

Chapter 21

Between a Rock and a Hard Place: Anticipating Poor Surgical Outcomes While Honoring Patient Autonomy



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Case Introduction

A 65-year-old male with Stage IIIB multiple myeloma, severe chronic obstructive pulmonary disease (COPD) substantially limiting any physical activity, and chronic kidney disease (CKD) is admitted to the intensive care unit (ICU) for treatment of recurrent and refractory *C. difficile* infection. Despite maximal intravenous, oral, and rectal antibiotic therapy, the patient develops worsening abdominal distension with possible compromised bowel. You are the general surgeon on call and your team has been consulted. Your assessment of the patient confirms toxic megacolon. As his illness worsens, his renal function deteriorates into oliguria. Vasopressors are initiated, and his oxygen requirement rapidly escalates.

Usual Approach

You confirm the patient has medical decision-making capacity by ensuring that he is able to understand his condition, appreciate the risks and benefits of treatment options, rationalize his decision, and finally, make a consistent choice [1]. Together

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with the patient and his only family who are out of state on speaker phone, you discuss goals of care.

Although he communicates with you that he does not want to pursue dialysis in the event of renal failure, this fact does not emerge when the family joins the conversation. The family urges you, “Don’t let him die.” You say he would survive the surgery, but he may be very sick with a long and difficult recovery. They remain singularly focused on survival, and the patient concedes to the family’s wishes. The patient gives consent and you proceed with an open total colectomy with end ileostomy. Post-op, he continues to decline into multiorgan failure, requiring permanent dialysis, tracheostomy, and long-term nursing care. He becomes increasingly depressed and withdrawn with no local family to provide support.

Palliative Approach

You believe that this operation may save this man’s life, but worry about the significant morbidity he will have post-op. He is a very high-risk surgical candidate. If he survives, he will likely need dialysis, possibly a tracheostomy and long-term nursing care. Patients and families often assume that the operation will “fix” everything, and the patient will go back to “normal.” You have an obligation to discuss possible scenarios with the patient and family to get an understanding of the patient’s goals of care. What is acceptable to him as an outcome?

Box 21.1 Be Goal-Directed, Not Disease-Directed

The patient is an older adult with multiple chronic medical comorbidities in addition to his acute illness. In such cases, a disease-directed care approach may result in overly aggressive treatment and may not address the patient’s health priorities. In comparison, a goal-directed care approach places value on the health outcomes that the patient values most, and treatment decisions are made in accordance [2].

Rather than consulting a palliative care specialist, the initial goal-directed care should be managed by the primary clinician, such as the surgeon. This model of primary palliative care delivery is necessary to address the growing shortage of palliative care specialists and reduce fragmentation of care. Primary palliative care delivered by the primary clinician should include basic symptom management and basic discussions regarding prognosis, goals of treatment, suffering, and code status – skills expected of all clinicians [3].

Decisions may involve not only the goals of the patient but also the goals of the family members who may be required to make decisions. Therefore, it is critically important to include the patient, their support, and others who may make surrogate decisions in a family meeting. Meetings should be held in a quiet, comfortable location and pagers or phones silenced [4].

You begin with the preoperative goals of care discussion with the patient and his family. Prior to this hospitalization, the patient had been quite active. Although he became short of breath with walking, he tells the family that his most important priority is to remain living independently. He is concerned that if he required an oxygen tank, he would not be able to manage his daily care. The family is concerned about the distance they live from the patient, that they would be unable to support him in this goal. You find out that the patient has been on dialysis before, at that time it was temporary. He is adamant about not wishing to pursue long-term dialysis because of the toll it took on his quality of life previously. He has not been able to see his mother in several years – she lives out of state – and his fear is that he will never see her again. His family is surprised by how sick he has become over the last few years and voices concern about seeing him again.

You describe your expectations should the patient elect to pursue an operation. Given his serious illness, you anticipate that he will require a total colectomy with permanent ileostomy. Although it is possible his kidneys might again recover after a period of dialysis, it is most likely that he will require long-term dialysis.

You clearly outline the pathways of care. He may proceed with surgery and suffer the possible complications and likely outcomes. You tell him he would require intubation for the surgery, and with his severe COPD, you expect that he will remain intubated for at least several days. While you imagine that he may eventually wean from the oxygen during the hospitalization or inpatient rehabilitation stay, it is more likely that he will permanently require oxygen.

You describe a second option in the event that the above scenario is not acceptable to him. If he is not willing to be more permanently debilitated and participate in long-term dialysis, then the other option is to transition to comfort care. Comfort care, you describe, is an aggressive focus on symptoms to support his body as he goes through the process of dying. You cannot promise he will live long enough to see his family again.

Box 21.2 Which Framework Is the Best?

A number of frameworks exist for guiding goal-directed care conversations, but little evidence exists as to the superiority of any one method. However, they all serve a common mission: to understand patient goals and align treatment decisions with goals. Examples of frameworks include best case/worst case [5], REMAP (reframe, expect emotion, map out patient goals, align with goals, and propose a plan) [6], and SPIKES (setup, perceptions, invitation, knowledge, empathize, summarize, and strategize) [7]. Use the method with which you feel most comfortable eliciting an in-depth understanding of the patient's values with a focus on functional and cognitive outcomes important to the patient's anticipated quality of life. Regardless of framework, effective communication during family meetings should include establishing trust, respect, support, hope, and attention to affect [4]. All relevant persons, including the patient, family members, and health-appointed decision-makers, should be involved in this conversation to provide a roadmap for future treatment decisions.

His family remains focused on survival, failing to appreciate the toll that illness and recovery will take. Although you share with them risk scores for complication rates including death, the family continues to urge you to “try everything.” They tell you stories of another family member who required surgery to remove part of his colon and reached full recovery (albeit a middle-aged family member with few medical comorbidities who presented with diverticulitis). The family assures the patient they are coming to be with him and encourages him to fight this. The patient agrees with some obvious misgivings. He says to you – at least with the operation I may live long enough to see them again.

Box 21.3 Your Guidance Demystifies the Potentially Long Journey to Come

Patients and families may not understand the physical and emotional toll associated with undergoing an operation and the relevant risk of adverse outcomes. Stories of others who were surgically cured, and inaccurate media depictions of intense illness and heroic saves, lead to unrealistic expectations [8]. In addition, they neither capture the days, weeks, and months of postoperative recovery nor the residual deficits in quality of life that linger after a major operation.

The preoperative discussion defines the direction of postoperative care and creates an informal contract between surgeon and patient. From the surgeon’s perspective, this discussion creates a commitment to the technical aspects of the operation and to the postoperative surgical care and includes shared hope, shared risk, and mutual respect [9]. Postoperative care should be explicitly described (i.e., potential for prolonged life support) in a narrative to place expectations for care into familiar language to the patient and family [10].

Case Continued

You proceed with an uneventful operation; exploratory laparotomy, total abdominal colectomy, and end ileostomy are performed. Postoperatively, the patient is transferred to your service. His hemodynamics rapidly improve and he is extubated within a few days. He continues to require renal replacement therapy without evidence of renal recovery. By now, the entire family including his aging mother has arrived at his bedside.

On postoperative day 5, plans are initiated for transition to intermittent dialysis in anticipation of future discharge to an inpatient rehabilitation facility. However, conflict begins to arise among the patient and his family. The patient is adamant that intermittent dialysis will limit his quality of life and he wishes to cease dialysis. Having seen the patient’s recovery thus far, the family is not willing to accept his decision. The patient won’t make this decision to pursue comfort care unless his family is in agreement.

Each time you see the patient, he appears increasingly depressed. He will not leave his bed and he speaks very little when his family is present. When his family leaves, he conveys tearful regret for proceeding with surgery and begs you to make his family change their mind. When you try and speak with them, they become increasingly angry and demand a second opinion.

Usual Approach

Unable to reconcile the patient's goals of care with the family's wishes, the case begins to wear on you. The patient is ready to transfer to inpatient rehabilitation on intermittent dialysis, giving you an opportunity to withdraw from the case. You sign the contentious case over to the medical team assuming his care.

Palliative Approach

Rather than transition his care, you approach with a new strategy: You reach out to the specialist palliative care team. The palliative specialist agrees to come to speak with the patient and family to help navigate the difficult situation.

Box 21.4 Concurrent Palliative Care Can Augment Surgical Care

Consultation for specialist palliative care should be considered for more complex cases. For example, indications for specialist palliative care consultation include need for assistance with conflict resolution regarding goals or treatment methods, management of refractory pain, management of complex mental health symptoms or existential distress, or assistance for addressing cases of near futility [3]. Interprofessional collaboration, particularly in difficult cases, is associated with improvements in the timing and delivery of palliative care [11]. Traditional surgical culture values an aggressive approach, which can be at odds with the patient's values. Integration of palliative care specialists into an interdisciplinary team can aid in elucidation of patient values and promote focus on symptom management, regardless of curative therapeutic intent [12].

Working closely with you, the palliative care physician helps to again navigate goals of care conversations in light of the current situation. The physician aligns the treatment options with the patient's goals of care. The patient and his family finally come together and request to cease dialysis and transition to hospice. Although the family is grieving, the patient and family are all happy that he underwent surgery to

allow the patient's family to be at bedside. Ten days later, the patient dies peacefully in hospice with family surrounding him.

Although in line with the patient's goals, you are constantly reminded and bothered by the case. By current 30-day quality metrics, a patient mortality is a failure. Presenting at your department's morbidity and mortality conference, you are met by questions that echo your concerns.

Box 21.5 30-Day Postoperative Mortality: Disincentivizing Best Care

Patient mortality in the postoperative period is often viewed as a failure on the part of the surgeon, regardless of whether care was electively transitioned to comfort care. Furthermore, current measures of quality of care are not centered on patient values and punish surgeons who may already be experiencing their own punishment for unanticipated outcomes. For example, 30-day mortality rates commonly used by hospital ranking and reimbursement systems do not account for transitions to comfort care that respects patient autonomy [13]. For example, when 30-day mortality rate in a trauma ICU was adjusted to exclude comfort care cases not due to failure of therapy, the adjusted mortality rate decreased by 23%. This mortality rate inflation may have negative implications for provider behaviors and reimbursement [14]. Single metrics such as the 30-day mortality rate fail to capture long-term survival, quality of life, and patient-centered outcomes, but currently remain a leading metric for surgical quality reporting and place undue pressure on the surgeon.

Box 21.6 Be Mindful of Second Victim Syndrome

When an adverse event occurs, the provider may also experience emotional and psychological effects collectively called the "second victim syndrome." This is characterized by feelings of failure, followed by a sense of chaos, and finally recovery. Throughout this process, clinical care may be affected and the ability of providers to reflect on events [15, 16]. This process may contribute to burnout. Burnout among surgeons is a pressing and current issue, particularly for younger ones. Training programs have continued to develop and refine surgical education approaches, but wellness initiatives remain a critical gap [17]. It is important that surgeons are equipped with strategies to mitigate the effects of provider burnout, depression, and suicidal ideation.

You reach out to the palliative care team to discuss your difficulty and the questions you are getting from your colleagues regarding the case. The palliative care physician is trained as both a surgeon and a palliative care specialist, allowing her

unique insight and perspective. She listens intently and offers you space and presence to process the case emotionally. She acknowledges the pressure placed on you from both internal expectations and external metrics. She also reminds you that your responsibility is to the patient and reassures you that aiding the patient in pursuing hospice is in line with the patient's values and wishes. You leave with a sense of comfort and growth, as well as an enriched sense of what it means for you to be a surgeon.

Traditional surgical metrics would deem this case as a failure – the surgical team was placed accountable for imposing the pain and stress of an operation, then supporting the patient in his decision to cease dialysis. However, it was exactly this approach that allowed the patient to achieve his goals, including time with family and maintaining autonomy, and to die peacefully. With this case, we propose an enhanced model for palliative care in which focus is both on the patient and the invested surgical team. The palliative care physician's role went beyond support of the patient and family, to support of the surgical team. This helped to build stronger networking relationship that will benefit not only this patient but also other patients who might benefit from earlier palliative care involvement in the future.

Take-Away Points

1. The surgeon's role in primary palliative care should consist of basic symptom management and discussions of prognosis, goals of treatment, suffering, and code status.
2. Goal-directed care should be used to align treatment decisions with functional outcomes important to the patient's anticipated quality of life. Several frameworks exist to help guide the discussion to elucidate a patient's health priorities.
3. Specialist palliative care consultation is indicated in the setting of complex symptom management, futile care, and assistance in navigating interpersonal conflict.
4. Quality metrics and the traditional surgeon mentality may be in conflict with goal-directed care. Seeking help for the surgeon to navigate through resistance, frustration, acceptance, and finally healing in difficult cases may lessen the emotional toll of unexpected outcomes.

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