

# A values-based conceptual framework for surgical appropriateness: an illustrative case report

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**Abstract:** Appropriateness in surgical decision-making necessitates that surgical treatments are aligned with patients' goals and values for care. To arrive at informed decisions for surgery, patients must have an understanding of post-operative recovery, the impact on quality of life, and expected functional outcomes. This article describes an illustrative case of an older patient who experienced a decline in health, functional status, and quality of life in the months following a major surgical operation that was not clearly aligned with her personal goals and priorities. Palliative care needs that arose during the course of the patient's treatment are identified and described, revealing opportunities for better integration between palliative and postoperative care. A conceptual framework for measuring appropriateness in surgery, which incorporates patients' goals, values and preferences for medical treatments, is proposed.

**Keywords:** Decision-making; palliative care; surgical patients; supportive oncology; terminal care

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## Introduction

Older patients are at higher risk for poor outcomes after surgery (1). Some experience incomplete recovery that leads to a decline in functional status and quality of life. In addition to treating physical symptoms, surgeons caring for patients with cancer may need to address diagnosis-related depression and difficulty coping. Although surgeons communicate technical information about diseases and interventions, discussions about patients' preferences for functional outcomes and quality of life are often inadequate to determine whether surgical care is concordant with patients' values and goals. In our conceptual framework, appropriateness in surgery requires: the best clinical evidence, a qualified surgeon, a healthcare facility equipped to capably manage the operation and post-operative care, and patients who are well-informed and meaningfully involved in surgical decision-making. Integrating palliative

care and improving communication may improve the outcomes most important to surgical patients (2).

## Case history

The patient was an 86-year-old woman who, over the course of several months, developed multiple urinary tract infections, gross hematuria, frequency, incontinence, and suprapubic and rectal discomfort. Prior to these symptoms, she enjoyed an active and independent lifestyle. With the onset of hematuria she developed anemia and felt easily fatigued and unsteady. During this time, she suffered a fall, fracturing her wrist. After multiple visits to the emergency department, workup for these symptoms revealed a high-grade, invasive bladder cancer. A transurethral resection was unable to completely remove the tumor, and she experienced a prolonged ileus and poor appetite after the

procedure, further impairing her quality of life. She was unsure whether she wanted to pursue further treatment, given her difficult recovery from the minimally invasive procedure. However, after speaking with her two adult daughters and primary care physician she agreed to see another surgeon to consider a more invasive operation. She and her family discussed multiple treatment options with the oncologist and urologist. Both recommended pelvic exenteration, bilateral pelvic lymph node dissection, and urostomy creation followed by chemotherapy, as this had the potential to palliate her symptoms and remove the primary tumor and a metastatic lymph node. The oncologist noted that the patient emphasized the importance of comfort and quality of life. However, there was no documentation of advance care planning discussions or an advance directive prior to surgery.

She consented to the recommended treatment plan and was admitted for surgery. After the operation, she had a prolonged hospital stay lasting 22 days, which was complicated by depressed mood, dysphagia, ileus, and failure to thrive. The oncology social worker was consulted after multiple nurses witnessed the patient crying in her room. In conversations with the oncology social worker, she spoke about the frightening experience of being hospitalized and in pain. In addition to coping with her cancer diagnosis, she struggled with accepting the patient role and an increasing reliance on her children. However, she remained optimistic that her mood would improve once her pain, which she described as overwhelming, resolved and she was able to reclaim some independence. Due to her continued dysphagia she underwent percutaneous endoscopic gastrostomy placement for nutritional support and was subsequently discharged to an inpatient rehabilitation facility.

In the months following surgery, she returned to the emergency room four times and was admitted twice. She developed urosepsis and endured weeks of pain from obstructing ureteral calculi, which required several invasive procedures. During one of her hospitalizations she developed a severe ileus and episodic delirium and confusion. The oncology social worker, who was again consulted for frequent tearful episodes, noted although she hoped to prolong her life, she stated her primary goal was controlling the pain and regaining strength, mobility, and independence. She expressed her frustrations with quality of life, saying: "One day I'm going to want to stop all of this". Throughout this time, there was confusion regarding

her code status, which had been listed as do-not-resuscitate at rehabilitation, but was changed to full code upon transfer for re-admission. Multiple clinician notes indicated that a family meeting was planned to discuss treatment goals, but the outcomes of these discussions were never recorded, so it is unclear whether a meeting took place.

In her terminal admission for phlegmasia cerulea dolens caused by an extensive deep vein thrombosis, vascular surgery deemed her a poor surgical candidate. At this juncture, a do-not-resuscitate directive was instated and palliative care was consulted to provide symptom-management recommendations. She became markedly distended due to a severe ileus and increasingly frequent episodes of delirium rendered her unable to participate in conversations with her clinicians. Given the rapid decline in her condition, the palliative care physician and oncologist determined that she likely had "days to weeks" left to live and, after 26 days in the hospital, the palliative care physician recommended transitioning the patient to inpatient hospice. She expired 5 days after being transferred to hospice, and approximately 6 months after her initial cancer diagnosis. Following surgery, she spent 41 of the 103 remaining days of her life in the hospital. For the remaining 62 days of her life, she was in post-acute institutions and mostly in pain.

## Discussion

In order for medical care to be appropriate, it must align with the patient's goals and preferences. As such, interventions that are discordant with patients' values are always inappropriate. However, at times the care needed to attain one goal conflicts with the ability to accomplish another. For example, the above case illustrates how quality of life and preservation of life are sometimes competing interests. This creates complexity in decision-making and requires a constant re-evaluation by clinicians and patients of how various treatments are able to facilitate patient-centered outcomes.

Currently, describing and evaluating surgical success largely relies on a "fix-it" model, whereby physicians depict disease as an isolated aberrance from normal health and medical intervention as the pathway to return to normalcy (3,4). This model can be detrimental to communicating risks, patient participation in complex surgical decision-making, and patient-centered care. The patient was initially hesitant to proceed with an invasive surgery because of

her concerns about quality of life. Curing her cancer and prolonging her life were important goals, but, prior to her surgery and throughout her recovery, she emphasized the value of independence, relief from pain, and spending time at home with her family. Given the complexity of the proposed surgery, it was unclear if these goals could be reasonably expected after surgery. Furthermore, there should have been a preoperative discussion of her treatment preferences in the event of complications. However, there was no documented advance care planning discussion or advance directive before surgery. Post-operatively, she experienced complications and again affirmed that comfort was her primary goal, yet this priority was not reflected in the medical treatments she received. The numerous diagnostic and therapeutic interventions that dominated her management at the expense of comfort and quality of life did not halt the progression of her complicated decline.

A recent study, using the Surveillance Epidemiology and End Results (SEER) Medicare database, found that 96% of patients diagnosed with stage IV cancer between 2002 and 2006 underwent an invasive procedure during the course of their oncologic care, with 25% receiving procedures in the last month of life (5). Given their frequent contact with patients during periods of critical illness, surgeons have an opportunity to stand at the forefront of initiating appropriate palliative care. Particularly in patients with chronic illness, engaging in early discussions that acknowledge the importance of quality of life can establish a dialogue and inform future conversations about preferences for treatments and goals of care. Studies have shown integrating early palliative care alongside disease-directed care is associated with higher satisfaction with communications, decreased healthcare cost, and increased survival (6-8). Integrating palliative care and surgical practice may lead to improved quality and value of care for seriously ill surgical patients.

In the case of the patient, among the many doctors she encountered, it was unclear who was primarily responsible for initiating a goals of care discussion. At various times, the patient was admitted to the urology, oncology, and hospitalist services, yet notes indicated that these clinicians deferred this responsibility to her primary oncologist, who was not directly involved in her inpatient management. Moreover, the only cancer treatment she received was surgery, which she chose during a time of relative good health, with an expectation that it could provide at least symptom relief. Multiple surgeons treated or evaluated her,

yet no such conversation was documented by any member of the surgical team. The majority of discussions regarding goals of care did not occur until she became profoundly ill and had a significantly diminished decision-making capacity. Earlier involvement of inpatient palliative care may facilitate these conversations and guide care transitions (8,9).

In conclusion, this case illustrates the necessity of shifting our current paradigms for success, failure, and appropriateness in surgery, such that the evaluation of these constructs accounts for more than cure and survival. It also illustrates opportunities to integrate palliative care in surgical decision-making goals setting, perioperative communication, and symptom management. There were a number of critical opportunities where a palliative approach to care could have alleviated this patient's distress. The incorporation of patients' goals, values, and preferences for medical treatments must emerge in forefront of the conceptual framework by which we measure surgical appropriateness.

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