# Patient and Surgeon Decision Making Regarding Surgery for Advanced Cancer

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**Purpose/Objectives:** To describe a program of research related to outcomes of palliative surgery and focus on one phase of this research involving decision making by patients and surgeons considering surgery for advanced disease.

**Design:** Descriptive.

**Sample:** 10 patients undergoing surgery and 3 oncology surgeons.

**Methods:** Qualitative interviews were conducted with patients and their surgeons pre- and postoperatively. Transcripts were content analyzed to identify major themes in patient and surgeon interviews based on study questions.

**Main Research Variables:** Decision making, palliative surgery, quality of life.

**Findings:** The study findings highlight the issues of greatest concern to patients and surgeons considering palliative surgery. This phase was an important component of the overall program of palliative surgery research.

**Conclusions:** Comprehensive care for patients with advanced cancer seeks to achieve a balance of providing aggressive care, ensuring optimum symptom management, and maintaining a focus on comfort. Further study of palliative surgery as an aspect of interdisciplinary care is warranted.

**Implications for Nursing:** Patients undergoing surgery for advanced disease require expert nursing care to address quality-of-life concerns. Further research is needed in this area.

Treatment decisions in the case of incurable disease can be difficult for patients and the physicians who treat them. Basic tenets of palliative care deem that a frank discussion takes place regarding the risks and benefits of any treatment and that these options take into consideration each patient's wishes. Perhaps in no aspect of palliative care is this more evident than for patients being considered for major palliative surgery, where risks often are greater than those faced from chemotherapy or radiation. Physicians may find difficulty in maintaining hope while effectively redirecting treatment goals from cure to symptom relief or quality of life (QOL). Better communication may translate into improved patient satisfaction, but how this is to take place and what patients want as part of the discussion are sources of considerable debate.

This article aims to contribute to an evolving understanding of decision-making and communication to improve patient care at the end of life. It describes a program of research in the area of palliative surgery and reports findings from one phase of that research. The purpose of this phase was to explore decision making by patients and surgeons considering surgery for advanced disease.

## Key Points . . .

- Surgery is an important aspect of comprehensive cancer care, potentially enhancing quality of life in advanced disease.
- Surgeons and patients face difficult decisions in determining treatment options to balance risks and benefits of care.
- Patients with advanced cancer need expert nursing care to support decision making and outcomes related to palliative surgery.

## Literature Review

Researchers have expressed the difficulty that comes with communication among patients, families, and physicians during the transition from curative to palliative care (Bruera, 2000; Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Jewell, 1994; Karlawish, Quill, & Meier, 1999; Petrasch et al., 1998). This becomes increasingly challenging when the intervention considered is operative. Several authors have investigated preferences of patients with cancer in the decision-making process (Bottorff et al., 1998; Rothenbacher, Lutz, & Porzsolt, 1997). Rothenbacher et al. evaluated the extent to which patients hospitalized with advanced cancer who were receiving palliative treatment wanted to be involved in the decision-making process. The vast majority of patients preferred a collaborative role and wanted to decide with their physicians,

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whereas some patients preferred to make treatment decisions alone. Less than 20% wanted to leave the decision making entirely to the physicians. However, other studies suggested that patients faced with a life-threatening disease do not necessarily want to make treatment decisions and would prefer a more passive role (Stiggelbout & Kiebert, 1997).

Braddock, Edwards, Hasenberg, Laidley, and Levinson (1999) documented the process of informed decision making between patients and their physicians, noting that only 9% of decisions met the definition of informed decision making and fewer than 10% included a discussion about treatment alternatives, risks, and uncertainties. Gattellari, Voigt, Butow, and Tattersal (2002) reported the extent to which patients with incurable cancer were able to make informed decisions about their treatment and explored the effect of information disclosure on patient well-being and satisfaction with their medical care. Although most patients were told about the aim of treatment, informed that their disease was incurable, and made aware of the uncertainty of whether treatment would achieve a benefit, few patients were explicitly offered a choice in their treatment and given time in the consultation to clarify their understanding.

Additional data suggest that patients with metastatic disease frequently may overestimate their survival time and that those who do so are more likely to favor life-extending treatment, perhaps without adequate understanding of the limitations of current available treatments to cure and without full knowledge of potential treatment-related side effects on QOL (Weeks et al., 1998). Reliable prognostic assessment assumes perhaps even greater importance in palliative care when patients may consider treatment-related morbidity if the likelihood of cure is remote given current treatment options. A number of studies have suggested that survival predictions of physicians are only moderately associated with survival (Maltoni et al., 1994).

Clinicians' primary obligation is to provide professional expertise in diagnosis and treatment of disease. Consequences of treatment, such as patient discomfort, associated treatment-related morbidity, or even mortality, may be viewed as acceptable risks when the goal of the treatment or surgery is cure. In the setting of a palliative intervention, however, the value of treatment outcomes relative to treatment risks is less well understood (Miner, Jaques, Tavaf-Motamen, & Shriver, 1999). Data regarding interventions for specific advanced malignant conditions are limited, and, thus, clinicians' knowledge base regarding outcomes may be limited.

Patients who are referred to surgeons after courses of chemotherapy or radiation have failed to contain their disease may feel desperate after having been informed that surgery is all that is left. Patients may not participate in active discussions about their options for care of symptoms when they anxiously hope and anticipate an offer of any anticancer treatment. In turn, surgeons may offer treatments to preserve patient hope. The fact that patients and physicians often avoid discussing prognosis in the case of incurable disease is well known, perhaps because frank palliative care discussions may uncover problems without solutions or are perceived as destroying any remaining hope for cure (Lo, Quill, & Tulsky, 1999).

The purpose of the current study was to allow for in-depth exploration and increased understanding of the complex process of decision making between surgeons and patients being evaluated for major surgery for treatment of advanced malignant disease. To explore those issues in depth, qualitative interviews were conducted. This method of data collection allowed patients and surgeons the freedom to express their perspectives about decision making in the context of the social, cultural, and illness views that affect their decision-making process. This article reviews the expectations and methods of decision making of patients and their surgeons before and following a surgical intervention for advanced disease.

# Methods

## Conceptual Model and Program of Research

Figure 1 presents the conceptual model for decision making in palliative surgery that has evolved across the program of research described in Table 1. As depicted, decisions are influenced by patients, family, and the healthcare team. The process of making decisions involves identifying goals, recognizing values, acknowledging alternatives, and weighing risks and burdens. Treatment choices are made that result in patient outcomes that affect dimensions of QOL as well as additional outcomes. This study contributed to the conceptual model by refining patient and surgeon factors that influence decisions. The investigators will apply the model to future phases of this research program to include evaluation of the model in a patient intervention.

# Sample

Patients were selected from a comprehensive cancer center if they met criteria of being aged 18 or older and were scheduled for surgery for advanced cancer. Advanced disease was defined as distant metastases, recurrent solid tumors, or initial presentation of suspected stage III or greater malignancy of particularly poor prognosis (e.g., esophageal, pancreatic, or gastric cancers). Patients were required to have a major operation, which was defined as involving general anesthesia and requiring an inpatient stay. Ten patients and their respective surgeons were interviewed. This included three surgeons across the 10 patients. Interviews were conducted preoperatively—generally one to three days before surgery—and approximately two to four weeks postoperatively. Interviews were tape-recorded, and the transcripts were prepared verbatim. A total of 556 single-spaced transcript pages resulted from the interviews. Key topics of the patient interviews are captured in Figure 2, and the topics of the surgeon interviews are identified in Figure 3.

## Analysis

The interview guides were developed by the research team, pilot tested, and refined based on pilot interviews. Patient interviews were conducted by a research nurse, and physician interviews were conducted by a physician. Mock pilot interviews were conducted, tape-recorded, and reviewed by the team to provide feedback for interviewing. A research team comprised of two surgical oncologists and three nurses with extensive experience in qualitative methods analyzed the interviews, and the principal investigator listened to all tape-recorded interviews and reviewed all transcripts. Members of the entire research team read the transcripts and discussed their interpretations. Transcripts were analyzed using content analysis methods as described by Krippendorff (1980). Meaningful statements were bracketed from the transcripts and then assigned to tables using a "cut-and-paste" approach in which key themes and subthemes

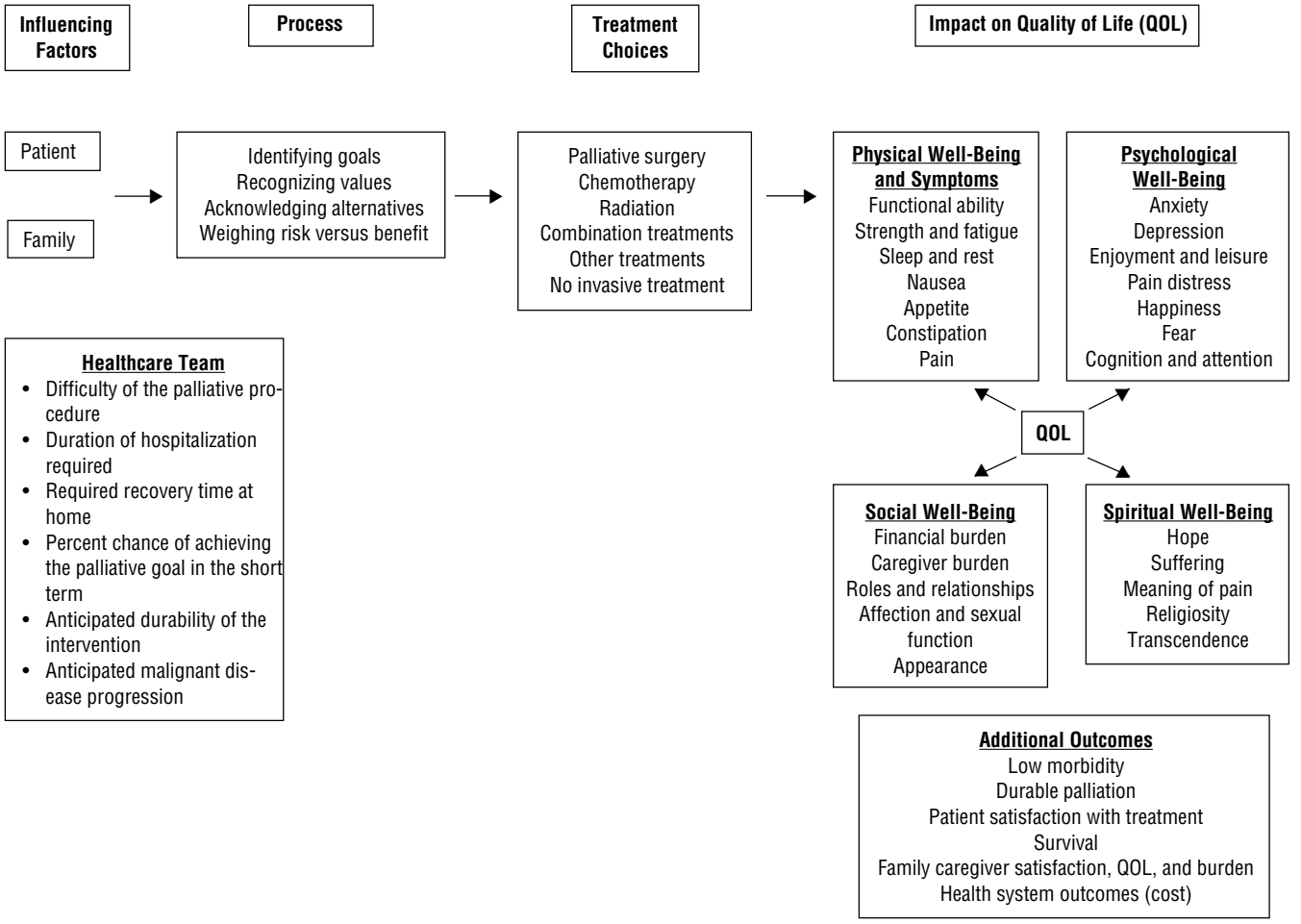


**Figure 1. Clinical Decision Making in Palliative Surgery**

were identified. Tables were reviewed and discussed by the research team during several meetings. The tables underwent numerous revisions based on team discussions.

# Results

## Demographics

Table 2 includes demographics of the patients and surgeons interviewed for the study. The mean age of the patients was 57, and frequently represented diagnoses were esophageal and colon cancer. Surgeons interviewed had a mean age of 48 years and had been in oncology practice an average of 15 years. Surgeons estimated their hours of palliative care education to be minimal.

## Patient Interviews

In exploring the decision-making process, the investigators first sought to describe patients' QOL to better understand the life circumstances that could contribute to patient decisions. Figure 4 lists patients' descriptions of their QOL considerations before surgery in terms of physical, psychological, social, and spiritual well-being. In the area of physical well-being, patients described symptoms, including pain, nausea, fatigue, and multiple symptoms occurring together. The physical distress of symptoms associated with disease was the primary motivation for seeking surgical treatment. In the area of psychological well-being, patients described anxiety and coping mechanisms predominantly as they related to anticipating a future surgery. In the area of social well-being, patients described changes in their lives as a result of advancing disease, including strain on personal relationships and their employment status. Patients generally believed that, through symptom relief, surgery could remedy some of the social strain brought on by disease. The social impact of symptoms was a clear secondary motivation for surgery beyond the physical impact. In the area of spiritual well-being, patients commonly acknowledged their faith as an integral part of coping, especially to combat surgery-related anxiety, and they indicated an increased reliance on faith as their disease progressed. A need to maintain hope in the face of advancing disease by continuing to receive treatment emerged as another important motivation for surgery.

The interviews also directly explored patients' decision-making processes regarding surgery for their advanced diseases (see Figure 5). Patients generally described the decision to have surgery as not a difficult one but rather as the only option at that point in their care, having exhausted other treatments such as chemotherapy and radiation. In general, patients were eager to pursue surgery rather than delay treatment. Consistent with the literature, although patients articulated their understanding of having advanced disease and often described how their surgeons had presented the operation as palliative in intent, most patients still hoped for the possibility of prolonged

**Table 1. Description of Program of Research of Palliative Surgery**

| Phase | Study | Design | Key Findings |
|---|---|---|---|
| I | Surgical Palliation at a Cancer Center (Krouse et al., 2001) | Retrospective review of surgical cases (N = 1,915) during a one-year period with a one-year survival follow-up. This descriptive study began exploration of the extent of palliative surgery to identify patient outcomes. | Palliative surgeries comprised 240 (13%) of 1,915 surgical procedures (170 major and 70 minor). Neurosurgical (46%), orthopedic (31%), and thoracic (22%) surgical procedures frequently were palliative. The most common primary diagnoses were lung, colorectal, breast, and prostate cancers. Mean length of hospital stay was 12.4 days (range = 0–99 days). Mortality for surgical procedures classified as major was 22% and 10% for those classified as minor. The investigators concluded that significant numbers of palliative procedures causing mortality were high; however, a significant number of patients had short hospital stays and low morbidity. Palliative surgery should remain an important part of end-of-life care. Patients and their families must be aware of the high risks and understand the clear objectives of these procedures. |
| II | Advancing the Evaluation of Palliative Surgery for Cancer Patients (Krouse et al., 2002) | Prospective review of palliative surgeons (N = 50). The interview guide was pilot tested for use with patients, family caregivers, and surgeons to explore decision making and goals. | Prospective design allowed expansion of outcomes to include quality of life (QOL) and to explore the involvement of family caregivers. |
| III | Indications and Use of Palliative Surgery—Results of Society of Surgical Oncology Survey (McCahill et al., 2002a, 2002b) | A survey (110 items) was mailed to members of the Society of Surgical Oncology (N = 419 responses). This phase was intended to provide a national perspective on the topic of palliative surgery and to expand knowledge of surgeons' decision making. | Surgeons estimated that 21% of their cancer surgeries were palliative in nature. Forty-three percent of respondents believed that palliative surgery was best defined based on preoperative intent, 27% based on postoperative factors, and 30% on patient prognosis. Only 43% considered estimated patient survival time an important factor in defining palliative surgery, 22% considered estimated patient survival time an important factor in defining palliative surgery, and 22% considered yearly survival rate important. Patient symptom relief and pain relief were identified as the two most important goals in palliative surgery, with increased survival the least important. On a scale of 1–7 (1 = uncommon to 7 = common), surgeons reported that the most common ethical dilemmas in palliative surgery were providing patients with honest information without destroying hope and preserving patient choice. On a scale of 1–7 (1 = not a barrier to 7 = severe barrier), surgeons rated the most severe barriers to optimum use of palliative surgery as limitations of managed care and referral to surgery by other specialists. They rated the least severe barriers to palliative surgery as surgeon avoidance of dying patients and surgery department reluctance to perform palliative surgery. |
| IV | A Prospective Evaluation of Palliative Outcomes for Surgery of Advanced Malignancies (McCahill et al., 2003) | Prospective evaluation of patients undergoing palliative surgery (N = 59) with longitudinal measures for one year. Outcomes expanded to provide more detailed evaluation of symptom management and QOL. Qualitative evaluation included in-depth interviews with patients, family caregivers, and surgeons pre- and postoperatively to further describe decisions and outcomes related to surgery. | Preoperatively, surgeons identified 22 (37%) operations as palliative and 37 (63%) as curative. Thirty-three of 59 patients (56%) were symptomatic preoperatively, and symptom resolution was documented in 79% surviving more than 30 days. Good to excellent palliation, defined as more than 70% symptom-free nonhospitalized days relative to postoperative days of life, was achieved in 53% of patients categorized as palliative. Among patients with postoperative survival of less than six months, 63% had good to excellent palliation. The majority of patients who were symptomatic and undergoing major operations for advanced malignancies attained good to excellent symptom relief. Outcome measurements other than survival are feasible and likely to play a large role in defining surgery as an important component of multimodal palliative care. |
| V | A Comparison of Resource Consumption in Curative and Palliative Surgery (Cullinane et al., in press) | Prospective evaluations of all surgeries during a three-month period (N = 319) with six-month follow-up. The investigators extended the outcomes of surgery to be evaluated based on phases I–IV. | The outcome and service needs of 302 consecutive patients with malignancies undergoing surgeon-defined curative or palliative surgery were analyzed over a four-month period. Previous treatment history, comorbidities, symptoms, procedures, outcomes, and use of supportive services were collected. Patients were followed for six months after the surgical procedures. Surgeries performed for cure were for breast or prostate cancer and for palliation were for breast, lung, and bone or soft-tissue tumors. Three (1%) curative and four (6%) palliative deaths occurred during surgical admission. Mean hospital stay was 5.1 days (range = 0–58 days) for curative and 1.9 days (range = 0–34 days) for palliative patients. Following discharge, a total of 4,690 encounters with the cancer center occurred, including 1,676 encounters with surgery, 1,595 encounters with medical oncology, 1,006 encounters with radiation oncology, 226 visits to medical specialists, and 187 visits to supportive services. Mean numbers of encounters for curative and palliative patients were 15 and 17, respectively (p = 0.41). |

*(Continued on next page)*

**Table 1. Description of Program of Research of Palliative Surgery *(Continued)***

| Phase | Study | Design | Key Findings |
|---|---|---|---|
| | | | Curative patients were more likely to have visits with therapeutic intent, including chemotherapy ($p = 0.01$) or radiation ($p = 0.003$). Readmission occurred for 82 (34%) curative and 28 (48%) palliative patients during the six-month period ($p = 0.04$). Palliative patients were more likely to be admitted for symptom management ($p < 0.0001$), whereas curative patients were more likely to be admitted for repeat procedures ($p = 0.006$). |
| VI | Concerns of Family Caregivers of Patients With Cancer Facing Surgery for Advanced Malignancies (Borneman et al., 2003) | Family caregivers were assessed prior to planned palliative surgery and at two and six weeks postsurgery. Quantitative assessment of caregiver QOL occurred at each time point. A subset of nine caregivers also participated in a structured interview presurgery and at two weeks postsurgery. | The study findings indicated important family caregiver QOL concerns and needs for support at the time surrounding surgery for advanced disease. Psychological issues were most pronounced with common needs of uncertainty, fears regarding the future, and loss. Family caregivers voiced concerns about surgical risks and care after surgery and experienced recognition of the patients' declining status. The investigators concluded that surgery is an important component of palliative care and is an area requiring further research and clinical attention. |



life with surgical treatment. For many patients, the surgery followed very extensive cancer treatment, often including chemotherapy and radiation and sometimes including multiple surgeries. Patients did not seem to believe that the risks of surgery were an important consideration in opting whether to have it, but rather considered that "all surgeries have risk." Patients acknowledged having been informed of the risks of surgery, including the possibility of death or worsening symptoms. However, most believed that the risks were known and that their decision to proceed was deliberate and independent.

In the interviews conducted postoperatively, patients discussed their overall QOL after surgery, the decision to have the surgery, suggestions that they would make for others, and plans following hospital discharge and for the future. Figure 6 includes examples of patient experiences related to physical, psychological, social, and spiritual well-being. Again, although most patients clearly had been told that the surgical intent was palliative and the degree of success might vary, most patients still focused on the possibility of continued treatment and prolonged life. Following subtotal resection of the disease, one patient said, "I feel the surgery is not complete. I still have a tumor in my kidney." Another described having "umpteen million brick walls thrown in my face" but planned to continue the battle against the disease. Patients commonly recognized that even symptoms that may have been effectively alleviated by surgery might return with future recurrent tumor growth. One patient described waiting for the "little time bombs" to go off in his body.

Patients frequently discussed the importance of having faith through the experience of surgery as well as for the future. One patient described God as guiding the surgeon. This time of illness was a time of reflection for patients. One patient described how "an unexamined life isn't worth living" and that he had, in fact, examined his life. Others seemed to see

**Preoperative**

1. How would you describe your overall status at this time?
2. Have you had any prior treatments for your symptoms or cancer?
3. What have you been told about the potential benefits of the surgery? What do you think this surgery will accomplish?
4. What are your thoughts about any risks associated with surgery?
5. Do you think other options are available to treat your problem besides surgery?
6. Was your decision to proceed with surgery difficult for you to make? Was anyone influential (your doctor, a family member, your surgeon), or did you make most of the decision yourself?

**Postoperative**

1. How would you describe your overall status at this time?
2. Can you recall the major problems or symptoms that led to your surgery?
3. How have those symptoms or problems been since surgery?
4. Do you feel the symptoms or problems that prompted your surgery have improved?
5. Have you had any unexpected problems or trouble after surgery?
6. Do you feel you were well aware of potential side effects or complications from surgery?
7. Do you feel good about your decision to have had surgery? Would you make the same decision again?
8. Do you feel the surgery has or will enhance your overall quality of life?

**Figure 2. Patient Interview Guide**

**Preoperative**

1. Describe the overall status of the patient, general condition for surgery, major comorbidities, concerns, or worries.
2. Please identify the major problems or symptoms that are prompting this operation.
3. What are the major goals which you hope to accomplish in this operation?
4. Do you anticipate that the proposed surgery will significantly alter this patient's disease course?
5. Are there any alternative options to treat this situation?
6. How was the decision to proceed with surgery made?
7. How likely is the proposed operation to result in good or excellent palliation for this patient?

**Postoperative**

1. How would you describe the overall condition of the patient?
2. Could you discuss what you found at surgery and whether your original operative plans were altered?
3. Were you able to accomplish your major intended goals of the operation?
4. How effective do you feel the operation was at alleviating the symptom or problem that prompted the operation?
5. Would you say you were successful at achieving good or excellent palliation?
6. Given the same set of circumstances, patient situation, and comorbidities, would you offer the operation again?

**Figure 3. Surgeon Interview Guide**

**Table 2. Demographics**

| Variable | n |
|---|---|
| **Patient (N = 10)** | |
| **Age (years)** | |
| $\bar{X}$ (Range) = 57.2 (42–74) | – |
| **Gender** | |
| Female | 4 |
| Male | 6 |
| **Ethnicity** | |
| Caucasian | 8 |
| Asian | 1 |
| Hispanic | 1 |
| **Primary language** | |
| English | 9 |
| Spanish | 1 |
| **Residence** | |
| Lives alone | 1 |
| Lives with extended family | 3 |
| Lives with spouse | 6 |
| **Employment** | |
| Disabled | 3 |
| Medical leave | 1 |
| Retired | 6 |
| **Patient and family income** | |
| $10,000–$45,000 | 6 |
| $46,000– > $80,000 | 4 |
| **Place of birth** | |
| United States | 8 |
| Other | 2 |
| **Years of formal education** | |
| College graduate | 6 |
| Graduate studies | 4 |
| **Religious preference** | 9 |
| **Diagnosis** | |
| Esophageal cancer | 2 |
| Colon cancer | 2 |
| Breast cancer | 1 |
| Kidney cancer | 1 |
| Stomach cancer | 1 |
| Melanoma | 1 |
| Hodgkin's disease | 1 |
| Leg squamous cell carcinoma | 1 |
| **Surgeon (N = 3)** | |
| **Age (years)** | |
| Range = 43–53 | – |
| **Gender** | |
| Female | 0 |
| Male | 3 |
| **Ethnicity** | |
| Caucasian | 1 |
| Asian | 1 |
| Hispanic | 1 |
| **Born in the United States** | |
| Yes | 1 |
| No | 2 |
| **Number of years in medicine** | |
| $\bar{X}$ (Range) = 22 (19–25) | – |
| **Number of years in oncology** | |
| $\bar{X}$ (Range) = 15 (10–19) | – |
| **Hours of palliative care education during medical school** | |
| $\bar{X}$ (Range) = 2.8 (0–4) | – |
| **Hours of palliative care education during residency or fellowship** | |
| $\bar{X}$ (Range) = 4.7 (0–10) | – |
| **Hours of palliative care continuing education** | |
| $\bar{X}$ (Range) = 13.3 (10–20) | – |

**Physical Well-Being**

**Pain**

Yes, um, pain, I think my spleen is starting to bother me. . . . Cancer seems to be more of a different kind of pain than other pains. I have had quite a lot of surgeries. And cancer is more of a dull, nagging pain. Um, sometimes kind of a stingy pain, but it's just there, so it gets kinda like a toothache. . . . I think it makes you irritable sometimes.

**Psychological Well-Being**

**Anxiety**

I'm very, very vulnerable. To dying. They haven't really told me much. No. You know nothing, ever, really; I don't have the experience that anything really gets nailed, you know? I mean, I wouldn't know whether they—I know it's all brand new. It seems to be brand new.

**Coping**

The treatment—the treatment's a bear. That is not a mind-over-matter situation. I'm a mind-over-matter person and I can usually say, okay, I'm sore from the surgery, and I listen to my body and the pain and what I can do and can't do, but the treatment . . . it controls ya. Yeah, so, you know, if I have to go. . . . You know, I just have to look at the positive of it and say it's going to keep me a little longer for my babies—that's how I look at it.

**Social Well-Being**

**Change in Relationships**

Everyone is coping great. My wife is, ah, wonderful; she's holding down a job and coming here, helping me, doing my bandage changes, and sitting with me. My oldest daughter is handling it very well. My youngest daughter is not handling it quite as well. She's tended to withdraw a little bit. And we're looking into getting her some professional help to get through this. But I think once I'm through the surgery, and she sees that my quality of life has improved 100%, then I'll be able to hang out with her and that should just solve everything.

**Spiritual Well-Being**

**Faith**

You know, God is with me, and, you know, God will help me. And try your best to meet whatever you need to cure illness. And I think God will help me. Whatever comes. You know, I don't worry. Yeah, because I know God. God will help me and, if not, then I will, I'll be going to the heaven.

**Figure 4. Patient Presurgery Quality of Life**

surgery as a pivotal time in their illness, allowing them time to pause and consider life's meaning and priorities.

Figure 7 includes some of the comments patients made in relation to their decision to have surgery. Patients seemed to generally affirm that the decision to have surgery had been a good choice and to recognize that, in most instances, surgery would give the physicians an opportunity to evaluate their advanced disease. Patients had a strong sense of "not giving up" and continued to search for traditional or alternative treatments that might lengthen life.

## Surgeons' Interviews

Figure 8 describes the key findings from the surgeons' interviews conducted preoperatively. In general, surgeons described symptoms leading to the decision for an operation and the goal for symptom relief. They described the importance of helping patients understand surgical options and, as reflected in the literature, the challenge of maintaining hope while being realistic and honest in communicating the goals as palliative rather than curative in nature.

When discussing decision making regarding code status of patients, surgeons were conflicted between avoiding resuscitation because of the patient's advanced disease while recognizing possible need for resuscitation in the situation of potentially

**Surgery-Only Option**
Because this is one of the slower—slower growing cancers, radiation and chemo wouldn't have helped at all. So, there was—there was no option other than—other than the surgery—there was no option.

**Cure or Palliation**
At least I'll have a chance of being cancer free. . . . Well, somewhat cancer free for a while before the next bombardment, since it's obviously—it's obviously a virus that I can't fight off. My immune system's been so compromised over the years that it's obviously one that I can't fight.

**Increased Length of Survival**
My understanding is just to slow it down, because it's all the way through my lymph system already. That means it's already metastasized. I'll guess we do the surgery and then I'll do treatment again. And then, if my body can withstand it, then I'll do the last series and probably just have my CAT scans and wait for it to pop up. That's my understanding. What they told me is I won't be in remission again. I'm in what's called a transition, and, um, so it just depends on how my body continues the transition—how fast or how slow it goes.

**Accepts Risk**
I don't see much risk. But I will accept the risk if there is a risk. Because that's, that's a condition. They will give me surgery; you got to accept the risks. So, in my previous experience, it was very easy to remove. You open, then you take tumor. So, I know there always was a risk, but I, I don't worry.

**Risk of Death**
It might have been me. [Laughs] That I could have died. You know I could die. They could go in, and I could die, right then and there.

**Risk of Complications**
If my, if my heart doesn't stop, if I don't internally hemorrhage, my lung doesn't collapse, they don't inadvertently paralyze me, ah, yeah, it—I have—I have pretty good odds. I think that they originally started out as 60/40 but I—I think they bumped them up a little so I have pretty good odds of surviving it. But you do have to—you have to live with those problems, all the excess baggage.

**Self-Directed Decision**
No, I, when I was evolving with all of this and watching Moyer [television special on death] and everything like that, I knew that no one else could do this. I mean, I couldn't have dumped this decision on anybody. If, for whatever the devil it was, I was trying to get clear about and what I was going to do, it had to be my decision.

**Figure 5. Patient Presurgery Decisions**

reversible complications. Physicians discussed an awareness of the risks involved with surgery and balancing this with potential palliative benefit. One surgeon described the challenge of continuing to provide care and his commitment to serve as the primary physician for patients even as their health declined. This surgeon described major fears of patients "being in pain and being abandoned." He described the value of assuring patients that the physician would "be there at the end" and the importance of continued care for the patient, despite the fact that there was no role for further surgical intervention.

Postoperatively, surgeons were interviewed regarding their perceptions of the outcomes of the surgery. They discussed the overall status of the patient, the operation itself, and their communication with the patient and the family. Figure 9 provides representative comments from those interviews. Surgeons described the status of the patient in terms of the extent of pain or other symptom relief that had been possible thus far. When discussing the effectiveness of the operation, surgeons acknowledged that the procedure often had been less than completely successful in eliminating symptoms. One surgeon described, in detail, his own philosophy of balancing the extent of surgically related hospital recovery time with the estimated

**Physical Well-Being**

**Gastrointestinal Symptoms**
I used to always, I had the constant urge that I was going to have a bowel movement. Well, I did not have a bowel movement, but, and this urge is so strong I, I'd go in and sit on the toilet. And then, of course, I would pass some mucous and stuff. Um, there for a while before the surgery, oh, it was just terrible. And a lot of it would be quite bloody. And, ah, you know, I had a good day yesterday. I had a good night last night and the night before that I had a good night.

**Pain**
So, because I've had the pain, it's been a different pain than, than it was. So, I guess, it, that part changed. Maybe after the pain goes away totally from the surgery, I would notice that part. Um. Unexpected, um. Maybe just the way the pain was. I thought it was going to be different than it was. And then how he told me how it was going to be, it was different than that. But, um, no. No. Not really. Just the worries that if it's done correctly, I guess, but I guess that will show itself.

**Psychological Well-Being**

But now I feel even the surgery's not complete. I still have a tumor in my kidney. But that is not operable based on what [the doctor] told me. Just, just a few alternatives. You know, it's a surgery, remove the whole kidney? Or do the gene therapy? Or do the freezing or burn technique, you know. So there's still a chance.

**Spiritual Well-Being**

It's, ah, I realize my days are numbered, you know. But, ah, and if, if I'm going to be in misery, I don't even want to be here. You know if, if, if they can, I'm sure that's what they're trying to do is make me comfortable. And, ah, and that's fine with me. I, ah, I, ah, you know, if I can go out and do a little bit of this and a little bit of that, and, ah, go watch my granddaughters play softball, what more? [Laughs]

**Figure 6. Patient Postsurgery Quality of Life**

Well, you know, this is really, it's difficult to answer because now [the doctor] has been in there and he has seen what is there. So, now, is it a question: Would I have another surgery, well really and truly knowing what [the doctor] knows, and he is the surgeon, would he perform another surgery? Yeah, I probably would. I think I probably would. 'Cause if you don't, if you don't do something, you're not going to get anything, you know. And, I put the faith in the doctors. I mean, the tumor in the lung is supposedly disappeared. . . . The ones on the lymph nodes is, is practically gone. The tumor that's on the liver is, is reduced significantly. So, he knows what he's doing. Yeah. So, no, I feel that [the doctor] did, when he got in there and saw what he was faced with, I'm sure that he did everything within his ability to help me.

I don't think there was anything left. I mean, when I came here for that surgery, it was the end to me. I needed to take care of what needed to be taken care of or I just didn't want to go on, really. I haven't eat right for three years, and when you spend all that time, you know, just having stuff go down your throat and pour out a hole and burn your skin. . . . It's just terrible. There's a place that you know it's over, you can't stand it anymore.

Yeah. Every time my friend, or whoever, has cancer, I told them don't give up. Try your best. Find an alternative. If you're rejected by this doctor, don't just give up. Keep on trying whatever possible, whatever you have to go through. So, that's the only way. A lot of my friends are cancer patients. When they come to the end of the tunnel, they don't know how to do and they are so depressed, I say don't worry. We already have the problem. You got to face it. Your worry doesn't help. You know, you got to ask God to give you a day. Use the medical technology available. . . . Somebody may save you. You know, a miracle. This could happen to you, too. It happened to me many times. And I do see something like this not just happen to me, happen to other people.

**Figure 7. Patient Postsurgery Decisions**

**Symptoms Leading to Surgery**
Drainage. Through the rectum. That he cannot control. He says it bothers him a lot all the time. He said it was a real burden over the Christmas and New Year's holidays. So, I think it, it interferes with him socially just because of the drainage and the lack of control and the fact that he just can't get comfortable.

**Goals of Surgery**
The major goal is cure. So, not only is it good in the sense of increasing survival, but it is also very good in decreasing symptoms such as swallowing and pain. So, although it does not affect the metastatic disease, obviously, it does affect quality of life, and most patients that undergo surgery eat the entire period until they die. And that is a major advantage of surgery. It has to be done with a low morbidity. If you have a high morbidity, then all the benefit of surgery is gone.

**Patient Decisions Regarding Surgery**
I don't think they [patient and family], they think of it as a curative, but I do think that they think that his life will be prolonged. They know that it's going to recur again, but they think if you can prolong the time between recurrences to one to two years, his chance will be better. And I think there's also that, ah, element of hope that a new drug may be developed or a new form of treatment. I don't think they're grasping at straws, but I think there is that, that element of hope.

**Discontinuing Treatment or Code Status**
I don't discuss code status, because I think this guy has a year to live. I think he's made the investment. He's made the commitment to go through a painful surgical procedure. . . . It's a big investment on the part of the patient. And I think he's made a decision that he's not ready to give up. And to me the DNR [do-not-resuscitate order] is a give-up. So, if he had a cardiac event during the operation, I wouldn't stop the operation. I'd try to deal with the cardiac event. If two days after a successful palliative procedure, he was still comatose and, um, had, ah, cardiac output of one, secondary to a myocardial infarction, then, then I would want to make that decision.

**Risks Involved With Surgery**
He has 30% three-year survival with chemo-radiation, but the five-year survival is less than 5%. Most patients die before the third year—70% of them die before. But, basically, there are virtually no patients that survive past five years with chemo-radiation alone. The combination of chemo-radiation followed by surgery achieves about 30% long-term survivors. And I think in, in young patients like this one, without significant additional morbidity that might be dying off, this is a rational treatment, and the patient understands those options and selected the most aggressive treatment, understanding that the risk is 5% mortality up front.

**Physician Communication With the Patient**
He had an excellent understanding of what we're going to do. I think he's probably more optimistic than I would tell him to be about just the complete nature of doing this. He doesn't completely understand his disease, but he understands the operation. He understands the goals of the operation, and he does know what the limitations are. But I think he's still very optimistic. A better outcome from his disease as a whole. He knows that, absolutely. He knows that this will define the fact that he will never be put back together.

**Figure 8. Surgeon Comments Presurgery**

survival time of the patient. In his example, he considered surgery that was anticipated to require minimal postoperative hospitalization time to be justified even if the patient had anticipated short survival time, but he considered it unjustified to perform surgery with prolonged postoperative hospitalization and recovery periods if the remaining life span was short.

## Discussion

The investigators believe that this study contributes to an understanding of palliative care by exploring patient and surgeon decision making in advanced disease. This qualitative study is one component of a program of research in the area of palliative surgery that began in 1999. To date, this research has included retrospective and prospective evaluation of the use of palliative surgery in a cancer center (Krouse et al., 2001), a national survey of surgical oncologists (McCahill et al., 2002a, 2002b), a study of QOL and symptom outcomes of palliative surgery, and an exploration of family caregiver perspectives surrounding surgery (Borneman et al., 2003). This study of patient and surgeon decision making contributes to this program of research by sharing subjective information and adds to the understanding of QOL factors in this population.

The study findings indicate that the physical impact of uncontrolled symptoms is the primary motivation to consider palliative surgery but that the social impact of these symptoms and the need to maintain hope also factor heavily. Thus, as future investigators evaluate palliative treatments, these outcomes are important to consider. Study findings also revealed that patients often held on to hope for cure even when they had been given information about the palliative intent of surgery. Patients generally considered surgery as the only option and saw surgical risks as inherent and not major influences in decision making. They believed that the decision to pursue surgery was made deliberately and independently by themselves, and they relied on faith to cope with the possibility of a negative outcome. Postoperatively, patients generally regarded surgery as the right choice because it served as a source of hope and gave them needed time for reflection.

An important methodologic note is that the investigators found that the two-week time period between surgery and the

**Status of Patient**
Postoperatively, the mucus discharge was markedly reduced. That was successful. The patient has a lot less pelvic pain in general, maybe due to a partial obstruction from the tumor in that area, even though he had been already diverted. And early on he had better spirits and was eating a little bit more. I told him that likely we would help at least the mucus discharge, but maybe not the pelvic pain. In general, he felt better at least early on. And, in fact, it helped the pelvic pain also, so he was happy with that.

**Surgery Effectiveness**
He wasn't in the hope of having normal bowel function. He was just in hopes of removing the side effects of the tumor being present in the rectum and bowel. So, if it's three months now postoperative for the palliation for the pain and for the mucus discharge, I'm satisfied. So, for one week in the hospital, that was rational. . . . And he's not only exceeded the three months, he's also gotten very good palliation for the specific symptoms that were addressed.

It's a question of how long it takes the patient to have the surgical palliation and recover from it to how long they are going to survive. So, if it's a 30-minute operation of removing that critical symptom and they die in three weeks, I'm okay with that. And if they die from progressive disease elsewhere three weeks later, I have no problem with that. If it requires one week of hospitalization. . . . An operation and one week of hospitalization, and the patient dies of their progressive disease three weeks later, I think that's unacceptable. So, there is some ratio there.

**Communication**
I met with [the patient's wife] on Thursday, spent an hour with her, going over all the issues, tried to help her deal with the loss of her husband. I usually do that. I invite my patient's family to come back and meet with me as many times as they need, because I think if you understand what went wrong, it doesn't bring people back, but at least you don't leave questions unanswered.

**Figure 9. Surgeon Comments Postsurgery**

postoperative interview was too brief to fully assess symptoms and the physical impact of surgery. Future phases of this research will delay postoperative follow-up to better capture patient outcomes. The investigators were impressed by the resolve of patients to keep fighting their advanced disease and their continued hope for extended life. These findings were important indicators of the need to understand patient perspectives of treatment options and the need for palliative care concurrent with active treatment of disease.

The surgeon interviews provided important perspectives about their roles in decision making and illustrated the importance of the interdisciplinary approach to care in advanced disease. Surgeons conveyed that the need to balance the risk of surgery with the physical and temporal benefit was foremost in their recommendations to patients. However, they were challenged frequently to maintain patients' hope while trying to communicate an honest assessment of patients' status. All surgeons emphasized the importance of ensuring that patients and their families have a clear understanding of the options available, although they did have some reluctance to discuss patient code status. Frequently, surgeons described the surgical outcomes as somewhat poorer than originally expected.

The surgeon interviews illustrated the commitment of these physicians to patient comfort, QOL, and maintaining hope amidst advanced disease. The nurse investigators were impressed by the evident compassion expressed by the surgeons and their difficult challenges in making treatment decisions.

## Conclusion

Comprehensive care for patients with advanced cancer seeks to achieve a balance of providing aggressive care, ensuring optimal symptom management, and maintaining a focus on comfort. Recent literature has explored the role of chemotherapy or radiation therapy with less emphasis on palliative surgery. This qualitative study is a component of a larger, longitudinal program of research that hopes to advance the understanding of the role of surgery in palliative care. Study findings helped to advance the conceptual model and provided direction for future intervention.

Patients with cancer undergoing surgery may be viewed in an acute care focus with attention given to physical needs. This study illustrates the comprehensive needs of surgical patients encompassing physical, psychological, social, and spiritual well-being. These findings also indicate the importance of coordinated interdisciplinary care in surgical oncology.

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