

# Concerns of Family Caregivers of Patients With Cancer Facing Palliative Surgery for Advanced Malignancies

Tami Borneman, RN, MSN, David Z.J. Chu, MD, Lawrence Wagman, MD, Betty Ferrell, PhD, FAAN, Gloria Juarez, RN, PhD, Laurence E. McCahill, MD, and Gwen Uman, RN, PhD

**Purpose/Objectives:** To describe the concerns of family caregivers of patients undergoing palliative surgeries for advanced malignancies.

**Design:** Descriptive study with repeated measures.

**Setting:** A National Cancer Institute-designated Comprehensive Cancer Center in the western United States.

**Sample:** Family caregivers (N = 45) of patients with cancer.

**Methods:** Family caregivers were assessed prior to planned palliative surgery and at two weeks and six weeks postsurgery. Quantitative assessment of caregiver quality of life (QOL) occurred at each interval. A subset of nine caregivers also participated in a structured interview presurgery and at two weeks postsurgery.

**Main Research Variables:** Caregiver concerns, QOL, decision making.

**Findings:** Family caregivers have important QOL concerns and needs for support before and after surgery for advanced disease. Psychological issues were most pronounced, and common concerns included uncertainty, fears regarding the future, and loss. Family caregivers have concerns about surgical risks and care after surgery and voiced recognition of the declining status of patients.

**Conclusions:** Surgery is an important component of palliative care and profoundly impacts family caregivers of patients with cancer. The needs of family caregivers are multiple and complex, requiring ongoing assessment to provide interventions that help them cope and ultimately improve their QOL. This important topic requires further research and clinical attention.

**Implications for Nursing:** Findings suggest that family caregivers experience their own trajectory during the course of their loved ones' cancer, with surgery being a part of the course. This includes their profound emotions that may swing like a pendulum from one minute to the next. Nurses need to assess family caregivers in addition to patients to provide support and resources that will help increase caregivers' QOL.

## Key Points . . .

- Surgery is an important component of palliative care and has a profound effect on family caregivers of patients with cancer.
- Psychological issues are particularly pronounced, and common concerns include uncertainty, fears about the future, and loss.
- Family caregivers are anxious about surgical risks and care after surgery.
- The needs of family caregivers are multiple and complex, requiring ongoing assessment to provide interventions that help them cope and ultimately improve their quality of life.

is to achieve the best quality of life (QOL) for patients and their families. The WHO definition and the literature consistently acknowledge families as a focus of palliative care.

From the surgical literature, Finlayson and Eisenberg (1996) provided three definitions of palliative surgery: (a) relief of symptoms with prior knowledge of the impossibility of removing the whole tumor, (b) resection with small or large amounts of residual tumor left at the end of the procedure, and (c) resection for recurrent or persistent disease after failure of primary treatment. Easson, Asch, and Swallow (2001) placed the need for palliative surgery in two procedural categories: (a) palliative, where the goal is symptom relief, and (b) supportive, where a technical intervention is performed as part of the multidisciplinary plan of care.

**A**mong the therapies available for cancer, whether curative or palliative, surgery remains a primary treatment. Approximately 90% of patients with cancer undergo a surgical procedure (Polomano, Norcross, & Wurster, 1994). Surgery has greatly improved in recent years because of advanced technologies that facilitate diagnosing, staging, treating, and palliating cancer (Field & Cassel, 1997; Hanson & Cuning, 2000; Mast, 2001).

The words palliate and palliative are defined as "reducing the severity of . . . affording relief, but not cure" (Anderson, 1994, p. 1217). The World Health Organization (WHO) (2003) defined palliative care as actively caring for patients whose disease is not responsive to curative treatments, including providing pain control, symptom control, and support for psychological, social, or spiritual problems. Overall, the goal

*Tami Borneman, RN, MSN, is a research specialist in the Department of Palliative Care in the Lombardi Cancer Center at Georgetown University Medical Center in Washington, DC; David Z.J. Chu, MD, is a surgeon in the Department of General Oncologic Surgery, Lawrence Wagman, MD, is chair of the Department of General Oncologic Surgery, Betty Ferrell, PhD, FAAN, is a research scientist in the Department of Nursing Research and Education, and Gloria Juarez, RN, PhD, is an assistant research scientist in the Department of Nursing Research and Education, all for the City of Hope National Medical Center in Duarte, CA. Laurence E. McCahill, MD, is a surgeon for the Department of Surgical Oncology at the University of Vermont in Burlington; and Gwen Uman, RN, PhD, is a biostatistician for Vital Research, LLC, in Los Angeles, CA. Research support was provided by the American Cancer Society. (Submitted April 2002. Accepted for publication December 30, 2002.)*

Digital Object Identifier: 10.1188/03.ONF.997-1005

Surgical oncology is a rapidly expanding field and is becoming integrated into multimodal treatment plans. Patients undergo surgery for cytoreduction, oncologic emergencies, and pain control. Data on the outcomes of palliative surgery are scant, and most studies have focused on particular procedures rather than summarizing surgeries and their outcomes (Krouse et al., 2001). Moving beyond the surgical procedure to evaluating patient and caregiver QOL outcomes, including physical, psychological, social, and spiritual aspects, helps healthcare providers better understand the impact of palliative surgery.

The purpose of the study was to address an important aspect of palliative surgery: the concerns of family caregivers. This study was a component of a program of research initiated by the investigators in the area of palliative surgery (Krouse et al., 2001; McCahill et al., 2002; McCahill & Ferrell, 2002; McCahill, Ferrell, & Virani, 2001).

## Literature Review

Oncology nursing literature consistently has addressed the needs of family caregivers as they experience a loved one's cancer. The focus of this literature has been on the family caregiver of the newly diagnosed patient during chemotherapy or at the end of life (Borneman, Stahl, Ferrell, & Smith, 2002; Ferrell, 2001). A paucity of research exists addressing family caregivers of patients undergoing surgery for advanced disease. Norcross and Edwards (1996) described the important role of nurses in ensuring that patients and families receive information and understand goals of the treatment options offered, advantages and disadvantages of these options, and immediate and long-term outcomes of their choices. Polomano et al. (1994) offered an excellent review of the many potential complications following surgery and provided examples of nursing care to meet the complex needs of patients and families after surgery. These authors described the need for psychological support for patients and families surrounding surgery, acknowledging that much of the literature has focused on initial cancer surgery or on procedures with curative intent.

The time of surgery has been described as a crisis situation for the entire family (McCorkle et al., 2000; Pfeifer, 1998). During the course of surgery, surgeons often discover that the cancer is more advanced than expected or that intended procedures cannot be completed. Surgery in advanced disease may lead to awareness in patients and families that the disease is progressing and patients are approaching end of life.

Family caregiver needs have been addressed in many oncology nursing studies with consistent findings that patient distress and uncontrolled symptoms result in caregiver burden and diminished QOL (Andrews, 2001; Given & Given, 1996; Keegan et al., 2001; Nijboer et al., 1998). Given, Given, and Kozachik (2001) recognized the need to move beyond these descriptive studies to test interventions to meet caregiver needs in advanced disease.

Burke (1999) emphasized the importance of family caregivers in planning home care after surgery. Assessment of family caregivers' abilities to meet patients' needs and secure necessary community resources is an important consideration. Burke also described the need for nursing research to evaluate various patient and family teaching methods postdischarge and monitor for postoperative outcomes.

In advanced disease, patients and families may have exhausted curative options but continue to face decisions regard-

ing palliation of symptoms, maintenance of organ function, and prevention of complications (Knobf, 1998; Kristjanson, Leis, Koop, Carriere, & Mueller, 1997). These decisions are difficult. The ultimate goal is to avoid unnecessary treatment and potential morbidity or mortality while continuing to embrace treatment options that could enhance QOL. Weighing factors in decision making, such as surgical morbidity, length of recovery, and time until recurrence, has been discussed in the literature only from a surgeon's perspective.

General oncology nursing texts and literature have acknowledged the vital role of nurses in surgical treatment. Decreased length of hospital stay, reliance on outpatient procedures, and need for continuity of care are issues cited as major challenges for nurses. Knobf (1998) identified key components of nursing practice in surgical oncology, including assessment, teaching, learning, emotional support, physical care, and rehabilitation. Each of these roles could be applied to the specific area of palliative surgery and the decisions associated with this time of the cancer trajectory.

Powazki and Walsh (1999) evaluated a structured psychosocial assessment of patients and caregivers in an acute palliative care setting. This study involved assessments of patient needs ( $n = 150$ ) for assistance in problem solving, adjustment and coping, communication of concerns, and achievement of realistic expectations for care. The results of this study revealed that specific, high-risk psychosocial issues that often affect discharge planning and patient care can be identified. The authors suggested that integrating psychosocial care with medical care ensures patients comfort and dignity toward the end of life. Osse, Vernooij-Dassen, de Vree, Schade, and Grol (2000) conducted a review of 471 articles related to patient and family caregiver needs in palliative care and an evaluation of the questionnaires available to assess these needs. They concluded that a need for clinically useful assessment tools existed and that current tools neglected spiritual needs of family members and continuity of care.

In summary, consensus exists in the literature that family caregivers require information and support to prepare and sustain them in the complex task of cancer care. Greater exploration of family caregiver needs surrounding surgery and enhanced understanding of treatment decision making may contribute to improved care of patients facing treatment for advanced disease.

## Methods

### Design and Sample

The descriptive study used a repeated measures design for pre- and postoperative evaluation to add to the literature related to family caregiving in cancer care. Sample patients were identified for participation in this study if they met the inclusion criteria of being aged 18 or older, diagnosed with cancer, and scheduled for palliative surgery for advanced disease as identified by the primary surgeon. Surgeries were defined as palliative if the intent of the surgery was symptom control or symptom prevention and the overall surgical goal was comfort rather than cure. Patients were required to have a major operation, which was defined as one that involved general anesthesia and required an inpatient stay. A total of 59 patients participated with a mean age of 59 years. The majority of the patients were diagnosed with either recurrent or metastatic gastrointestinal malignancies or recurrent sarcomas.

## Procedures

Patients were asked to identify a primary family caregiver who could participate in this study. A total of 45 family caregivers participated, and a subset of nine caregivers were included in qualitative interviews. Data collection was conducted preoperatively (generally one to three days prior to the surgery) and at approximately two weeks and six weeks postoperatively. The interviews were conducted preoperatively and at two weeks postoperatively. Data collection and interviews occurred primarily in a quiet location at the hospital, with a few family caregivers preferring to be interviewed at home. All interviews were conducted by a master's-prepared research nurse with extensive experience in qualitative methods and palliative care. Interviews were tape-recorded and then transcribed verbatim. A total of 556 single-spaced transcript pages resulted from the interviews.

The research team, including two surgical oncologists and three nurses familiar with both the population and methodology, validated samples of the coding. The research team read the transcripts and discussed their interpretations. The transcripts were analyzed using content analysis methods as described by Krippendorff (1980). Meaningful statements were bracketed from the transcripts and assigned to tables using a "cut and paste" approach in which key themes and subthemes were identified. The same research team also validated the logic of the final categories, with 100% approval.

## Instruments

The key items of the caregiver interviews are captured in Figure 1. The interview guides were developed by the research team, pilot tested, and revised based on pilot interviews.

### Preoperative

1. How would you describe the overall status of your family member at this time?
2. What is your understanding of your family member's current state of illness and prognosis?
3. How active are you in your family member's care?
4. What are the major problems or symptoms your family member is experiencing currently related to the cancer?
5. What impact do they have on your life?
6. Have treatments or therapy other than surgery been tried? Were they helpful or successful?
7. Surgery is now being considered. What is your understanding of how surgery is likely to improve your family member's situation?
8. Do you feel the potential benefits and risk of surgery were explained clearly? Do you think your family member has a good understanding of the situation/surgery?

### Postoperative

1. How would you describe your family member's condition currently?
2. Overall, how would you say he or she is doing as compared to before his or her surgery?
3. Has the surgeon indicated any new information or change regarding overall prognosis following the surgery?
4. Do you feel that the goals of the planned surgery were met?
5. Have there been any unanticipated outcomes or problems after surgery?
6. How has the surgery affected your life?
7. Do you feel your family member overall has been pleased with his or her decision to pursue surgery? Would he or she do it again? In hindsight, do you have any feelings regarding the decision to pursue surgery?

Subjects completed a **Family Demographic Data** instrument preoperatively, and the **Quality of Life–Family (QOL–F)** tool was completed preoperatively and at two weeks and six weeks postoperatively to evaluate family caregiver outcomes. The QOL–F tool measured family caregiver outcomes in the domains of physical, psychological, social, and spiritual well-being. This 37-item instrument uses a 0–10 ordinal scale. Items were coded for analysis as 0 (worst outcome) to 10 (best QOL outcome). Psychometric analysis of the QOL–F tool has been reported with established content validity, internal consistency ( $r = 0.69$ ), test-retest reliability ( $r = 0.89$ ), and factor analysis confirming the four QOL domains as subscales (Ferrell, Grant, Borneman, Juarez, & terVeer, 1999).

## Results

### Quantitative Analyses

**Demographics:** Demographic data for the study sample ( $N = 45$ ) are presented in Table 1. The nine interviewees were

**Table 1. Family Caregiver Demographics**

	Interviewed Participants (N = 9)		Total Sample (N = 45)	
Variable				
Age (years)	Range = 20–81 X̄ = 48 Median = 49 SD = 15.41		X̄ = 52 Median = 51 SD = 14.38	
Hours spent working	X̄ = 26.5 Median = 27 SD = 11.70		X̄ = 33.9 Median = 30 SD = 16.31	
Years of formal education (5–22)	X̄ = 14 Median = 14 SD = 1.92		X̄ = 14 Median = 13 SD = 2.92	
	Interviewed Participants (N = 9)		Total Sample (N = 45)	
Variable	n	%	n	%
Female gender	9	100	31	69
Relationship to patient				
Child	3	33	10	22
Spouse	6	67	32	71
Parent	–	–	1	2
Other	–	–	2	4
Ethnicity				
Caucasian	6	67	28	62
Asian	1	11	3	7
Hispanic	1	11	12	27
African American	–	–	1	2
Other	1	11	1	2
Residence				
Lives with patient	8	89	41	91
Employment				
Not employed	4	44	19	42
Employed	5	56	26	58
Place of birth				
United States	8	89	34	76
Other	1	11	11	24
Family caregiver chronic illness	3	33	14	31
Religious preference (Yes)	8	89	40	89

Note. Because of rounding, percentages may not equal 100.

**Figure 1. Family Caregiver Interview Guide**



similar to the total sample (n = 45) in age, relationship to the patient, ethnicity, residence with the patient, employment status, years of formal education, proportion having a chronic illness, and proportion having a religious preference. The sample consisted predominantly of Caucasian spouses who resided with patients, were born in the United States, had at least a partial college education, and stated a religious preference.

**QOL assessment:** QOL indicators for family caregivers prior to palliative surgery, by domain, sorted in ascending order for analysis are presented in Table 2. Forty-three of the

45 participants completed the presurvey. Items within the domain of physical well-being indicated that caregivers reported positive scores with all items rated as greater than or equal to 6 and the physical well-being total rated at  $\bar{X} = 7.26$ .

Psychological well-being ranged from very low (distress at initial diagnosis,  $\bar{X} = 1.33$ ) to very positive (feeling useful,  $\bar{X} = 7.63$ ). Fears about recurrence and the distress of treatment represented indicators of the lowest QOL. However, overall QOL, life satisfaction, and feeling useful all were rated very high.

The most negative QOL factor in the domain of social well-being was family distress ( $\bar{X} = 2.70$ ). The most positive QOL factors were receiving support from others ( $\bar{X} = 7.58$ ) and not being isolated ( $\bar{X} = 7.14$ ). The least positive indicator of quality of spiritual well-being was uncertainty ( $\bar{X} = 4.52$ ). Hope ( $\bar{X} = 8.26$ ) and purpose or mission in life ( $\bar{X} = 8.28$ ) were rated the most positive. Overall QOL was rated 6.06 (SD = 1.46, median = 6.19). Only the psychological well-being scale score was rated lower than overall QOL.

Thirty-six caregivers completed the QOL scale at three consecutive time periods (prior to palliative surgery and two and six weeks later). A one-way repeated measures analysis of variance revealed significant differences over time for the psychological, social, and total QOL scale scores. Among the individual indicators, overall QOL estimate, overall social well-being, uncertainty, and psychological, social, and spiritual well-being showed a significant change over time. As shown in Table 3, the general pattern of change was a decrease in QOL for caregivers following palliative surgery.

To examine the data for differences in QOL according to demographic variables, t tests were conducted on composite QOL scores at each of the three time periods. To control for inflation of alpha, a conservative  $p = 0.01$  was used. No significant differences existed between spouse and adult child caregivers on any of the composite QOL scores. Likewise, no differences in QOL between caregivers of different genders or between different ethnic groups were found.

Qualitative Analyses

Figures 2–7 present examples of data from the family caregiver interviews conducted before surgery. The major themes derived from the analysis included Overall Status of the Patient, Role in Family Member’s Care, Impact of the Illness on the Family, Coping, Surgery, and Spiritual Needs.

Within the discussion of the Overall Status of the Patient, subthemes included Understanding of the Current State of the Illness as well as Patient Symptoms (see Figure 2). Family members were aware that the cancer had progressed and that the patient’s condition had worsened. Yet, at the same time, they felt stressed and concerned about facing an additional surgery.

In discussing symptoms, family caregivers identified patients’ symptoms as a major reason for pursuing surgery and also emphasized the impact of symptoms on the patient’s QOL. Many reported the presence of multiple symptoms; one caregiver said, “I don’t know if we ever even noticed any other symptoms, because . . . she couldn’t eat and it burned her skin and she just had all this horrible pain and no nutrition from stuff going in her mouth.”

Family members described the theme Role in Family Member’s Care primarily in terms of presence and psychological support (see Figure 3). A spouse described her

Table 2. Quality-of-Life Indicators for Family Caregivers

Categories	$\bar{X}$	Median	SD
<b>Physical well-being</b>			
Appetite changes	8.14	9.00	2.71
Pain or aches	7.42	9.00	2.90
Overall physical well-being	7.21	7.00	2.13
Fatigue	6.77	7.00	3.15
Sleep changes	6.77	8.00	2.96
Physical subscale total	7.26	7.40	2.18
<b>Psychological well-being</b>			
Feeling useful	7.63	8.00	2.61
Overall psychological well-being	7.28	8.00	2.70
Satisfying	7.12	8.00	2.62
Concentrate/remember	6.84	7.00	2.47
Overall quality-of-life (QOL) estimate	6.60	7.00	2.61
Happiness	6.44	7.00	2.68
Depression	6.23	7.00	3.34
In control	6.19	7.00	3.27
Distress after treatments ended	4.15	4.00	3.20
Difficulty coping	5.09	6.00	3.24
Anxiety	4.09	3.00	2.88
Fear of second cancer	2.95	2.00	3.28
Fear of metastasis	2.80	1.00	3.37
Distress during cancer treatments	2.79	2.00	2.81
Fear of recurrence	2.49	0.00	3.24
Distress at initial diagnosis	1.33	0.00	1.86
Psychological subscale total	5.12	5.21	2.18
<b>Social well-being</b>			
Support from others	7.58	8.00	2.44
Not being isolated	7.14	9.00	3.34
Financial burden	7.05	8.00	3.34
Overall social well-being	6.88	7.00	2.62
Employment	6.67	8.00	3.61
Personal relationships	6.63	8.00	3.47
Sexuality	6.24	7.50	3.93
Activities at home	5.93	8.00	3.67
Family distress	2.70	2.00	2.34
Social subscale total	6.31	6.75	1.97
<b>Spiritual well-being</b>			
Purpose or mission in life	8.28	10.00	2.76
Hope	8.26	9.00	2.35
Overall spiritual well-being	7.98	9.00	2.37
Personal spiritual activities	7.84	8.00	2.03
Religious activities	6.90	7.00	2.87
Positive changes	4.88	5.00	3.54
Uncertainty	4.52	4.50	3.21
Spiritual subscale total	6.95	7.29	1.90
<b>Overall QOL</b>	<b>6.06</b>	<b>6.19</b>	<b>1.46</b>

N = 43

Note. All items are coded as 0 (worst outcome) to 10 (best outcome).

**Table 3. Changes in Quality of Life Over Time**

Quality-of-Life (QOL) Indicator or Scale	Preoperative			Two Weeks Postoperative			Six Weeks Postoperative		
	$\bar{X}$	SD	Median	$\bar{X}$	SD	Median	$\bar{X}$	SD	Median
Overall QOL estimate	7.36	2.76*	8.00	6.53	2.32	7.00	6.56	2.06	7.00
Overall social well-being	7.03	2.64*	8.00	6.20	2.32	6.00	6.17	2.19	6.00
Uncertainty	4.29	3.05*	4.50	3.06	2.42	3.00	3.35	2.59	3.00
Psychological well-being	5.19	1.76**	5.38	4.58	1.52	4.61	4.89	1.40	5.00
Social well-being	6.45	2.06**	7.06	5.38	1.81	5.76	5.79	1.68	5.83
Spiritual well-being	6.79	1.97*	7.36	6.23	1.79	6.14	6.30	1.46	6.29
Total QOL score	6.11	1.56**	6.43	5.42	1.44	5.48	5.71	1.28	5.76

\* Preoperative QOL is significantly higher than subsequent measures of QOL,  $p < 0.05$ .

\*\*Preoperative QOL is significantly higher than subsequent measures of QOL,  $p < 0.01$ .

*Note.* All items are coded from 0 (worst) to 10 (best outcome).

husband's care by saying, "His care was more supportive. Saying I love you a lot. He just wanted to be sure that I wasn't going to go away because he was sick—that I wasn't that upset about it." In discussing the theme Impact of the Illness on the Family, the analysis revealed themes of loss (see Figure 4). Families discussed the theme Loss of Relationships and clearly anticipated the potential death of the patient. One person said, "When it's your time, it's your time. . . . That's what really hits me when I think about it. She's sick and she's not going to get better. She may get better for a while or seem to get better, but it's always going to be there and eventually it's going to take her from us."

The Loss of Future Plans theme captured loss of events or significant experiences for which the caregiver anticipated the patient would not be a part. A wife reported, "All the plans that we had, you know, the traveling we were going to do and all the things we were going to do are just gone. And we don't, we didn't have a choice; if he didn't try [the surgery], there was no future." Participants also discussed the theme Loss of Life as It Was Known in facing how the patient's worsened condition and potential outcomes of the surgery would likely alter the status of the patient and result in a different life for both patient and caregiver than what was known previously. Caregivers questioned any return to normal life as in the words of this caregiver, "Our goal is to have a life that I'm not worried every day if something awful is going to happen. And I don't know if that will ever go away from this moment on."

#### Understanding of the Current State of Illness

"He does everything. It's actually kind of nice right now. It was horrible while he was in chemo, having radiation and chemotherapy but not now. . . . He's doing very well and I'm doing very well, and together our life seems pretty normal right now."

"Her condition, I think, is pretty bad. She's just really positive and stuff. Um, but her condition, it's bad. I'd say as far as her, the cancer and stuff, it's at, like, it's last stage, and she's sick. She's really sick."

#### Patient Symptoms

"Well, she, when, went, you know, metastatic, she's had so many different things happen. One of them was that she had, and I don't know that they ever decided what this was, um, but she had a constriction of her esophagus, which was her initial 'can't eat' problem."

#### Figure 2. Preoperative Family Caregiver Interview Data: Overall Status of Patient

A major theme of the interviews prior to surgery focused on Coping (see Figure 5). Within this theme, subthemes were Denial, the balance of Coexistence of Hope and Fear, Anticipating Death, Feeling Overwhelmed, and being Unprepared for Death. The poignant comments seemed to capture the delicate balance of being very hopeful that surgery would improve patients' status, yet their growing awareness that patients were, in fact, getting sicker and that the patients might die either from the surgery or the disease in the foreseeable future. Caregiver hope was expressed in these words: "When we first found out . . . it was just unbearable to even talk about, to think about it. And then, when the treatment started, it, it was sort of an acceptance for a little while and the hope that, you know, that you're going to be one of the 15%. . . . After it was all over and they said there was still some there but the tumor was very small, I have hope. But I have a lot of fear."

The preoperative family caregiver interviews also discussed the surgery itself with major subthemes of Concerns About the Surgery and Risks, Benefits of Surgery, and their role in Decision Making (see Figure 6). The intensity of the decisions was captured by a daughter who said, "We had the conversation on the last surgery which was basically, you know, she could die from this."

The final theme from the preoperative interviews was Spiritual Needs (see Figure 7). Family caregivers clearly disclosed heightened spiritual needs at this critical time of the illness, with the subthemes of Faith in God, Reluctant Faith, and Search for Meaning. Caregivers expressed the balance of being aware of the possibility of death yet having hope for survival. One caregiver shared, "I have a lot of faith that God won't take her from us yet. [Begins crying.] But if she has to go, she has to go. We're really in touch with things like that. Like God and angels and stuff."

The key themes from the interviews conducted postsurgery are summarized in Figures 8–10. Three key themes were

"She lives separate from me, but I'm . . . always calling her every day, at least three to four times a day. I'm always just making sure she's feeling okay. I'm there for her a lot. I'm very there for her in her life."

"We talk every once in a while, and I'm reading my book and he's watching TV and taking naps and going to the bathroom. But we're here together today. So, I just told my boss that I, I'm not going to be at work today."

#### Figure 3. Preoperative Family Caregiver Interview Data: Role in Family Member's Care

### Loss of Relationships

"I have two kids that are four and two. So, probably the hardest part, when my daughter was born, my mom watched her. She was my day care for the first year. . . . And she even did some with my son. So, you know, just kind of thinking about the fact that she's probably not going to be around to watch them grow up."

### Loss of Life as It Was Known

"Especially because he went in thinking he might have an ulcer or a hiatal hernia. And one minute you're going in with that thought, and, a few hours later, the doctor came in. . . . He knew it was cancer. Your life changes. . . . It just seems like a death sentence as soon as you hear the word 'cancer.'"

## Figure 4. Preoperative Family Caregiver Interview Data: Impact of Illness on Family

identified: Patient's Overall Status, the Surgical Experience, and Spiritual Needs.

Family caregivers described the patient's overall status (see Figure 8) with subthemes of Affected by Pain, Affected by Nausea, Symptom Relief, and No Change in Prognosis. These expressions captured the varied experiences in which palliative surgery may have brought about additional symptoms, resulted in symptom relief, or had no effect. Despite advanced disease, family members seemed focused on active treatment and were hopeful for improvement.

Family members voiced many experiences surrounding the surgery, which are captured in Figure 9. Subthemes identified included Uncertain Survival, Reconsidering Decision for Sur-

### Denial

"We both are trying to maintain a positive attitude. It's hard to be positive if you're talking about 'what if I die.' So, we really don't talk about it a lot. I think he just assumes I'm going to be okay. We've talked a little bit about what he would like for himself if it did happen but not a lot. . . . Yesterday we talked about the do not resuscitate [order]. Having that. He didn't want it."

### Coexistence of Hope and Fear

"But he trusts [the doctor]. We both think he's wonderful. And he has just been, he's, he's given us the hope that we need. Because even though he gave us those terrible statistics, he, he let us realize that there are 15% of people who do make it. And he has done these kinds of surgeries before. . . . He just made us feel like he was skilled, competent, knew what he was doing, and was going to give [my husband] the best chance that he could possibly. And you have to have that faith in the surgeon, otherwise you don't want to go on. You just say forget it."

### Anticipating Death

"Facing the fact that I may be alone. . . . You know? Which I don't want to even deal with most of the time."

### Feeling Overwhelmed

"I have to spend time with [my husband]. I have to spend time with my mother 'cause they're both at that point where . . . yeah. And one of them can go at any time; who knows. And then you're working the other days so it's just sometimes I feel overwhelmed. It's, sometimes it's fine and other days I just feel like falling apart. But I can't 'cause I'm strong and I have to take care of everybody."

### Unprepared for Death

"You can never prepare yourself for the whole thing. We never had a loss, like a big loss. . . . I've had people around me, and I've seen how they've gone through it, and you could be there for them. But you never know until you are in the position. . . . Because it might not be tomorrow, but we know that, you know, it's coming."

## Figure 5. Preoperative Family Caregiver Interview Data: Coping

### Concerns About Surgery and Risks

"I'm scared. I worry about just him getting through it. . . . For the first few days, I'll still be worried, and I'll just be glad when he comes home. I'll be glad to do anything, you know, just to have him come home again. I know it's good to know the truth, and I'm glad that [the doctor] was so up front with us. But it's just so hard to deal with. Surgery's very scary. The chemotherapy and radiation were not scary. I knew he would get sick, but I knew that there was no chance of him dying from it. This is a whole different animal."

"I think they were explained over and over again on several occasions. I think it is our own stress and dealing with this horrible thing that popped into our lives that it is no one's fault, and it's not the doctor's fault if we don't understand it right. It's just because we're trying to process, and maybe we hear things differently. I think, yes, it was explained well."

### Benefits of Surgery

"I think it's a good thing. Because, you know, your immune system concentrates on, like, if you have tumor, they concentrate all over the body. By taking this out, this is a big thing that, you know, it has cancer in it. By taking that out I feel like maybe her body can concentrate on other parts a little bit better than with, you know, with this in her. And then they're going to take the one out of her hip and I, I think it's a good thing. I'm glad that she's having the surgery."

"Yeah. The benefits are that it fixes her GI [gastrointestinal] tract and she can eat. You know, and that was the goal. For her to be able to take food in adequate amounts. Yeah, so, hopefully, she'll be able to eat again and this will work."

### Decision Making

"We talked about everything from day and minute one. I know that I laughed about it and said I would never let him do a DNR [do-not-resuscitate order], but it's really not true. If he had made that decision, I would never go against what he wanted to do. Because I know how he feels. He would never want, I mean, everybody talks about that they don't want to be a vegetable. They don't want to be to where they have to be taken care of and brought to the bathroom and all this."

## Figure 6. Family Caregiver Interview Data Preoperative: Surgery

gery, Uncertainty of Surgical Benefit, Feeling Abandoned, and emotions surrounding Patient Death. Each example illustrates the powerful emotions experienced, regardless of the patient outcome. The roller coaster of emotions included the immediate postoperative time when a patient's prognosis was changing rapidly and the theme of Feeling Abandoned, in which a wife felt left alone by the physicians as her husband's condition declined. Feelings of hopefulness before surgery sometimes were replaced by doubt or guarded opinion. For the one family member whose loved one died, the postoperative interview was a time of sharing profound grief (see Figure 10).

## Discussion

Previous literature has focused on the experience of family caregivers at time of diagnosis, during chemotherapy, or in hospice settings (Davies, 2001; Emmanuel et al., 1999). The results of this study indicate that family caregivers also require intense support when the patient undergoes palliative surgery for advanced disease. Data derived from the QOL scale indicated several areas of disruption across QOL domains with special concerns in aspects of psychological well-being regarding initial diagnosis, recurrence, and treatment. These findings are consistent with much of the caregiver literature in the area of oncology. Polomano et al. (1994) reported that, after the shock of an initial diagnosis of cancer, caregiver concerns



---

### Faith in God

"No matter what, though, I know we're all going to be together any ways. So, I mean, that kind of makes me feel a little bit better, just knowing that it's not really over. It's not the last time I'll ever be with my mom. . . . Having faith and knowing God helps because you know really what's going to happen in the end of it all. It's just like mixed emotions I guess. Like, I don't get mad at Him, I just get mad at the situation."

### Reluctant Faith

"I'd say, she pretty much, she said it. We could want her to stay here, but it's not our choice. It's not our choice. And that's the hard part. We have no control over it. And that's probably what's the hardest thing, because we can't, we don't have control over helping her. If we could, we would do anything, you know."

### Search for Meaning

"I think spirituality affects it in two ways. One is, sometimes, I just, I want to get so mad. And I guess I want to question Him why, you know, I want my mom to see my baby grow up. I want my mom to see my nephews grow up. Just stuff like that. It's like, why? But, then it brings me closer to Him, too, because you gotta have your faith, you gotta, you got to turn to Him in things like that. But, really, if I didn't have my faith in God, I think I'd be a total mess."

---

## Figure 7. Preoperative Family Caregiver Interview Data: Spiritual Needs

may shift from immediate recovery to future treatments and overall survival of their loved one. A recurrent cancer may evoke past memories and even despair.

Morse and Fife (1998) found in their study of 175 partners of patients with cancer that psychological distress increases and coping becomes more difficult as the patient's illness worsens. Specifically, psychological distress escalates with either a recurrence of the disease or with the occurrence of metastases. Northouse, Dorris, and Charron-Moore (1995) also found that

---

### Affected by Pain

"It's not too good. And every day he say it's pain here, there, but, no, really the pain is, like, moderate. So, he take a pain pill and then, ah, every day he say 'I don't want to eat.' But when I cook, I think he eats as much as me. . . . He's just thinking that."

### Affected by Nausea

"But, before surgery, she was actually trying more food, so I guess the thing that's worse now is the nausea, and we don't really know if that's a side effect of radiation or just postoperative thing."

### Symptom Relief

"Well, um, the biggest thing before the surgery was that everything that went in she would throw back up. I mean, as far as her eating. And then she also had the pain in her, in her eye and in her mouth, which they had done the radiation for. So, um, between the two things, she's not having, she's not vomiting and she's not having that pain. So, yeah, I mean that, from that perspective, it was, it's helping."

### No Change in Prognosis

"It was more of a quality-of-life thing. They'd like to get her eating, like to get her home. Like to get her spending her time in a way that she finds, you know, enjoyable. But, um, they're not planning on curing her or anything like that. I think she is aware of the prognosis. But, you know, like she said, she want to still be in the treatment category more than, she doesn't want hospice at this point. So, although she knows that, she's not ready to just say that's it and prepare to die. She's wanting to do whatever she can to keep going."

---

## Figure 8. Postoperative Family Caregiver Comments: Patient's Overall Status

---

### Uncertain Survival

"The last day, of course, he was sleeping. I couldn't stand to even see him because his eyes were all swollen and his face was all swollen. But he never woke up that second day anyway. That very morning, [the doctor] told me that it would be a long, slow recovery, but he was going to do okay and he had a 50-50 chance that morning. And that was at about nine o'clock in the morning. And at seven o'clock that night, [the doctor] told me he wasn't going to make it through the night. Do you know how that can throw a person emotionally? Do you? You have no idea what kind of an emotional roller coaster I was on for those 13 days. One day, everything's looking better. The next day everything was just horrible. I'm surprised I didn't end up having a heart attack myself or a nervous breakdown."

### Reconsidering Decision for Surgery

"I think my biggest regret is if this were God's will and it were going to happen anyway, I wish that we wouldn't have done it till January. So, I guess I would have a little bit more apprehension. I would not just jump the hoops the way people told me to."

### Uncertainty of Surgery Benefit

"Well, you know, I'm still reserving judgment on that to see if she'll get back to food. If she doesn't, then I guess it was kind of here nor there if she had done it or not. But the fact that the things that she is taking in, as little as that is, is staying down is encouraging. You know, so I'm still hoping that she's going to actually be able to up her intake and do okay. In which case, it would be worth it."

### Feeling Abandoned

"[My husband], at one point, wrote me a note on the board and said he thought nobody cared about him anymore. That they had given up. I do think that the care diminished as this time went on. The last two days when I kind of made a fuss about it and said he thinks you don't care anymore. They were doing everything they could. That's what they said. They were doing everything they could. Maybe that's true; maybe it isn't. I'll never know."

### Patient Death

"I think about, mostly, it's the hospital. I can't get those two weeks off my mind. All of the years of good, happy memories are gone right now. And all I see is him laying in the hospital and saying to me, 'I wish I would have never had this operation.' Telling me he was sorry for all the trouble he's caused. I, I just can't get it out of my mind. And then I get these awful thoughts that maybe he wasn't really dead. I know the doctors know if they're dead or not. But since I wasn't there, I was there when his heart stopped, but the ventilator was still going so he was still breathing, you know. When I saw him, his chest was still moving even though the monitor showed that he had no heart rate and no blood pressure. But that's the way I remember is that his chest was still breathing. I don't know, I should have gone back to him and made sure he was cold. Because then, then I have these awful thoughts. Like what if they cremated him and he wasn't dead. That's really bad."

---

## Figure 9. Postoperative Family Caregiver Comments: Surgical Experience

caregivers experienced hopelessness when the patient was diagnosed with a recurrence and that this hopelessness affected their ability to cope. A loss of hope can prompt a sense of uncertainty and bring family caregivers to question the meaning of life (Borneman, 1998; Dufault & Martocchio, 1985; Farran, Herth, & Popovich, 1995; Nuckolls, 2000; Parse, 1999; Yates & Stetz, 1999). On the other hand, family caregivers who are hopeful are better able to maintain meaning in their lives in the midst of all that they are experiencing. The fact that caregivers felt supported by others and did not feel isolated is consistent with the oncology literature as well. Morse and Fife reported that adjustment of family caregivers was correlated significantly with social support from all sources.

In the area of spirituality, the data from this study further validate findings in the literature. A sense of uncertainty

"Hopefully, God will give me the insight to know why. But, for now, He just took away the most precious person in my life. No one would ever live up to the kind of love we had. So, what does that mean to me? It means I'm going to be alone for the next 30 years. Thanks, God. You're just real kindhearted. No, I'm not happy with Him now. I don't find the loving God that I tell everybody about. That I tell my children about. That I grew up with. That I was an adult with. That we believed together. Where is He now? Maybe [my husband] is happy where he is, but what about me? No. I haven't been to church since the funeral. If there's a future for me, God better step in pretty soon, because I, I have no reason right now that I want to do anything."

### Figure 10. Postoperative Family Caregiver Comments: Spiritual Needs

concerning the future, whether related to loved ones or themselves, is a difficult issue to confront and may intensify as family caregivers share their loved ones' cancer trajectory (Ferrell & Borneman, 1999; Nuckolls, 2000). Family caregivers may be uncertain about the future with concerns about their own health, autonomy, loneliness, cognitive impairment, dying, death, or afterlife (O'Brien, 1999). The repeated measures of QOL from presurgery to two months postoperative indicate worse QOL scores in family caregivers. This time is dynamic because families often confront worsening disease and the threat of death.

The interviews of family caregivers provided valuable insight into their needs for support. Profound emotions, such as balancing hope and fears and dealing with losses, were important messages derived from the data. These findings support existing data in the literature. Yates and Stetz (1999), through interviews with 20 family caregivers, identified two stages of hoping. Hope almost always started as a hope for cure, many times continuing until close to the time of death. Through the course of the disease, hope sometimes shifted from hope for cure to hope for relief from suffering. Hope also ties in closely with uncertainty in that hope dwells in the future. Caregivers facing a potential or real loss of the future, or a loss of hope in ways not intended or expected, experience feelings of uncertainty and sometimes despair (Amenta, 1986; Borneman, 1998). Dufault and Martocchio (1985) reported that hope becomes an anesthetic or insulation during difficult times.

The issues addressed in the quantitative and qualitative findings demonstrate that family caregivers of patients with cancer at various stages and facing palliative surgery have multiple and sometimes complex needs. Family members constantly must adapt to the course of the disease, treatments, and changing needs of loved ones.

The study limitations are derived from the purposeful sampling of subjects caring for loved ones with advanced cancer. The sample was a small subset of interviewed caregivers, and the qualitative findings cannot be generalized to all primary caregivers who care for patients with advanced cancer.

## Conclusions

The impact of palliative surgery on family caregivers of patients with cancer is an important component of palliative care and an area requiring further research and clinical attention. This study's findings support the existing literature in suggesting that there is a great need to assess the caregivers of patients with cancer. Although this suggestion has been put forth many times and in numerous studies, the literature presents almost no specific suggestions for assessment and support of caregivers. Caregivers need to be assessed for specific psychological, social, and spiritual distresses as evidenced in this study's findings and further supported in the literature. Healthcare professionals need to make a united effort to identify and implement more effective interventions for supporting family caregivers. Nurses can ensure that these caregivers are directed toward support services such as social workers, psychologists, support groups, and bereavement counseling. Family conferences to facilitate difficult decision making or to address conflicts within families also can lend support. Although caregiver concerns cannot always be eradicated, interventions to support family caregivers in coping with the situation are vital to improving their QOL.

*The authors acknowledge consultation by David Smith, PhD.*

**Author Contact:** Tami Borneman, RN, MSN, can be reached at [tbornema@earthlink.net](mailto:tbornema@earthlink.net), with copy to editor at [rose\\_mary@earthlink.net](mailto:rose_mary@earthlink.net).

## References

- Amenta, M. (1986). Spiritual concerns. In M. Amenta & N. Bohnet (Eds.), *Nursing care of the terminally ill* (pp. 115–161). Boston: Little, Brown.
- Anderson, D. (1994). *Dorland's illustrated medical dictionary* (28th ed.). Philadelphia: Saunders.
- Andrews, S.C. (2001). Caregiver burden and symptom distress in people with cancer receiving hospice care. *Oncology Nursing Forum*, 28, 1469–1474.
- Borneman, T. (1998). Caring for patients with cancer at home: The effect on family caregivers. *Home Health Care Management Practice*, 10(4), 25–33.
- Borneman, T., Stahl, C., Ferrell, B.R., & Smith, D. (2002). The concept of hope in family caregivers of patients with cancer at home. *Journal of Hospice and Palliative Nursing*, 4, 21–33.
- Burke, C.C. (1999). Surgical treatment. In C. Miakowski & P. Buchsel (Eds.), *Oncology nursing: Assessment and clinical care* (pp. 29–58). St. Louis, MO: Mosby.
- Davies, B. (2001). Supporting families in palliative care. In B.R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 363–373). New York: Oxford University Press.
- Dufault, K., & Martocchio, B. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379–391.
- Easson, A., Asch, M., & Swallow, C. (2001). Palliative general surgical procedures. In B. Cady (Ed.), *Surgical oncology clinics of North America* (pp. 161–184). Philadelphia: Saunders.
- Emmanuel, E.J., Fairclough, D.L., Slutsman, J., Alpert, H., Baldwin, D., & Emmanuel, L. (1999). Assistance from family members, friends, paid caregivers and volunteers in the care of terminally ill patients. *New England Journal of Medicine*, 341, 956–963.
- Farran, C., Herth, K., & Popovich, J. (1995). *Hope and hopelessness: Critical clinical constructs*. Thousand Oaks, CA: Sage.
- Ferrell, B.R. (2001). Pain observed: The experience of pain from the family caregiver's perspective. *Clinics in Geriatric Medicine*, 17, 595–609.
- Ferrell, B.R., & Borneman, T. (1999). Pain and suffering at the end of life (EOL) for older patients and their families. *Generations*, XXIII(1), 12–17.
- Ferrell, B.R., Grant, M., Borneman, T., Juarez, G., & terVeer, A. (1999). The impact of pain on quality of life: A decade of research. *Nursing Clinics of North America*, 30, 609–624.
- Field, M.J., & Cassel, C.K. (1997). *Approaching death: Improving care at the end of life* [Report of the Institute of Medicine Task Force]. Washington, DC: National Academy Press.



- Finlayson, C.A., & Eisenberg, B.L. (1996). Palliative pelvic exenteration: Patient selection and results. *Oncology, 10*, 479–484.
- Given, B.A., & Given, C.W. (1996). Family caregiver burden from cancer care. In R. McCorkle, M. Grant, M. Frank-Stromborg, & S.B. Baird (Eds.), *Cancer nursing: A comprehensive textbook* (pp. 93–107). Philadelphia: Saunders.
- Given, B.A., Given, C.W., & Kozachik, S. (2001). Family support in advanced cancer. *CA: A Cancer Journal for Clinicians, 51*, 213–231.
- Hanson, M., & Cuning, S. (2000). Surgical therapy. In C. Henke, M. Goodman, M. Hansen, & S.L. Groenwald (Eds.), *Cancer nursing: Principles and practice* (pp. 272–286). Boston: Jones and Bartlett.
- Keegan, O., McGee, H., Hogan, M., Kunin, H., O'Brien, S., & O'Siorain, L. (2001). Relatives' views of health care in the last year of life. *International Journal of Palliative Nursing, 7*, 449–456.
- Knobf, M.T. (1998). Surgery. In B.L. Johnson & J. Gross (Eds.), *Handbook of oncology nursing* (pp. 22–35). Boston: Jones and Bartlett.
- Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. Thousand Oaks, CA: Sage.
- Kristjanson, L.J., Leis, A., Koop, P., Carriere, K.C., & Mueller, B. (1997). Family members' care expectations, care perceptions, and satisfaction with advanced cancer care: Results of a multi-site pilot study. *Journal of Palliative Care, 13*(4), 5–13.
- Krouse, R.S., Nelson, R.A., Ferrell, B.R., Grube, B., Juarez, G., Wagman, L.D., et al. (2001). Surgical palliation at a cancer center: Incidence and outcomes. *Archives of Surgery, 136*, 773–778.
- Mast, M. (2001, October). New surgical procedures diagnose, cure, and palliate cancer. *ONS News, 16*(10), 4–6.
- McCahill, L., & Ferrell, B.R. (2002). Palliative surgery for cancer pain. *Western Journal of Medicine, 176*, 107–110.
- McCahill, L., Ferrell, B.R., & Virani, R. (2001). Improving cancer care at the end of life. *Lancet Oncology, 2*(2), 103–108.
- McCahill, L.E., Krouse, R., Chu, D., Juarez, G., Uman, G.C., Ferrell, B., et al. (2002). Indications and use of palliative surgery—Results of Society of Surgical Oncology survey. *Annals of Surgical Oncology, 9*, 104–112.
- McCorkle, R., Strumpf, N.E., Nuamah, I.F., Adler, D.C., Cooley, M.E., Jepson, C., et al. (2000). A specialized home care intervention improves survival among older post-surgical patients with cancer. *Journal of the American Geriatrics Society, 48*, 1707–1713.
- Morse, S., & Fife, B. (1998). Coping with a partner's cancer: Adjustment at four stages of the illness trajectory. *Oncology Nursing Forum, 25*, 751–760.
- Nijboer, C., Tempelaar, R., Sanderma, R., Triemstra, M., Spruijt, R.J., & van den Bos, G.A. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psycho-Oncology, 7*, 3–13.
- Norcross, F., & Edwards, D. (1996). Surgical oncology. In R. McCorkle, M. Grant, M. Frank-Stromborg, & S.B. Baird (Eds.), *Cancer nursing: A comprehensive textbook* (pp. 315–330). Philadelphia: Saunders.
- Northouse, L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine, 40*(1), 69–76.
- Nuckolls, J. (2000). Spirituality. In B. Nevidjon & K. Sowers (Eds.), *A nurse's guide to cancer care* (pp. 438–449). Baltimore: Lippincott Williams and Wilkins.
- O'Brien, M.E. (1999). *Spirituality in nursing: Standing on holy ground*. Boston: Jones and Bartlett.
- Osse, B.H., Vernooij-Dassen, M.J., de Vree, B.P., Schade, E., & Grol, R.P. (2000). Assessment of the need for palliative care as perceived by individual patients with cancer and their families. *Cancer, 88*, 900–911.
- Parse, R. (1999). *Hope: An international human becoming perspective*. Boston: Jones and Bartlett.
- Pfeifer, K.A. (1998). Surgery. In S.E. Otto (Ed.), *Oncology nursing* (4th ed., pp. 585–605). St. Louis, MO: Mosby.
- Polomano, R., Norcross, F., & Wurster, A. (1994). Surgical critical care for patients with cancer. *Seminars in Oncology Nursing, 10*, 165–176.
- Powazki, R.D., & Walsh, D. (1999). Acute care palliative medicine: Psychosocial assessment of patients and primary caregivers. *Palliative Medicine, 13*, 367–374.
- World Health Organization. (2003). Focus 4: Noncommunicable diseases. Retrieved September 8, 2003, from [http://www.wpor.who.int/themes\\_focuses/theme2/focus4/themes2\\_focus4cancer.asp](http://www.wpor.who.int/themes_focuses/theme2/focus4/themes2_focus4cancer.asp)
- Yates, P., & Stetz, K. (1999). Families' awareness of and response to dying. *Oncology Nursing Forum, 26*, 113–120.

## For more information . . .

- National Hospice and Palliative Care Organization  
[www.nhpc.org](http://www.nhpc.org)
- The Center to Advance Palliative Care  
[www.capcmssm.org](http://www.capcmssm.org)
- International Association for Hospice and Palliative Care—  
Hospice Palliative Care Information and Services  
[www.hospicecare.com](http://www.hospicecare.com)

*Links can be found at [www.ons.org](http://www.ons.org).*