the family. As the stress and demands of caregiving increase, the family benefits from the support of members of the hospice and palliative care team, who address the holistic needs of the patient and provide both patients and family with ongoing physical, emotional, social, and spiritual support.

Palliative care is viewed as a dynamic process responsive to the changing needs of patients and their families. Quality palliative care therefore means a shift not only in the philosophy of care, from cure to care, but a shift in the focus of care from the patient to the family as it is realized that the entire family unit is affected when one of its members is terminally ill. Given that the "unit of care" is the patient and family, palliative care offers not only a support system to help patients live as actively as

possible until death, but to help the family cope during the patient's illness and in their own bereavement.⁴⁷

The principles of palliative care focus on the individual's right to be informed; respect for the patients and families' needs regarding the sharing of information, timely access to information and services in a language that can be understood; the availability of palliative care services 24 hours a day, 7 days a week; the assurance of confidentiality; and the commitment that continuity of care will be offered by an interdisciplinary team of caregivers working collaboratively with the individual and family.⁴⁸

The palliative care model considers the patient's and family's subjective experience of illness to be as important as objective clinical data. Palliative care, as a model of care, is more tolerant of incomplete medical data, is more accepting of medicine's limitations, and does not equate death with defeat but rather views death as a natural process and conclusion to life.⁴⁹ The palliative care model therefore stresses the humanistic qualities of the patient, the family, and care providers and alleviates suffering within the context of these intrapersonal and interpersonal relationships.

Assessment of patients' and family caregivers' needs and concerns about quality of life will facilitate referrals to the appropriate members of the palliative care team and promote quality of life and quality of dying.⁵⁰ In improving the quality of life for patients and families, it is suggested that palliative care clinicians begin with an assessment of the dynamics of the family caregiving system.⁵¹ Understanding the family organization and functioning, particularly as it relates to the family membership, structure and roles, family cohesion, communication patterns, and decision-making processes, is important in recognizing areas of strength and limitation in dealing with terminal illness. Clinicians need to be aware that the type and stage of illness also may influence changes in the family organization and functional and the need for various intervention strategies to maintain quality of life over the course of the illness.

The family life cycle stage and the developmental tasks of the main family caregiver and each family member also need to be consid-

ered. The terminal illness of an immediate family member often leads to the postponement or cancellation of educational plans, life events such as marriage, or career goals. The level of distress experienced by family members also may be related to other factors, such as the patient's emotional adjustment, gender, age, socioeconomic status, personality, social support, and coping skills, as well as the marital adjustment of the patient and caregiver.²¹ Equally important is knowledge of the family's previous experience with illness and the ethnic or cultural values associated with illness and caregiving. Medalie⁵¹ has suggested assessing family caregivers' knowledge about the illness; their ability and willingness to care for the patient and provide emotional support; their personal needs; their knowledge of community resources and willingness to accept external support; and their expectations of the palliative care team.

Palliative care interventions that support the patient and family will change as the patient's disease progresses. Helping family caregivers and patients deal with imminent death must involve discussing advance directives and preferences regarding where to die; preparing for death both emotionally and practically, for example, making funeral arrangements; helping families deal with "unfinished business" and resolve family-patient conflicts; and supporting patients and families in the relief of emotional or spiritual suffering through active listening, meaningful presence, and the teaching of healing strategies such as relaxation, imagery, or meditation.

It is important to respect the family caregiver's knowledge of the patient, including the patient's desires and preferences, and to encourage family caregivers to participate in all aspects of the patient's care. However, it is also important to recognize the stress of being both caregiver (i.e., "pillar of strength") and griever in need of support, and to frequently assess the caregiver's well-being, coping abilities, needs, and expectations. The clinician needs to acknowledge the caregiver's efforts and assess his or her relationship with the patient and other family members, while encouraging the expression of fears, concerns, loss, and grief. It is important to put the caregiver in touch with

respite services before stress, emotional and physical exhaustion, and depression take their toll.

Within the context of the family as a system, keeping other family members informed of the progression of the patient's illness through periodic family meetings is often appreciated. Family differences, with regard to values, priorities, and attitudes that may place the main caregiver in a difficult or confrontational position, may be more objectively discussed in this forum. Family meetings also provide the family and palliative care team members an opportunity to discuss treatment goals and options, to solve problems, and to identify available resources and support networks. The meetings allow family members a chance to "vent," to voice their opinions, discuss feelings and needs, describe painful past experiences that relate to the present experience, and discuss changes in role responsibilities and potential role conflicts. Health providers also may use this occasion to reinforce the importance of their continued support of the patient and main family caregiver.⁵¹ Through such open discussions with patients and family members, it is possible that each may come to a new appreciation of their relationship with an expression of care and concern for the other's needs. The intent is that the supportive efforts of the palliative care team may protect both the patient's and family's quality of life as death approaches.

As more patients and families receive palliative care, there is a need to validate its effectiveness in promoting both the patients' and family caregivers' quality of life. The value of hospice and palliative care to the quality of life for the terminally ill and their family caregivers has been supported by two studies by McMillan and Mahon.^{52,53} Based on a sample of 31 patient-caregiver dyads, over half of the patients reported an increase in their quality of life 3 weeks after their enrollment in hospice or palliative care, whereas an even higher percentage of caregivers reported a significant increase in the patient's quality of life.⁵² In the second study, based on 68 adult primary caregivers of 68 patients with cancer, it was found that the caregiver's and patient's quality of life were positively correlated and that caregiver's

quality of life was maintained during the first month of hospice care.⁵³

IMPLICATIONS FOR RESEARCH

Documenting the quality of life experiences of terminally ill patients and their families will enable researchers to compare the relative importance of the various dimensions of quality of life along the illness trajectory; compare alternative approaches to end-of-life care, such as traditional care versus hospice or palliative care; compare outcomes across health care settings, specifically home, inpatient, or outpatient hospice and palliative care settings; and compare the impact on quality of life made by different types of health care providers.³³

To date, few studies have systematically documented the family's and patient's quality of life and their experience in dealing with a terminal illness, as well as the value of palliative care to patients and family caregivers along the illness trajectory.⁵⁴ Furthermore, most studies that have been done are retrospective, using interviews with family members after the patient's death. Longitudinal, prospective quality-of-life studies are needed to help providers determine the type and timing of appropriate health care interventions. Given that the patient is central to the family's experience, it is now recognized that both patient and family should be included in the research.²

Although studies have identified the stress of family caregivers, particularly in caring for a relative with terminal illness, there has also been little or no agreement about the characteristics of caregivers who may benefit from intervention.¹⁹ The assessment of caregivers' functional and emotional status is extremely important, particularly in light of the current restrictions in health care reimbursement for hospitalization and palliative care services and the imposed expectations on families who may not be physically and emotionally able to handle the responsibility of end-of-life care.

Two other areas present research opportunities. Little attention has been focused on the importance of caregiver function and quality of life and their effect on the patient's quality of life. Little information is available about dif-

ferences in the quality of life of patients within and across various end-stage illnesses, such as patients with end-stage respiratory, cardiovascular, renal, or neurodegenerative diseases, and the effects on the caregiver's quality of life as the patient's illness progresses.

The lack of attention to family concerns may be associated with the logistics of conducting research, such as identifying patient-caregiver dyads, and the willingness of both to participate in research. Establishing a trusting relationship with the patient and family and assuring them that the researcher will meet with them on their terms at a time and place that is most convenient is very important.

To reduce subject attrition, the length of the interviews also must be guided by the reactions and needs of patients and families. The difficulties encountered in terms of the high percentage of missing data warn against the use of only one assessment instrument. In studies involving patient-caregiver dyads, the problem of subject attrition due to patient mortality presents statistical challenges with regard to missing data. Multilevel models for repeated measurement data, specifically hierarchical random coefficient models, can be successfully used in analyzing longitudinal, multidimensional quality-of-life data. Such models allow the investigation of underlying behavior of response, such as the estimation of treatment effects, as well as permitting a description of differences between subjects and an analysis of multidimensional outcomes.⁵⁵

Through research, new insights can be gained regarding the changes in quality of life of patients and their family caregivers as the disease progresses. Such information informs the practice of palliative care both in terms of the parameters of assessment and the types of intervention strategies that support the quality of life.

CONCLUSION

In their daily practice and research endeavors, health care providers must continue to analyze how they can best support not only the

dying patient, but his or her family, and safeguard the quality of their lives as death approaches. Through palliative care, they can take the trembling hands of patients and their families, warm them with care and concern, relieve their pain and symptoms, and support them in their spiritual journey. With knowledge, skill, and compassion, health professionals can alleviate the reciprocal suffering of terminally patients and their families, improving their quality of life until it ends.

REFERENCES

1. Schacter S, Coyle N: Palliative home care-impact on families. In Holland J (eds): *Psychooncology*. New York: Oxford University Press, 1998.
2. Davies B, Reimer J, Marten N: Family functioning and its implications for palliative care. *J Palliative Care* 1994;10:35-36.
3. Lederberg M: The family of the cancer patient. In Holland J (eds): *Psychooncology*. New York: Oxford University Press, 1998.
4. Canadian Palliative Care Association: *Palliative Care: Towards a Consensus in Standardized Principles of Practice*. Ontario, Canada: Author, 1995.
5. Byock I: *Dying Well: The Prospect for Growth at the End of Life*. New York: Riverhead Books, 1997.
6. Saunders C: *The management of terminal illness*. London: Edward Arnold, 1967.
7. Foley K: Pain, physician-assisted suicide, and euthanasia. *Pain Forum* 1995;4:163-176.
8. Chapman CR, Gavrin J: Suffering and its relationship to pain. *Palliative Care* 1993;9:95-113.
9. Ferrell BR: *Suffering*. Massachusetts: Jones and Bartlett Publishers, Sudbury, 1996.
10. Higginson IJ: Introduction: defining the unit of care: who are we supporting and how? In: Bruera E, Portenoy RK (eds): *Topics in Palliative Care*, Vol. 2. New York: Oxford University Press, 1998.
11. Loscalzo M, Zabora J: Care of the cancer patient: response of family and staff. In Bruera E, Portenoy RK (eds): *Topics in Palliative Care*, Vol. 2. New York: Oxford University Press, 1998.
12. Klein SJ: *Heavenly Hurts: Surviving AIDS-related Deaths and Losses*. New York: Baywood Publishing, 1998.
13. Hays JC: Patient symptoms and family coping: predictors of hospice utilization patterns. *Cancer Nursing* 1986;9:317-325.
14. Hinton J: Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Med* 1994;8:183-196.
15. Beeney L, Butow P, Dunn S: Normal adjustment to

- cancer: characteristics and assessment. In Portenoy RK, Bruera E (eds): *Topics in Palliative Care*, Vol. 1. New York: Oxford University Press, 1997.
16. Hoskins CN, Baker S, Budin W, et al.: Adjustment among husbands of women with breast cancer. *J Psychosocial Oncol* 1996;14:41-69.
17. Kaye J, Gracely EJ: Psychological distress in cancer patients and their spouses. *J Cancer Educ* 1993; 8:47-52.
18. Omne-Poten H, Holmberg L, Bergstrom R, Sjoden P, Burns T: Psychosocial adjustment among husbands of women treated for breast cancer: Mastectomy vs. breast conserving surgery. *Eur J Cancer* 1993;29: 1393-1397.
19. Meyers C: The Blanchard/Albrecht/Ruckdeschel article reviewed. *Oncology* 1997;11:201-202.
20. Doyle D: *Caring for a Dying Relative: A guide for Families*. New York: Oxford University Press, 1994.
21. Blanchard C, Albrecht T, Ruckdeschel J: The crisis of cancer: psychological impact on family caregivers. *Oncology* 1997;11:189-194.
22. Addington-Hall J, McCarthy M: Dying from cancer: results of a national population-based investigation. *Palliative Med* 1995;4:295-305.
23. Davies B, Reimer J, Brown P, Marten N: *Fading Away: The Experience of Transition in Families with Terminal Illness*. New York: Baywood Publishing, 1995.
24. Cella DF: Quality of life: the concept. *Palliative Care* 1992;8:8-13.
25. Finlay IG, Dunlop R: Quality of life assessment in palliative care. *Ann Oncol* 1994;5:13-18.
26. Dalkey N, Rourke D: The delphi procedure and rating quality of life factors. In: Dalkey N, Rourke D (eds): *The Quality of Life Concept*. Washington, DC: Environmental Protection Agency, 1973. pp. 209-221.
27. Ragsdale D, Kotarba J, Morrow J: Quality of life of hospitalized persons with AIDS. *Image* 1992;24: 259-265.
28. Hanestad R: Errors of measurement affecting the reliability and validity of data acquired from self-assessed quality of life. *Scand J Caring Sci* 1990;4: 29-34.
29. Aaronson N: Quality of life research in cancer clinical trials. A need for common rules and language. *Oncology* 1990;4:59-66.
30. Cella DF, Tulsky DS: Measuring quality of life today: methodological aspects. *Oncology* 1990;4:29-38.
31. Ferrans C, Powers M: Quality of life index: development and psychometric properties. *Adv Nurs Sci* 1995;8:15-24.
32. King C, Haberman M, Berry D, et al.: Quality of life and the cancer experience: the state of the knowledge. *Oncol Nursing Forum* 1997;24:27-41.
33. Stewart A, Teno J, Patrick D, Lynn J: The concept of quality of life of dying persons in the context of health care. Unpublished manuscript, 1998.
34. Kruse A: Patients in the terminal phase and their caregivers as a dyad: how do they perceive the finite stage of life, how do they cope with it? *Gerontol Geriatr* 1995;28:264-72.
35. Cheng W, Schuckers P, Hauser G: Psychosocial needs of family caregivers of terminally ill patients. *Psychol Rep* 1994;75:1243-1250.
36. Kristjanson L: Quality of terminal care: salient indicators identified by families. *J Palliative Care* 1989; 5:21-28.
37. Smeenk F, de Witte L, van Haastregt J, Schipper R, Biezemans H, Crebolder H: Transmural care of terminal cancer patients: effects on the quality of life of direct caregivers. *Nursing Res* 1998;47:129-136.
38. Miaskowski C, Zimmer E, Barrett K, Dibble S, Wallhagen M: Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain* 1997;72: 217-226.
39. Ell K, Nishimot R, Mantell J, Hamovitch M: Longitudinal analysis of psychological adaptation among family members of patients with cancer. *J Psychosomatic Res* 1998;32:429.
40. Hodgson CS, Higginson IJ, McDonnell M, Butters E: Family anxiety in advanced cancer. *Br J Cancer* 1997; 6:120-124.
41. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E: Family members' perception of palliative cancer care: predictors of family functioning and family members' health. *J Palliative Care* 1996;12:10-20.
42. Zacharias D, Gilg C, Foxall M: Quality of life and coping in patients with gynecologic cancer and their spouses. *Oncol Nursing Forum* 1994;21: 1699-1706.
43. Wicks MN, Milstead EJ, Hathaway DK, Cetingok M: Subjective burden and quality of life in family caregivers of patients with end-stage renal disease. *ANNA* 1997;24:527-8.
44. Dunn SA, Lewis S, Bonner P, Meize-Grochowski R: Quality of life for spouses of CAPD patients. *ANNA* 1994;21:237-246.
45. Fields M, Cassel C: *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press, 1997.
46. Hwang SS, Chang VT: The use of quality of life and symptom assessment instruments to chart the course of terminal cancer patients over time. *Oncol Nursing Forum* 1996;23:352-360.
47. Bone R: Hospice and palliative care Disease-a-Month 1995;61:773-825.
48. Ferris F, Flannery J, McNeal H, Morissette M, Cameron R, Bally G: *Palliative Care: A Comprehensive Guide for the Care of Persons with HIV Disease*. Ontario, Canada: Mount Sinai Hospital/Casey House Hospice, 1995.
49. Fox E: Predominance of the curative model of medical care: a residual problem. *JAMA* 1997;78:761-763.
50. Kristjanson L: Indicators of quality of palliative care from a family perspective. *J Palliative Care* 1986;1: 8-17.
51. Medalie J: The patient and family adjustment to

- chronic disease in the home. *Disabil Rehabil* 1997; 19:163-170.
52. McMillan SC, Mahon M: A study of quality of life of hospice patients on admission and at week 3. *Cancer Nursing* 1994;17:52-60.
53. McMillan SC, Mahon M: The impact of hospice services on the quality of life of primary caregivers. *Oncol Nursing Forum* 1994;21:1189-1195.
54. O'Boyle CA, Waldron D: Quality of life issues in palliative medicine. *J Neurol* 1997;244:18-25.
55. Beacon H, Thompson S: Multi-level models for repeated measurement data: application to quality of life data in clinical trials. *Stat Med* 1996;15: 2717-2732.
- Address reprint requests to:
Deborah Witt Sherman, Ph.D., R.N., A.N.P., C.S.
New York University
School of Education
Division of Nursing
429 Shimkin Hall
50 West 4th Street
New York, NY 10012