Chapter 38
Goals of Care with Palliative Surgery

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Abstract Almost all surgical procedures have a palliative component to them in that they aim to relieve symptoms of some disease process or injury. Some patients who have life-threatening illnesses or are at the end of their lives may still benefit from surgical procedures, even if the goal of the therapy is not curative. In this chapter, we explore the reasoning prerequisite to offering palliative surgical procedures. The surgeon, the patient, and/or the patient's surrogate may be confused about the goals of care for palliative surgical therapy. The patient's goals of care may change as the disease progresses and curative management may transition into palliative management. It is important to explore goals of care at pivotal decision points with the patient, family members, and friends in a multidisciplinary care setting that ideally includes the patient's primary care physician, relevant specialists, critical care team, and surgeon in order to fully explore all palliative options and set realistic goals and expectations in line with the patient's wishes and values prior to offering palliative surgical therapy.

Keywords Palliative surgery · Surgical ethics · Goals of care · Outcome measures Complications · Surrogate decision-maker

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Search Strategy
Medline, EMBASE, and Google Scholar were searched without filters or language restrictions from inception to July 10th, 2020, using a combination of the terms: palliative care, palliative surgery, palliative goals of care, palliative surgery ethics. 10,369 articles were found in this manner and 40 were screened manually based on relevance to ethics and palliative surgery, and fourteen were chosen as references for this chapter due to relevance.

Case
A 74-year-old male presents to his primary care doctor with abdominal discomfort and unintentional weight loss. Further work-up reveals intermittent blood in his stools. He is referred to gastroenterology. Upper and lower endoscopy is performed and reveals a 3-centimeter mass in his transverse colon that is biopsied and found to be adenocarcinoma. Imaging shows that the tumor has grown through the wall of the colon but staging shows that the patient does not have any evidence of metastatic disease or involved lymph nodes. The patient is referred to a colorectal surgeon who discusses surgical options with the patient. The patient undergoes a partial colectomy with accompanying lymph node dissection and does well post-operatively without the need for adjuvant therapy.

Case continued
The now 76-year-old patient, after his successful prior colon cancer resection, on surveillance imaging, is noted to have a recurrence of a mass at his prior colon resection site. Repeat colonoscopy and biopsy confirms recurrence of colon cancer. Further work-up and cancer staging show no signs of metastatic disease and he is prepared for another operation for possible resection of this local recurrence. At operation, however, small nodules are found throughout the peritoneal cavity without the presence of ascites. Biopsy confirms metastatic disease. The operation is stopped, and the patient is referred for palliative chemotherapy.

38.1 Introduction

Medical and surgical care should strive to address issues beyond the physiologic state of the disease process being treated. Patients who have advanced illness, particularly cancer diagnoses, often suffer from poor symptom control and struggle with medical decision-making. Patients' families may also suffer physically, mentally, and even economically [1]. Attention to palliative care in the United States has increased following the publishing of an Institute of Medicine Report in 1997 that evaluated challenges associated with end of life care [2]. Palliative care is described by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" [3]. By extension, palliative surgery focuses on using surgical procedures as a part of the management plan to reach palliative goals. The goal of palliative surgery is not to cure an ailment, but to ease suffering, including but not limited to when patients are at life's end or are facing a life-threatening illness.

Recently, the role of the surgeon has become more prominent in the palliative care process. The American College of Surgeons (ACS) has defined palliative surgery as "surgical procedures used with the primary intention of improving quality of life or relieving symptoms caused by an advanced disease" [4] and the ACS published a statement of principles of palliative care for its membership (see Table 38.1) [5].

Table 38.1 Statement of principle of palliative care, American College of Surgeons [5]

Statement of principles of palliative care
1. Respect the dignity and autonomy of patients, patients' surrogates, and caregivers.
2. Honor the right of the competent patient or surrogate to choose among treatments, including those that may or may not prolong life.
3. Communicate effectively and empathically with patients, their families, and caregivers.
4. Identify the primary goals of care from the patient's perspective, and address how the surgeon's care can achieve the patient's objectives.
5. Strive to alleviate pain and other burdensome physical and nonphysical symptoms.
6. Recognize, assess, discuss, and offer access to services for psychological, social, and spiritual issues.
7. Provide access to therapeutic support, encompassing the spectrum from life-prolonging treatments through hospice care, when they can realistically be expected to improve the quality of life as perceived by the patient.
8. Recognize the physician's responsibility to discourage treatments that are unlikely to achieve the patient's goals, and encourage patients and families to consider hospice care when the prognosis for survival is likely to be less than a half-year.
9. Arrange for continuity of care by the patient's primary and/or specialist physician, alleviating the sense of abandonment patients may feel when "curative" therapies are no longer useful.
10. Maintain a collegial and supportive attitude toward others entrusted with care of the patient.

The case scenario presented above represents initially treating the patient surgically with a curative intent. It is important to remember that all surgical care has a palliative intent embedded within its care goals. Some part of all surgical care focuses on minimizing symptomatology and suffering. The patient in the scenario above may find relief from his abdominal discomfort, so his symptoms are palliated, and while he does face a possible life-threatening illness, the goal of his initial surgical care is to cure him of his disease and restore him to his prior quality of life. For the purposes of this chapter, we will focus more on how to approach goals of care when the outcome of surgical interventions aim to palliate patient symptoms when there are no surgical options for curing them of a disease.

38.2 What Palliative Surgery Is and Is Not

The second surgery in the case scenario above illustrates a common misconception among surgeons regarding palliative surgery. Surgery with a curative intent in which a tumor is not fully resected, leaving behind residual tumor, is not palliative surgery. A majority of surgical oncologists responding to a 2002 Society of Surgical Oncology survey reflected this mistaken view of 'palliative surgery'. The survey responses revealed that many surgeons equate palliative surgery with non-curative surgery [6].

The patient in the case scenario above had a surgical procedure that may be described as non-curative surgery in that his disease process, colon cancer, could not be cured with his planned surgery. However, he was not palliated of any specific symptoms. It is also important to distinguish palliative surgery from palliative care for surgical patients, which describes attaining the goals of palliative care for patients after they have had surgery but do not need another operation.

Many surgical procedures are considered palliative in that they aid in treating the symptoms of patients at the end of their lives or with life-threatening illnesses. The most common surgical palliation occurs in the care of patients with cancer. Palliative surgical procedures are now routinely included among the therapies offered at comprehensive cancer centers. At one tertiary cancer center, 12.5% of surgical cases could be classified as palliative procedures [7]. In cancer care, surgical procedures may be helpful for cancer-associated pain, bleeding from tumors, obstructions such as intestinal obstructions, and malignant fluid re-accumulations. Specific examples of palliative procedures for cancer patients include:

palliative tumor resection to address bleeding or obstruction such as an obstructing or bleeding gastric cancer

drainage of fluid accumulation as can be seen in metastatic disease to the pleural spaces from a number of cancers, which can also be treated with pleurodesis or placement of an indwelling pleural catheter that can be intermittently drained to aid respiration

intestinal bypass operations to aid obstructions from gastrointestinal malignancies including colon caner

cancers amenable to debulking procedures where tumor burden is relieved, which may help symptomatology but does not cure the cancer itself (e.g., therapy for unresectable malignant mesothelioma, multiorgan colorectal cancer metastases, and certain cases of peritoneal carcinomatosis)

Case continued

Our 76-year-old patient with metastatic colon cancer, while undergoing palliative chemotherapy, presents to the emergency room with nausea, vomiting, and increasing abdominal pain and distension. He notes he has not had a bowel movement in 3 days. Cross-sectional imaging shows distended loops of small bowel and mesenteric nodularity likely to be metastatic disease throughout the peritoneal cavity. There is no ascites, and a single transition point is identified with distal small bowel decompression. He is diagnosed with a malignant bowel obstruction and admitted to the hospital. A nasogastric tube is placed for gastrointestinal decompression and combined with anti-emetics to relieve the patient's nausea. The surgeon is consulted to evaluate the patient for possible surgery to relieve his small bowel obstruction. The patient wants to know what his quality of life will be after surgery.

The patient has now presented with a life-threatening complication, quite possibly near the end of his life, with a surgical problem that is difficult to manage. Malignant bowel obstruction represents a particularly problematic decision in that surgery may be able to relieve the patient's obstruction, but then the patient may be confined to care in the hospital for his post-operative care and exhaust many of the few remaining weeks he has to survive. These patients are also often poor candidates for surgery due to malnutrition and deconditioning associated with their gastrointestinal malignancy [8]. This scenario illustrates a common ethical dilemma that must be addressed in a timely fashion by the care team. In current medicine, these patients may be admitted to an oncology service. Additionally, if they are particularly ill, they may be admitted to the intensive care unit with a team of critical care specialists managing their care. Due to advanced illness, a palliative care physician may be consulted to help manage the patient's symptoms and goals of care. The surgeon is added to this multidisciplinary care team, a hallmark of modern medicine, in which physicians and healthcare professionals from multiple fields must coordinate and effectively communicate their care plans to provide the best possible care for the patient.

38.3 Ethical Framework

Multiple care teams are seeing the patient in the above scenario who has a malignant bowel obstruction and is now admitted to the hospital for further management. How is the patient encouraged to trust the care team? The answer lies with each of the

Table 38.2 Core ethical principles and the goals of surgery

Ethical responsibility	Curative/Restorative surgery	Palliative surgery
To avoid additional harm to the patient (i.e., non-maleficence)	Prevent post-operative complications, pain, or functional debility and allow restoration of quality of life acceptable to the patient	Prevent post-operative complications, and prevent further pain or debility brought on by the patient's advanced or terminal disease process
To deliver benefit to the patient (i.e., beneficence)	A recovery of quality of life acceptable to the patient results from a successful surgical intervention.	Pain/suffering no longer undermine the patient's quality of life (or dying) after a successful surgical intervention.
To respect the patient's goals (i.e., patient self-determination)	The patient is discharged with a feasible return to pre-operative quality of life after a successful surgical intervention.	Pain/suffering no longer keep the patient from experiencing a desired quality of life (or dying) after a successful surgical intervention.
To protect the patient from bias (i.e., fairness or justice)	The patient's demographics do not alter the outcome after a successful surgical intervention.	The patient's demographics do not alter the outcome after a successful surgical intervention.

pillars of clinical ethics (see Table 38.2), i.e., beneficence, non-maleficence, self-determination or autonomy, and fairness or justice. The medical team aims to make a positive valued difference in the patient's wellbeing (beneficence) while being careful to avoid harming the patient (non-maleficence), honor the patient's wishes in accordance with their values (autonomy), be free of bias, and good stewards of medical resources (justice or fairness). In addition, the medical and surgical teams must effectively and professionally communicate amongst themselves, and with the patient. The patient must have sufficient time to clarify his preferences, ask questions, and reconsider the focus of care as new information arises or management plans change.

This trust is difficult to establish and fragile. Most patients requiring evaluation for a palliative surgical procedure have a life-threatening condition or are at the end of their lives. They represent a vulnerable patient population, and their families are also vulnerable due to significant stresses on both the patient and family that may be physical, psychological, social, or even economic in nature. These stresses may significantly strain effective communication between the patient and his family, and also with the care team.

The surgeon must weigh a duty to benefit the patient without causing avoidable harm. Surgeons have historically been stereotyped as authoritative and paternalistic, thereby prone to undermine the patient's and the patient's families' autonomy [4]. From a more pragmatic standpoint, the array of surgeries available to the surgeon to help aid the patient can be the source of distrust. Palliative surgical procedures are some of the least studied in the surgical profession. There is scant medical evidence that demonstrates support for many such procedures even though they may theoretically be expected to help alleviate patient symptoms. Thus, palliative procedures are often offered to patients based on the discretion of the surgeon or the palliative care team, creating significant variance in what is offered to patients. This complexity

may be further compounded by the care providers' lack of familiarity with existing procedures that may help palliate the patient. Palliative surgeries aid the patient's quality of life and relieve suffering. In some cases, the palliative goal is not achieved, in which case further harm may have been done to that patient. This uncertainty may account for some of the variability in what may or may not be offered to patients in terms of palliative surgical procedures. The potential for miscommunication when multiple medical teams and family members are involved in decision-making for a patient's clinical care is obvious. Palliative care discussions are additionally challenging when the patient, family, or even care givers insist that they want to "do everything". This appeal has different connotations that can lead to significant confusion about the patient's goals of care.

Goals of care may be curative, rehabilitative, life-prolonging, or comfort focused [9]. In this regard, there should be ongoing goals-of-care discussions for all medical and surgical therapies. The point of these patient-centered discussions is to establish the patient's healthcare preferences so that their management remains consistent with their values, with help from family or surrogate decision makers. All surgical procedures that are not emergent are preceded by a discussion with the patient or family/surrogate decision-maker about the risks and benefits of the procedure in an informed consent process. This discussion presents an opportunity for clarification of the patient's goals of care and has the additional benefit of involving all of the same stakeholders in the overall care of the patient including the patient, their family or surrogate decision-maker, the primary care team, the palliative care team, and the surgical team. Medicine necessitates collaboration among these complex, multidisciplinary care teams. For a patient being evaluated for palliative surgery, management often involves a service such as hospital medicine taking primary care of the patient, with a palliative care service assisting to make recommendations, and with the possible addition of a surgical service to address surgical palliation. It is particularly important that the surgeon approach the patient with a plan in coordination with these other care services to offer therapy that is clear and in line with the patient's values.

38.4 Discussion: Ethical Analysis

The priority of palliative surgery is to reduce pain and suffering. When a consult is sought for a palliative surgical procedure, the most important factor patients consider is the physical impact of uncontrolled symptoms [7]. Secondary decision-altering factors include the social impact of symptoms and maintaining hope. Treatments that in the care team's best professional judgment will not have a reasonable chance of benefiting the patient and will serve only to prolong the dying process or place undue burden on the patient should not be offered, initiated, or continued. Pain and suffering are of course not isolated to the patient. The patient's family and friends often report significant distress linked to the uncertainty of the patient's clinical situation and prognosis.

It is difficult to establish outcome measures by which to define success in palliative surgery. Unlike outcomes measured for curative surgery (e.g., survival or event-free or cancer-free survival), only the patient or patient's family can finally determine the benefit of palliative surgery. Complications after palliative surgeries are common though not numerically defined for all palliative procedures. These complications can significantly limit the palliative effect of the surgery. For cancer patients, a significant postoperative complication following a palliative procedure diminished the chances of symptom resolution to just 17% in a study of 59 patients who underwent palliative surgery for advanced malignancies [10]. While there is no standardized or validated tool to measure outcomes in palliative surgery, there are a few measures currently being used to predict procedural success e.g., the absence of post-operative complications, and the need for prolonged hospitalization. One tool that is favorably reviewed is the Palliative Surgery Outcome Score (PSOS). The PSOS calculates the number of symptom-free, non-hospitalized days as a fraction of the number of post-operative life days (up to 180 days). Both patients and their families have identified a PSOS value of 0.7 as an acceptable positive outcome [11]. This score can be applied to any palliative surgery situation, but the validating study was completed for patients with advanced malignancies. As focus and research on palliative surgery grows, additional tools for reliably and meaningfully measuring outcomes of palliative surgery should emerge.

Prior to any surgical procedure, the surgeon and patient exchange information and preferences in an informed consent process. This process can be particularly complicated prior to palliative procedures. While the details of the informed consent process may vary based on the medical society or group defining the critical steps, most standards include the core elements of: competence and voluntariness of the patient, disclosure of procedural risks and assessment of patient understanding, and a decision or authorization for the procedure to continue [12]. Since the outcomes of palliative procedures remain poorly measured, discussions with patients and families about procedural outcomes often lack medical evidence. Patients requiring palliative surgery are more likely to lack decisional capacity due to their advanced illness. If a patient lacks decisional capacity, an appropriate surrogate (usually but not necessarily a close family member) should assist in the decision making (1) ideally/preferably by representing the patient's known values and goals or (2) if such are not known, then by promoting the patient's best interests. However, the care team is not obligated to adhere to a surrogate's input if the surrogate seems to lack decisional capacity or their decision seems to be contradictory to the patient's expressed values or goals (see Chap. 39). In such circumstances, utilizing Social Services, Spiritual Care (see Chap. 19), the Ethics Committee, and/or Risk Management is strongly encouraged. If no other options exist, the hospital may pursue action through the courts to establish a guardian for the patient. In the case of suspected patient abuse or neglect, the appropriate administrative agency should be notified. The informed consent process provides an opportunity to review and further discuss goals of care for the patient's disease process as a whole and advance directives, beyond just the surgical procedure.

In reviewing goals of care for a patient being assessed for palliative surgery, clarifying what is medically and surgically feasible becomes particularly important.

Patients and their families may see the involvement of a surgeon as new hope for cure or improved chances of survival. Surgeons may be concerned that being frank will risk taking hope away from the patient and family. A survey of physicians about palliative surgery in patients with advanced cancer found that the greatest ethical dilemma for surgeons was providing patients and their families with honest information without destroying hope [13]. Ethically skilled care team members are prepared to move discussions with patients or surrogates toward consensus regarding the patient's outcome/discharge expectations. A patient's expectations may be restoration to preadmission functional status, relief from pain and suffering, survival regardless of quality of life, or survival long enough for desired closure. Quality of life outcomes that may be unacceptable to a patient include being permanently unconscious, being permanently unable to remember or make decisions or recognize loved ones, being permanently bedridden and dependent on others for activities of daily living, being permanently dependent on hemodialysis, or being permanently dependent on artificial nutrition and/or hydration. A 'Goals of Care—Communication Template' (see Table 38.3) can help frame/guide this discussion [14].

The focus of care for most patients is to restore the patient to a level of function compatible with the patient's expectations, with all appropriate therapies being initiated and continued. Not all patients who are assessed for palliative surgery will benefit from a procedure. If the care team concludes that the desired restoration cannot be achieved with surgical palliation, further discussion with the patient and family members is needed in order to reconsider the expectations for the hospitalization. Based on this discussion, current management may not be escalated, additional interventions may not be introduced, and current life-sustaining treatments may be discontinued so as not to place undue burden on the patient. Regardless of the patient's suitability as a surgical candidate, the duty of the care team is to further discuss goals of care (see Chap. 7) and expectations as the situation changes with gradations of palliation. It is important to remember that the surgeon is not merely a technician, but a member of the multidisciplinary care team that must address the patient's needs whether a surgical procedure is planned or not. In some cases, the focus of care should shift to concentration on the patient's comfort during the dying process.

Case Closure

Our 76-year-old patient with metastases and malignant bowel obstruction is seen by the surgeon and discusses the case with the multidisciplinary health care team. The surgeon offers exploratory laparotomy and possible small bowel resection, bypass, or diversion for relief of his obstruction as cross-sectional imaging shows a single transition point. He emphasizes that while the patient's symptoms may be relieved if the surgery is successful, there is an approximate 50% chance of recurrence of his obstruction in the coming month, and the surgeon quotes him a 25–30% risk of mortality in the same time frame. After deliberation with his family, and due to his advanced symptoms, the patient decides to undergo surgery. During surgery, the patient's

small bowel obstruction is treated with short-segment small bowel resection and primary anastomosis. The patient recovers in the following week, has minor drainage from his surgical wound, is able to restart per oral intake, and is discharged home with opioids for pain control.

Approximately five weeks later, he presents once again to the hospital with another small bowel obstruction. His symptoms are partially relieved with insertion of a nasogastric tube. The palliative care team sees him once again along with the surgeon. The surgeon this time does not recommend redo surgery because it is unlikely to help him symptomatically and is even a higher risk than the first time around. The patient and his family are thankful for the past month he was able to spend with them, but now they decide to forego any further invasive interventions. The medical care team controls his symptoms with a combination of nasogastric drainage, anti-emetics, pain medications, and anti-secretory agents. He goes home with hospice care where he passes away approximately one week later.

Table 38.3 Goals of Care—Communication Template [14]

PART A: Document Goals of Care

Based upon comprehensive discussion between the patient _____ (or surrogate) and the treating physician, the following explanation best describes the patient's current goals of care:

_____

_____

EXAMPLES include but are not limited to: "return to prior living situation at previous functional status" or "return to prior living situation after physical therapy" or "remain in my home" or "be free of pain or breathlessness" or "maintain my privacy and dignity" or "be able to interact with my loved ones" or "attend my granddaughter's graduation".
NOTE: "Do everything" is NOT a goal of care. Ask the patient (or surrogate) what 'everything' is intended to achieve.
NOTE: To set realistic goals, the patient (or surrogate) needs a clear description of what to expect.

Discuss and document if the patient wants aggressive **life-support measures** stopped and wants treatment instead to focus on comfort and dignity if any one or combination of the following is the most likely outcome:

____ being permanently unconscious (i.e., completely unaware of surroundings with no chance of regaining consciousness)
____ being permanently unable to remember, understand, make decisions, recognize loved ones, have conversations
____ being permanently bedridden and completely dependent on the assistance of others to accomplish daily activities (e.g., eating, bathing, dressing, moving)
____ being permanently dependent on mechanical ventilation
____ being permanently dependent on hemodialysis
____ being permanently dependent on artificial nutrition (tube feedings) and/or intravenous hydration for survival
____ death likely to occur within days to weeks and treatments are only prolonging the dying process
____ other(specify): _____
_____

Table 38.3 (continued)

PART B: Document Focus of Care
Based upon the above understanding of the patient's goals of care: ☐ The focus of care will be to restore the patient to a level of function compatible with the goals outlined above. Specific testing and treatments will be ordered by the patient's physicians with the intent to achieve these goals. ☐ The focus of care will concentrate on the patient's comfort. Treatments that serve only to prolong the process of dying or place undue burden on the patient will not be initiated or continued.
PART C: Recommend Resuscitation Status
1. Based on the current condition, prognosis and comorbidities, and on weighing likely benefits, harms and goals outlined above -- A. The treating physician **does / does not (circle one)** recommend CPR in the event of cardiac arrest. B. The treating physician **does / does not (circle one)** recommend intubation in the event of impending respiratory arrest. C. The treating physician at this time **cannot make a definitive recommendation(circle)** regarding CPR or intubation. 2. These recommendations have been discussed with the patient (or surrogate) with reassurance that if resuscitation is not performed, treatment will be provided with the goal of comfort and dignity: **Yes / No** 3. For the patient (or surrogate) who decides to be resuscitated (i.e., Code 1) despite the treating physician's recommendation against such, the treating physician has discussed the likely immediate consequences of CPR if successful: **Yes / No** 4. **Person with whom to speak if the patient lacks decisional capacity:** Name: _____ Relation: _____ Phone Number: _____

38.5 Conclusion

Palliative surgery continues to grow as an essential component of comprehensive palliative care services. The success of a palliative surgical procedure is difficult to measure in quantitative terms, leaving the final assessment to the patient or their family members. The ethically sound delivery of palliative care including palliative surgical procedures requires a multidisciplinary care team that effectively communicates and delivers procedural options and outcomes aligned with the patient's preferences and values.

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38.6 Selected References

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  - The author, a colorectal surgeon and palliative care specialist, describes the work-up and palliation of patients with unresectable colorectal cancer. Barriers to proper palliation, a comprehensive multidisciplinary approach to palliative needs assessment, and different models to deliver palliation are discussed. How specific symptoms may be addressed, including appropriate surgical therapies and how to assess the needs of the patient's family are detailed.
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  - This is a retrospective review of surgeries at a NCI-designated comprehensive cancer center over a one year period with a one year follow-up. They enumerate the indications, risks, and outcomes of surgical interventions on cancer patients. A significant portion of these procedures, 12.5% (240 of 1915), are completed with palliative rather than curative intent.
- Hofmann B, Håheim LL, Søreide JA. Ethics of palliative surgery in patients with cancer. Br J Surg. 2005;92(7):802–9. https://doi.org/10.1002/bjs.5104.
  - The authors go beyond the clinical decision-making process for patients with advanced malignancies that may benefit from palliative surgery and explore the moral and ethical challenges these situations present. These challenges are analyzed in terms of the core ethical principles describing respect for patient autonomy, 'duty to help', benevolence, and delivering proper information to patients. The lack of a standardized vocabulary and limited clinical evidence to guide the discussion about palliative procedures provides additional methodological and moral challenges.
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  - A survey of 110 questions consisting of case vignettes evaluated how surgeons selected treatment for symptomatic patients with advanced malignancies and what ethical dilemmas they encounter in the act. The most common ethical dilemmas were providing patients with honest information without destroying hope and preserving patient choice. The most common barriers were referral to surgery by other specialists and limitations imposed by managed care.

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