

Palliative Surgery

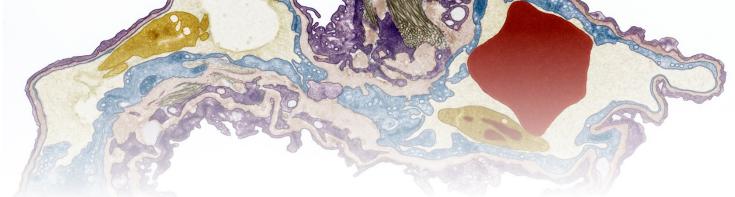
October 2021, Volume 23, Number 10: E757-831

From the Editor	
Cutting Without Hope of Cure	759
C. Alessandra Colaianni, MD, MPhil and Alexander Langerman, MD, SM	
Case and Commentary	
Who Should Decide When Palliative Surgery Is Justifiable?	761
Joshua T. Cohen, MD and Thomas J. Miner, MD	
Holding Curative and Palliative Intentions	766
Antoinette Esce, MD and Susan McCammon, MD, MFA	700
Antomette Esce, MD and Susan McCammon, MD, MI A	
How to Support Patients Near the End of Life Whose Pain Is Best Treated With	
Surgery?	772
Elle L. Kalbfell, MD and Margaret L. Schwarze, MD, MPP	
How Should Surgical Palliative Success Be Defined?	778
Pringl Miller, MD, Preeti R. John, MD, MPH, and Sabha Ganai, MD, PhD, MPH	
M/hon Chould Neurophdeurophiler Core for Datients M/th Agute Studie De Dallistice?	702
When Should Neuroendovascular Care for Patients With Acute Stroke Be Palliative? Michael J. Young, MD, MPhil, Robert W. Regenhardt, MD, PhD,	783
Leonard L. Sokol, MD, and Thabele M. Leslie-Mazwi, MD	
Leonard E. Sokol, MD, and Habele M. Lesile Mazwi, MD	
How Should Surgeons Communicate With Cancer Patients About Palliative and	
Curative Intentions, Purposes, and Outcomes?	794
Charles E. Binkley, MD	
Medical Education	
Teaching Palliative Care in Surgical Education	800
Jessica H. Ballou, MD, MPH and Karen J. Brasel, MD, MPH	

In the Literature Which Priorities Should Guide Palliative Surgical Research? Zara Cooper, MD, MSc and Christy Cauley, MD	806
AMA Code Says AMA Code of Medical Ethics' Opinions Related to Palliative Surgical Care Shreya Budhiraja	811
Medicine and Society Where's the Value in Preoperative Covenants Between Surgeons and Patients? Robert Ledbetter and Buddy Marterre, MD, MDiv	814
"Aren't Surgery and Palliative Care Kind of Opposites?" Myrick C. Shinall Jr, MD, PhD	823
Viewpoint Whoever Does Image-Guided Palliative Care Needs to Be Properly Trained to Do So Jay A. Requarth, MD	826

Podcast

Why "Palliative Surgery" Is Not Like "Jumbo Shrimp": An Interview With Dr C. Alessandra Colaianni and Dr Wynne Morrison



AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E759-760

FROM THE EDITOR Cutting Without Hope of Cure

C. Alessandra Colaianni, MD, MPhil and Alexander Langerman, MD, SM

In the past decade, defining a "good death" has become imperative in American health care. Once taboo, aggressive end-of-life care is now regarded as expensive, ineffective, and frequently neither concordant with patients' goals nor in their best interests.¹ Concurrent with this public discourse, palliative care—intervening to relieve suffering and support quality of life for seriously ill patients—is now an independent, growing specialty.²

Palliative intervention is defined by intention. Unlike other specialties, palliative care aims not to cure disease or to prolong life but to improve the quality of a patient's remaining life. Palliative care in oncology and cardiology is well established, but appropriate palliative care can also be invasive and surgical. This issue of the *AMA Journal of Ethics* explores *palliative surgery* as any procedure for which symptom mitigation is the main goal, without causing premature death, in the care of patients with noncurable disease.³ Palliative surgery can include straightforward procedures (eg, placing a feeding tube to enable nutrition) and more complex interventions (eg, partial tumor removal to ease breathing). The stakes are high: in patients with limited life expectancy, complications can be devastating, and noncurative palliative procedures still pose great risk. Palliative surgery is complex and understudied and raises key clinical and ethical questions.

Studies in oncology have shown that most patients receiving palliative chemotherapy believe they are receiving curative treatment, even when educated to the contrary.⁴ So, we ask in this issue: Should a higher standard of informed consent be required for palliative surgery? When a patient consents to a palliative procedure, should consent be regarded as extending to care needed to remediate complications?⁵ According to which criteria should we assess whether and when it is just to spend limited resources on surgery that does not prolong life?⁶ Surgeons and patients routinely balance risks and benefits together, but when cure is not the goal, decisions and decision making change. These questions and ideas are the heart of this theme issue, which brings surgical palliation further into the light in hopes of guiding present and future difficult decisions about what end-of-life palliation means.

References

1. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press; 2015.

- Palliative care continues its annual growth trend, according to latest center to advance palliative care analysis. News release. Center to Advance Palliative Care™; February 28, 2018. Accessed November 30, 2020. https://www.capc.org/about/press-media/press-releases/2018-2-28/palliativecare-continues-its-annual-growth-trend-according-latest-center-advancepalliative-care-analysis/
- 3. Hofmann B, Håheim LL, Søreide JA. Ethics of palliative surgery in patients with cancer. *Br J Surg*. 2005;92(7):802-809.
- 4. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367(17):1616-1625.
- 5. Pecanac KE, Kehler JM, Brasel KJ, et al. It's big surgery: preoperative expressions of risk, responsibility, and commitment to treatment after high-risk operations. *Ann Surg.* 2014;259(3):458-463.
- 6. Childers CP, Maggard-Gibbons M. Understanding costs of care in the operating room. *JAMA Surg.* 2018;153(4):e176233.

C. Alessandra Colaianni, MD, MPhil is an otolaryngologist-head and neck surgeon focusing on the treatment of patients with benign and malignant tumors of the head and neck at Harvard Medical School in Boston, Massachusetts. While working toward her MD at Johns Hopkins Medical School, she concurrently completed an MPhil in history and philosophy of science as a Gates Cambridge Scholar at the University of Cambridge, where her thesis focused on historical and sociological elements of end-of-life care. Her academic interests include surgical ethics and narrative medicine.

Alexander Langerman, MD, SM is an associate professor of otolaryngology-head and neck surgery as well as radiology and radiological sciences at Vanderbilt University Medical Center (VUMC) in Nashville, Tennessee. He also directs the Surgical Ethics Program at the Center for Biomedical Ethics and Society at VUMC and the Surgical Analytics Lab in the Vanderbilt Institute for Surgery and Engineering. He is a founding member of the Consortium for Surgical Ethics and is an affiliated scientist at the International Centre for Surgical Safety in Toronto.

Citation AMA J Ethics. 2021;23(10):E759-760.

DOI

10.1001/amajethics.2021.759.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E761-765

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE Who Should Decide When Palliative Surgery Is Justifiable?

Joshua T. Cohen, MD and Thomas J. Miner, MD

Abstract

No one person has the right or ability to make decisions about to whom or according to which criteria palliative surgery should be offered. Instead, patient and surgeon together must consider symptom severity, goals of care, and the value palliative surgery could add to the patient's health experience or quality of life.

Case

Mr J had a slow-growing facial tumor, which had rendered him essentially housebound: the tumor was fungating, rotting from the inside out, and causing a terrible odor and unrelenting pain. He was becoming increasingly unable to go out in public. His doctors had told him that the tumor could not be removed in its entirety due to its involvement of his carotid artery and the proximity of the tumor to his brain; cure, therefore, was impossible. Nevertheless, at each clinic visit, Mr J pressed his surgeon, Dr G, to cut out as much of the tumor as he safely could. Mr J had already undergone maximal "noninvasive" therapy with radiation, but the tumor continued to grow. Eventually, he was told that the tumor would kill him—by eroding a major vessel and causing a life-ending bleed or by compressing his brainstem and causing him to stop breathing—but that the tumor's growth was slow and nobody could tell him how much time he had left.

Every few weeks, Mr J was hospitalized for pain or bleeding from the tumor, and each time he saw Dr G, he was more and more depressed. This time, he was at his wit's end, all but begging for surgery. "Please," he said, "All I want is to visit my mother before I die. She cannot travel. I can't get on a plane like this. Please, please take the tumor away. Please help me."

Dr G was troubled. Mr J was in a terrible state, and there was a real possibility that surgery would make his condition worse. To help his pain and the appearance of his wound, surgery would require debulking of the tumor and then covering the wound with a free flap—harvesting skin, an artery, and a vein from a healthy area of the body in order to cover the hole caused by the resection. In the best-case scenario, the case would take at least 8 hours in the operating room, and the patient would require at least a 7-day hospitalization thereafter for monitoring and rehabilitation—if there were no unforeseen complications. Worse, there was no guarantee that the surgical wound would heal—the free flap would essentially be lying on a bed of tumor. There was scant medical literature on the subject, and any predictions for success or failure were

basically guesswork. But if Mr J survived the operation and if the wound healed, there was a chance that he would be able to achieve his goal of flying to say goodbye to his mother. Surgery was a lot of investment for a lot of uncertainty.

After many frank conversations with Mr J, Dr G felt that his duty to help Mr J outweighed the risks of the surgery and that Mr J understood the risks of the procedure and wanted to proceed. Dr G decided to offer surgery. Dr G's colleague, Dr N, learned about the operation and could not hide his dismay: "You're going to do a free flap on that patient? Do you know how much that will cost the hospital? Will his insurance even pay for it? And what about the patients that have curable disease whose care you're postponing in order to care for him? What if he never gets out of the hospital? You are making a big mistake."

Commentary

Clinicians should offer interventions within the spectrum of safe and indicated options that neither harm patients nor violate their autonomy.^{1,2} Shared decision making, however, is limited by patients' understanding of their condition and the limitations of their treatment options. If a patient with decision-making capacity insists on a treatment that is neither safe nor indicated, a clinician must refuse to provide the requested treatment.^{2,3} Conversely, when a patient with decision-making capacity refuses treatment, a clinician must respect the patient's autonomy and cannot force a treatment on that patient.^{2,4}

These decisions are commonplace and fairly straightforward, as they represent extremes of the spectrum. Decision making becomes more challenging when options fall somewhere in between. Furthermore, defining what is safe is influenced by what degree of risk the patient and clinician are willing to accept.

Palliative surgery adds its own layer of complexity. The metrics that define successful outcomes often are more nuanced. Traditional measures, including overall survival and disease-free survival, become secondary to symptom control and quality of life.^{5,6} Moreover, patients receiving end-of-life palliative care require highly individualized treatment plans to address complex disease processes. The choice of appropriate palliative therapy has become increasingly complex as the armamentarium of systemic therapies, minimally invasive surgeries, endoscopic procedures, and percutaneous interventions for supportive care has expanded.⁷

Determining Possible Impact

Given these advances, determining which procedures fall within the spectrum of indicated palliative intervention and thus should be offered to the patient is becoming increasingly challenging. Similarly, the degree of risk that patients at the end of life are willing to incur for a procedure they consider safe is variable and depends on their goals and preferences. It can be useful to simplify these complex situations by considering what option will have the largest positive impact.⁷

As we have noted elsewhere, the impact of a palliative procedure can be determined from its value, defined as the ratio of patient benefit to "cost to patient experience."⁷ A high-value operation is one that offers a large potential benefit at minimal cost. The value of a palliative procedure is modulated by the anticipated length of duration of palliation. Patients who are expected to live longer can be expected to enjoy the benefits of an operation for a longer period, resulting in a higher value surgery. On the flip side, a

patient who dies the day after undergoing an operation that results in complete symptom resolution with minimal treatment toxicity and resource utilization extracts only minimal value from the surgery.

Analysis

The concept of value should inform decision making about palliative surgery,⁷ since it determines the spectrum of options presented to a patient and can help guide decision making. With this in mind, we now examine the case presented with respect to the patient's symptom severity and goals of care and the value to the patient of the proposed surgery.

Symptom severity. Mr J is pleading with Dr G to perform tumor debulking with free flap coverage. The patient is currently enduring pain, bleeding, and an unrelenting odor. He is essentially housebound because of his symptoms, which have resulted in repeated hospitalizations. Mr J is experiencing severe and pervasive symptoms, which, if palliated, could have a positive impact on his life.

Goals of care. The patient understands that his tumor will be fatal, and he wishes to be able to visit his mother. Presumably, Mr J also wishes to avoid additional hospitalizations. An operation that facilitates travel aligns with his goals, but a free flap, as discussed, would require extensive postoperative care and could require more operations to address complications. Furthermore, prior to surgery, it is imperative for Dr G to explain that, in a worst-case scenario, if a free flap fails, it's possible that Mr J's wound won't heal. This scenario would prevent Mr J from leaving his home, contrary to his stated goal of visiting his mother. Given that surgery could support or undermine Mr J's goals, a more comprehensive goals-of-care discussion is necessary to assess whether surgery would reasonably achieve his goals. Dr G should plainly state the surgical risks without false reassurance and clearly gauge Mr J's risk tolerance.

Value of surgery. The benefits of palliative surgery are symptom control and improved quality of life. In the best case scenario, an operation for Mr J would control his pain and bleeding. It would also debride necrotic tissue, mitigate odor, and make it easier for him to be in public. With these symptoms addressed, Mr J could probably travel, avoid hospitalizations, and improve his quality of life. His tumor is slow growing and, though his prognosis is unclear, Mr J has potential to live for months, so he would have time to enjoy benefits of his operation should he survive it and leave the hospital.

The costs of palliative surgery include treatment toxicity (eg, morbidity and mortality), duration of treatment (eg, length of stay, need for repeated interventions), and resource utilization. Which costs a patient is willing to incur is patient specific and often related to symptom severity.⁷ Dr G has no data to determine morbidity, mortality, length of stay, or need for repeated interventions. This lack of data alone should give pause. Because Dr G cannot determine costs, the value and impact of surgery cannot be assessed relative to costs. One could, however, assume high levels of toxicity and a long treatment duration, using available data as a starting point.

Even assuming a long treatment duration, Dr N's concerns persist about resource utilization and its toll on the health care system and on other patients. However, in a resource-rich country like the United States, where operating rooms are utilized at 60% to 70% of capacity,⁸ those concerns should probably not supersede patient autonomy. Rather, health care financing concerns should be addressed at a policy and population,

not a bedside, level. If Mr J could benefit from surgery that accords his goals of care and risk tolerance, Dr N should offer it.

Conclusion

No single person should decide whether and when palliative surgery is justifiable. It is the surgeon's responsibility to share this decision, assess symptom severity, invite conversation about goals, and then offer high-value interventions based on a patient's needs and prognosis. It is patients' responsibility to assess their symptoms' tolerability and severity, their goals, and which risks and costs to accept. Based on collaborative discussion, surgeon and patient can determine what might constitute high value and positive impact in a specific case.

References

- 1. Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implement Sci.* 2016;11:114.
- 2. Gillon R. Medical ethics: four principles plus attention to scope. *BMJ*. 1994;309(6948):184-188.
- 3. American Medical Association. Opinion 1.1.2 Prospective patients. Code of Medical Ethics. Accessed July 6, 2021. https://www.ama-assn.org/deliveringcare/ethics/prospective-patients
- 4. Shah P, Thorton I, Turrin D, Hipskin JE. Informed consent. In: StatPearls. StatPearls Publishing; 2021.
- 5. Lilley EJ, Cooper Z, Schwarze ML, Mosenthal AC. Palliative care in surgery: defining the research priorities. *J Palliat Med*. 2017;20(7):702-709.
- 6. Dunn GP. Surgery, palliative care, and the American College of Surgeons. *Ann Palliat Med.* 2015;4(1):5-9.
- 7. Cohen JT, Miner TJ. Patient selection in palliative surgery: defining value. *J Surg Oncol*. 2019;120(1):35-44.
- 8. Li F, Gupta D, Pottoff S. Improving operating room schedules. *Health Care Manag Sci.* 2016;19(3):261-278.

Joshua T. Cohen, MD is a surgical resident at the Warren Alpert Medical School of Brown University in Providence, Rhode Island. He has research interests in palliative surgery as well as the immune response to malignancy and trauma.

Thomas J. Miner, MD is a professor of surgery at the Warren Alpert Medical School of Brown University in Providence, Rhode Island, where he is also the associate residency program director for general surgery and chief of the Division of Surgical Oncology. He has research interests in palliative surgery, melanoma, gastric cancer, hyperthermic intraperitoneal chemotherapy, and sarcoma.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2021;23(10):E761-765.

DOI

10.1001/amajethics.2021.761.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E766-771

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE Holding Curative and Palliative Intentions

Antoinette Esce, MD and Susan McCammon, MD, MFA

Abstract

When a patient is diagnosed with an advanced head and neck cancer, a decision about whether to have surgery can dominate what remains of that patient's life: prospective benefits can be limited, and complication risks can be high. Realizing dual curative and palliative intention with a single operation can be a reasonable surgical oncological care goal. In such cases, differentiating between the curative and palliative potential of surgery is key to developing dual intentional clarity. Informed consent should be generated by clear communication exchanges about patients' and surgeons' hopes and expectations, patients' and surgeons' risk tolerance, and the risk that surgeons or patients could experience regret.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Case

Mr H, a 75-year-old former carpenter, was diagnosed with advanced cancer just above his esophagus. He had spent a long time in a rehab facility recovering from chemotherapy and radiation treatments. After 2 months, he could swallow soft foods again and recovered enough to move home. But 3 weeks later, he experienced pain, weight loss, and couldn't swallow his own saliva. A biopsy confirmed that the persistent cancer above his esophagus had now spread to a lymph node in his neck. It was unclear from imaging studies whether or to what extent the cancer was safely resectable from either site. Mr H was clear with his radiation oncologist, medical oncologist, and surgeon, Dr L, that he wanted everything done to try to remove the cancer.

Dr L explained, "We'd do a major surgery called a salvage laryngopharyngectomy,¹ in which we'd try to remove all of the cancer. We'd remove your voice box and pharynx, so you might never swallow again. We'd also try to remove cancer in the neck lymph node. Due to chemotherapy and radiation, your tissues are less likely to heal after surgery, so here is higher risk for complications with this surgery, but salvage surgery, after primary chemotherapy and radiation, is your best hope for a cure." Mr H consented to surgery.

Dr L presented Mr H's case at a multidisciplinary tumor board meeting that week. Dr L's colleague, Dr M, pointed out, "There's a good chance you'll find out intraoperatively that

the cancer encases the carotid artery or has spread to the spine fascia. Then you'll have to abort the case, and he will be worse. Either way, rates of successful salvage for hypopharyngeal recurrence go as low as 15%.² At the very least, I wouldn't call this surgery 'curative.'"

"He wants surgery," replied Dr L. "I agree that we could find unresectable disease, but we'll go in with intention to cure his cancer. So, surgery should be presented to him as curative."^{3,4}

Colleagues in the meeting considered how to respond.

Commentary

We clinicians often begin simultaneously to diagnose and treat a patient's illness before we know exactly what is wrong. We titrate medicines to maximize their benefit and minimize their side effects, simultaneously reducing disease burden and limiting harm. But should surgeons' intentions be both curative and palliative at the same time? We argue that realizing dual curative and palliative intention with a single operation can be a reasonable surgical oncological care goal. However, during informed consent, surgeons must seek to understand a patient's expectations and hopes or their intentions are moot.

Concurrent Care

Characterizing Mr H's decision as either curative *or* palliative expresses an outdated understanding of palliative care as only offered subsequent to attempts to cure (ie, when disease-modifying treatment no longer works, palliate until death). This sequential model has evolved into a concurrent model in which treatments with both curative and palliative intent can be delivered simultaneously.^{5,6} Patients like Mr H should thus be presented with a care plan that aims to cure their underlying disease, treat them as a whole patient, respond to their symptoms, and improve their quality of life.⁵ Evidence suggests that a concurrent approach improves quality of life, patient satisfaction, and survival,⁷ and palliative practices (eg, good communication, symptom management, and advance care planning) are beneficial throughout a patient's journey with life-limiting disease. The American Society of Clinical Oncology recommends early integration of palliative care with curative treatment for patients with cancer.⁸

Yet, especially for head and neck cancers, concurrent pursuit of curative and palliative interventions can seem antithetical. In cases, a surgeon is likely right to intend to eradicate a patient's cancer (ie, not to prioritize ease of reconstruction, aesthetic consequences, functional outcomes, symptom improvement). Nevertheless, surgeons performing operations primarily intended to be curative can achieve palliative goals (eg, relief from pain and suffering, mitigation of disfigurement, and improvement of some functions). Partial glossectomy, for example, can be both curative and palliative when pursued by a surgeon intending to delay growth of a painful, disfiguring, debilitating, fungating oral cavity mass. Historically, most surgical interventions have been palliative to some extent, as they did little or nothing to change a disease's underlying pathophysiology and instead sought to remove, bypass, or otherwise change the mechanics of end-organ damage suffered by a patient.⁹ The clinical and ethical upshot here is that the terms curative and palliative should be neither construed by surgeons nor presented to patients as opposites. Surgical interventions with concurrent curative and palliative goals can be described as falling along a spectrum. That is, some surgical interventions are most accurately presented as exclusively curative or exclusively

palliative, but many fall somewhere in between, where both health and experiential outcomes must be considered.

Concurrence and Communication

"One-choice" situations. When confronted with a new serious diagnosis or when asked to consider choices regarding their cancer care, patients tend to focus on whether to do something rather than on specifically what to do.¹⁰ Cases in which only one treatment choice is medically reasonable can lead to disagreement between patient and physician, especially when a patient wants a procedure that offers no clinical benefit or rejects palliative goals as unworthwhile.¹¹ In such cases, in order to help refocus discussion on possible outcomes of treatment and treatment refusal, a surgeon might consider adumbrating a possible time down the line in a patient's illness trajectory when surgical intervention would be too high risk to be offered. In our experience, the following openended questions have also been helpful in discussions with patients and surrogates:

- 1. If, at the end of this year, you die of this disease, how would you have wanted to spend this time?
- 2. If we perform an operation that fails to cure you or fails to make you feel more comfortable, you might look back and be glad we tried it. Or you might look back and regret being in the hospital, away from your home. What do you think about those possibilities?
- 3. If we do not operate and focus on managing the symptoms that are most distressing to you, you might look back and be glad. Or will you look back at the end of the year and regret not having tried one last treatment? What do you think about those possibilities?

Sharing decisions well with patients and their surrogates can also mean canvassing preferences (eg, in terms of "least bad" options or "least acceptable" outcomes)¹² and imagining possible outcomes (eg, as best- or worst-case scenarios).¹³

Health outcomes variation. Curative effects of surgeries vary widely. The oncologic literature contains uncertainty and can be difficult to apply to individual patients' cases.¹⁴ Five-year survival rates after salvage surgery for hypopharyngeal cancer, for example, range from 16% to 40%.^{2,15,16,17} Yet, even when curative surgical interventions fail to completely eliminate (cure) disease in patients, their lives can be extended. Medical palliative interventions (eg, immunotherapy or chemotherapy) can provide durable progression-free or indolent progression survival for some patients.

Experiential outcomes variation. Interventions' risks and benefits must be discerned, interpreted, and conveyed by surgeons, and decisions must be carefully considered with patients or appropriate surrogates. Especially with head and neck procedures, wounds and iatrogenic aesthetic insults are often visible; clear communication is key to helping patients and their loved ones prepare visually for what they're likely to see postoperatively. Furthermore, when data are lacking about whether surgery can palliate current symptoms (eg, motivate wound healing, mitigate pain, limit obstruction) or prevent future suffering (eg, diminish risk of death by hemorrhage), clinicians should avoid promises to keep patients comfortable, especially when patients' symptoms are difficult or impossible to palliate without proportional sedation to the point of unconsciousness.

Intending to Mitigate Regret

Regional recurrence of Mr H's cancer in a previously treated surgical field worsens his prognosis, but surgical intervention could palliate his symptoms (ie, improve his swallowing, delay or prevent onset of additional symptoms, or mitigate pain).¹⁸ Communicating clearly with patients like Mr H who might experience both health and experiential outcomes of surgeries is key to managing patients' expectations, learning about their priorities, and mitigating later regret about current decisions. Most head and neck cancer patients initiating treatment with curative intent have prioritized survival; secondary goals include preserving vocal and swallow function and controlling pain, with patients' rankings being largely unrelated to clinical or demographic factors.¹⁹ Patients' priorities, however, do influence their experiences of regret.²⁰ Whether surgery is actually palliative for patients like Mr H depends on their priorities and how they define suffering.²¹

Such goals-of-care conversations are hard to complete satisfactorily during 30-minute outpatient surgery consultations, so early integration of palliative principles in oncologic care will help facilitate fuller discussion and promote better understanding. Since surgical interventions often serve multiple goals, it is reasonable and helpful in our relationships with patients to have both curative and palliative intentions.

References

- 1. Iseli TA, Agar NJ, Dunemann C, Lyons BM. Functional outcomes following total laryngopharyngectomy. *ANZ J Surg.* 2007;77(11):954-957.
- 2. Taki S, Homma A, Oridate N, et al. Salvage surgery for local recurrence after chemoradiotherapy or radiotherapy in hypopharyngeal cancer patients. *Eur Arch Otorhinolaryngol.* 2010;267(11):1765-1769.
- 3. Schubart JR, Green MJ, Van Scoy LJ, et al. Advanced cancer and end-of-life preferences: curative intent surgery versus noncurative intent treatment. *J Palliat Med.* 2015;18(12):1015-1018.
- 4. Gaertner J, Knies A, Nauck F, Voltz R, Becker G, Alt-Epping B. "Curative" treatments and palliative care: the lack of consensus. *Curr Opin Oncol.* 2014;26(4):380-384.
- 5. Hawley PH. The bow tie model of 21st century palliative care. *J Pain Symptom Manage*. 2014;47(1):e2-e5.
- Sadler EM, Hawley PH, Easson AM. Palliative care and active disease management are synergistic in modern surgical oncology. Surgery. 2018;163(4):950-953.
- Bauman JR, Temel JS. The integration of early palliative care with oncology care: the time has come for a new tradition. *J Natl Compr Canc Netw.* 2014;12(12):1763-1771.
- 8. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*. 2017;35(1):96-112.
- 9. Dunn GP. Restoring palliative care as a surgical tradition. *Bull Am Coll Surg.* 2004;89(4):23-29.

- 10. Davies L, Rhodes LA, Grossman DC, Rosenberg MC, Stevens DP. Decision making in head and neck cancer care. *Laryngoscope*. 2010;120(12):2434-2445.
- Whitney SN, Holmes-Rovner M, Brody H, et al. Beyond shared decision making: an expanded typology of medical decisions. *Med Decis Making*. 2008;28(5):699-705.
- 12. Schwarze ML, Campbell TC, Cunningham TV, White DB, Arnold RM. You can't get what you want: innovation for end-of-life communication in the intensive care unit. *Am J Respir Crit Care Med*. 2016;193(1):14-16.
- 13. Schwarze ML, Kehler JM, Campbell TC. Navigating high risk procedures with more than just a street map. *J Palliat Med*. 2013;16(10):1169-1171.
- 14. Lamont EB, Christakis NA. Complexities in prognostication in advanced cancer: "to help them live their lives the way they want to." *JAMA*. 2003;290(1):98-104.
- 15. Chu PH, Tsang NM, Lee LA, Liao CT, Fang TJ. To do or not to do: salvage management for hypopharyngeal cancer after chemoradiation therapy. *Eur Arch Otorhinolaryngol.* 2018;275(8):2119-2126.
- Godballe C, Jørgensen K, Hansen O, Bastholt L. Hypopharyngeal cancer: results of treatment based on radiation therapy and salvage surgery. *Laryngoscope*. 2002;112(5):834-838.
- 17. Ho AS, Kraus DH, Ganly I, Lee NY, Shah JP, Morris LG. Decision making in the management of recurrent head and neck cancer. *Head Neck*. 2014;36(1):144-151.
- Hamoir M, Schmitz S, Suarez C, et al. The current role of salvage surgery in recurrent head and neck squamous cell carcinoma. *Cancers (Basel)*. 2018;10(8):267.
- 19. List MA, Stracks J, Colangelo L, et al. How do head and neck cancer patients prioritize treatment outcomes before initiating treatment? *J Clin Oncol*. 2000;18(4):877-884.
- 20. Shuman AG, Larkin K, Thomas D, et al. Patient reflections on decision making for laryngeal cancer treatment. *Otolaryngol Head Neck Surg.* 2017;156(2):299-304.
- 21. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306(11):639-645.

Antoinette Esce, MD is a second-year otolaryngology head and neck surgery resident at the University of New Mexico in Albuquerque. She earned a BA in economics and public health and an MD from the University of Rochester. She is interested in examining surgical culture, improving health care policy, and discussing the role of ethics in surgical education.

Susan McCammon, MD, MFA is a head and neck surgeon at the University of Alabama at Birmingham, where she holds dual appointments in the departments of otolaryngology and internal medicine and is an assistant director of the Center for Palliative and Supportive Care.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2021;23(10):E766-771.

DOI

10.1001/amajethics.2021.766.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E772-777

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How to Support Patients Near the End of Life Whose Pain Is Best Treated With Surgery?

Elle L. Kalbfell, MD and Margaret L. Schwarze, MD, MPP

Abstract

For seriously ill patients whose pain is best treated with surgery, it is important to discuss and explore treatment goals preoperatively. Knowing which health states a patient would tolerate helps the surgeon identify interventions that are overly burdensome, overreach survival goals, or undermine the patient's quality of life. Surgical success should be defined by how well an intervention aligns with patients' goals. Early integration of specialty palliative care can help identify surgical patients with unmet needs, optimize symptom management, clarify preferences, and improve end-of-life care.

Case

Mr F is 80 years old and has peripheral vascular disease with arterial insufficiency in his left leg. He has excruciating pain in his foot that wakes him up at night and is relieved by hanging his foot over the side of the bed. He also has a small ulcer on his left big toe. Some nights, he sleeps in his recliner with his foot down to mitigate the pain (gravity increases blood flow). He also has emphysema and diabetes and has suffered a major heart attack and several small strokes. He and his primary care physician, Dr K, agree that because of his multiple medical problems, he is "wearing out." Mr F thinks of himself as a "tough cookie," but he understands his remaining life is limited and agrees to an out of hospital do-not-resuscitate (DNR) order.

However, the pain in Mr F's foot is making his life unbearable. Dr K refers him to a vascular surgeon, Dr T, to discuss treatment to improve blood flow and relieve his pain. After noting that endovascular intervention is not an option for Mr F because of his severe common femoral disease, Dr T notes, "We can offer you major surgery to address your symptoms, but it won't prolong your life. And if you have complications, it could shorten your life." "I'll take the risk of surgery," Mr F responds. "Life with this much pain isn't worth it. Maybe I'll die during the surgery, and that's OK."

Mr F undergoes a left common femoral endarterectomy and lower extremity bypass graft. The long operation and significant blood loss generate major complications, including postoperative myocardial infarction and aspiration pneumonia requiring intubation. When Mr F is weaned from the ventilator after an extensive intensive care

unit (ICU) stay, he has lost weight, is severely deconditioned, and has a decubitus pressure ulcer. Throughout Mr F's decline, Dr T says, "I'll get you through this." Dr T feels guilty and sad about Mr F's decline and difficult postoperative course. Dr T visits Mr F again after another bout of aspiration pneumonia requiring Mr F's urgent transfer to the ICU for respiratory distress. "I'm so sorry to see you so sick, Mr F," says Dr T. "If I'd known it would be like this," says Mr F, "I never would have let you operate on me. You shouldn't have offered me surgery if there was even a chance for things to turn out this way. You're the expert, but I didn't know any better." Subsequently, Mr F declines intubation, transitions to comfort measures, and dies several hours later.

At the surgical morbidity and mortality (M and M) conference, Dr T presents Mr F's case. "I feel terrible about how things turned out," says Dr T, speaking in front of a room of surgeons. "From an operative standpoint, I'm not sure what I could have done better. Surgery was risky, but he was adamant he wanted to try. Complications of surgery unquestionably shortened and worsened his remaining lifetime. But how could I not have offered him surgery when I thought it could help him? What would you have done?" M and M conference attendees consider how to respond.

Commentary

When considering any surgical intervention, it is important to understand the patient's treatment goals. How can surgery help the patient? Will it prolong life, alleviate pain, or prevent disability? Mr F's sole reason for pursuing surgery was pain relief; for patients like him, for whom surgery has exclusively palliative goals, treatment decisions require clear delineation of the trade-offs between surgery and what the patient is willing to endure to feel better. For patients like Mr F, there are 3 *surgical* options: (1) femoral endarterectomy, which will control rest pain but is unlikely to remedy tissue loss; (2) femoral endarterectomy and bypass, which will decrease both pain and tissue loss; and (3) a below-knee amputation. To treat the entirety of Mr F's problems, a common femoral endarterectomy and bypass would have been ideal, as it attends to pain and tissue loss. However, the perceived best or ideal procedure may not have been the right procedure for the patient.

Although the endarterectomy and bypass mitigated Mr F's pain, postoperative complications and prolonged hospitalization severely compromised his quality of life and remaining lifespan. The burdens of the perceived best operation overshadowed his goal of pain control when a less extensive operation might have attended to his pain but allowed him to return home or at least avoid a long postoperative hospitalization. Interventions like the best case/worst case communication tool can be used to generate dialogue about the patient's goals and preferences for treatment limitations and to introduce alternative strategies.¹ By using scenario planning to tell a plausible story about the experience of surgery and recovery, this framework allows patients to anticipate and prepare for unwanted events and to articulate their fears about interventions and outcomes that are unacceptable to them.²

Identifying Preferences

In the presence of severe pain, patients are often willing to undertake major risks to feel better.³ Surgery can improve symptoms and prolong life, but it can also lead to significant cognitive and functional changes.^{4,5} Discussing poor outcomes and postoperative rescue treatments (eg, a risk of death or prolonged intubation) might prompt patients to talk about the treatments or health states they are willing or not willing to accept. When a patient has an existing DNR, reconsideration of the use of

cardiopulmonary resuscitation (CPR) during surgery, not automatic suspension, is required.^{6,7} Consistent with this long-standing policy of the American College of Surgeons and the American Society of Anesthesiologists, this case should have presented the opportunity for Dr T to discuss more than just CPR with Mr F.

For patients with life-limiting illness, surgeons need to know what to do if an adverse event occurs. Although many surgeons believe that they routinely discuss advance directives and postoperative life-sustaining treatments during informed consent,⁸ in reality, they rarely do.^{9,10} Mistakenly, surgeons infer that a patient who commits to an operation has also committed to the necessary postoperative life-supporting treatments.^{11,12,13} Dr T knew Mr F's operation was high risk and might shorten his remaining life, yet he failed to discuss Mr F's preferences should postoperative life-supporting treatments be needed. How would Mr F feel about being in the ICU on a ventilator? Would he accept a feeding tube if he were unable to eat or drink? Knowing what the patient would want if he could no longer speak for himself can help surgeons direct care when the goal of surgery is no longer achievable or the burdens of treatment are no longer acceptable to the patient. Disscusion about treatment limitations should include patients' reasoning and thoughts about the use of postoperative life-sustaining treatments, as such treatments are often temporary and the range of outcomes is not easily categorized as "alive" or "dead," as Mr F had assumed.

Defining Success

Surgeons are focused on avoiding postoperative mortality, which may directly conflict with the provisions of palliative surgery. Appropriately, they feel strong responsibility for the lives of their patients and are required to report 30-day mortality publicly for certain procedures.¹⁴ This requirement can lead surgeons to refuse surgery for high-risk patients (even for palliative needs) and be reluctant to withdraw postoperative lifesustaining treatments.¹⁴ Because of the surgeon's personal investment in patient care and recovery, survival is regularly viewed as a marker of surgical success, whereas postoperative death is viewed as a failure. However, the surgeon's actions should be guided by the patient's autonomous wishes, even when these conflict with surgeons' emotional need to ensure survival¹³ or personal concerns about how they will be viewed by others.¹⁵ As such, conversations at M and M conferences should shift from consideration of physician-defined adverse events (ie, complications and death) to consideration of outcomes and morbidity from the patient's perspective. Dr T's colleagues should note that the morbidities in this case stemmed from providing treatment inconsistent with Mr F's preferences during a 10-day ICU course. They might also point out that the limb-salvaging procedure performed overreached Mr F's goals of pain reduction and led to unwanted outcomes. Using outcomes measures that align with patient goals rather than traditional metrics of success would improve palliative surgical opportunities for patients and recenter surgical care around the outcomes that matter to patients.

Integrating Palliative Care

Specialists in palliative care are skilled in supporting patients with serious illness and navigating complex medical decisions and treatments, such as surgery. Despite the documented benefits and increased awareness of concurrent palliative care for surgical patients, integration of palliative care into surgical practice remains limited.^{16,17} Barriers include misconceptions about the role of palliative care (eg, it hastens dying or is only focused on comfort) and lack of access to specialty palliative care. The culture of surgery prompts some surgeons to focus exclusively on rescue; these surgeons might

view palliative care as conflicting with the goals of surgery and might consider consultation to be giving up on or abandoning a patient. Overcoming these barriers and identifying surgical patients who would benefit from early integration of palliative care is important. Guidelines recommend screening surgical patients for frailty and serious chronic illnesses^{18,19} and seriously ill patients with burdensome symptoms and complex or unmet needs.²⁰ Palliative care concurrent with surgical care can increase patients' understanding of their disease, improve symptom management, alleviate emotional and spiritual suffering, and promote goal-concordant care.

Conclusion

Supporting patients near the end of life whose pain is best treated with surgery is important for improving quality of life, even when the patient's remaining lifetime is short. However, surgical benefits should be balanced against the burdens of surgical treatment. Preoperative discussion and documentation of patients' preferences for postoperative life-sustaining treatments in relation to their goals helps avoid unwanted interventions in the setting of bad complications or outcomes. Knowing patient preferences for life-sustaining treatments also helps mitigate the emotional cost and professional demands of poor surgical outcomes that might push surgeons to continue aggressive care that extends beyond patient wishes. Surgical success should be synonymous not with patient survival but with outcomes that respect patient autonomy and align with patients' health goals. Moreover, early integration of palliative care can help align patient goals with treatments when choosing among a range of invasive therapies and can improve complex decision making.

References

- Taylor LJ, Nabozny MJ, Steffens NM, et al. A framework to improve surgeon communication in high-stakes surgical decisions: best case/worst case. JAMA Surg. 2017;152(6):531-538.
- 2. Schwarze ML, Taylor LJ. Managing uncertainty—harnessing the power of scenario planning. *N Engl J Med*. 2017;377(3):206-208.
- Case SM, O'Leary J, Kim N, Tinetti ME, Fried TR. Older adults' recognition of trade-offs in healthcare decision-making. *J Am Geriatr Soc.* 2015;63(8):1658-1662.
- Gleason LJ, Schmitt EM, Kosar CM, et al. Effect of delirium and other major complications on outcomes after elective surgery in older adults. *JAMA Surg.* 2015;150(12):1134-1140.
- 5. Gajdos C, Kile D, Hawn MT, Finlayson E, Henderson WG, Robinson TN. Advancing age and 30-day adverse outcomes after nonemergent general surgeries. *J Am Geriatr Soc.* 2013;61(9):1608-1614.
- 6. American College of Surgeons. Statement on advance directives by patients: "do not resuscitate" in the operating room. *Bull Am Coll Surg*. 2014;99(1):42-43.
- American Society of Anesthesiologists. Ethical guidelines for the anesthesia care of patients with do-not-resuscitate orders or other directives that limit treatment. Updated October 16, 2013. Reaffirmed October 17, 2018. Accessed July 6, 2021.

https://www.asahq.org/~/media/sites/asahq/files/public/resources/standards -guidelines/ethical-guidelines-for-the-anesthesia-care-of-patients.pdf

- Redmann AJ, Brasel KJ, Alexander CG, Schwarze ML. Use of advance directives for high-risk operations: a national survey of surgeons. *Ann Surg.* 2012;255(3):418-423.
- Tang VL, Dillon EC, Yang Y, et al. Advance care planning in older adults with multiple chronic conditions undergoing high-risk surgery. *JAMA Surg.* 2019;154(3):261-264.
- 10. Kalbfell E, Kata A, Buffington AS, et al. Frequency of preoperative advance care planning for older adults undergoing high-risk surgery: a secondary analysis of a randomized clinical trial. *JAMA Surg.* 2021;156(7):e211521.
- 11. Schwarze ML, Bradley CT, Brasel KJ. Surgical "buy-in": the contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy. *Crit Care Med.* 2010;38(3):843-848.
- 12. Nabozny MJ, Kruser JM, Steffens NM, et al. Patient reported limitations to surgical buy-in: a qualitative study of patients facing high-risk surgery. *Ann Surg.* 2017;265(1):97-102.
- 13. Pecanac KE, Kehler JM, Brasel KJ, et al. It's big surgery: preoperative expressions of risk, responsibility, and commitment to treatment after high-risk operations. *Ann Surg.* 2014;259(3):458-463.
- Schwarze ML, Brasel KJ, Mosenthal AC. Beyond 30-day mortality: aligning surgical quality with outcomes that patients value. *JAMA Surg.* 2014;149(7):631-632.
- 15. Schwarze ML, Redmann AJ, Brasel KJ, Alexander GC. The role of surgeon error in withdrawal of postoperative life support. *Ann Surg*. 2012;256(1):10-15.
- 16. Yefimova M, Aslakson RA, Yang L, et al. Palliative care and end-of-life outcomes following high-risk surgery. *JAMA Surg.* 2020;155(2):138-146.
- 17. Olmsted CL, Johnson AM, Kaboli P, Cullen J, Vaughan-Sarrazin MS. Use of palliative care and hospice among surgical and medical specialties in the Veterans Health Administration. *JAMA Surg.* 2014;149(11):1169-1175.
- Ernst KF, Hall DE, Schmid KK, et al. Surgical palliative care consultations over time in relationship to systemwide frailty screening. *JAMA Surg.* 2014;149(11):1121-1126.
- 19. Sihra L, Harris M, O'Reardon C. Using the Improving Palliative Care in the Intensive Care Unit (IPAL-ICU) project to promote palliative care consultation. *J Pain Symptom Manage*. 2011;42(5):672-675.
- 20. Lilley EJ, Cooper Z, Schwarze ML, Mosenthal AC. Palliative care in surgery: defining the research priorities. *Ann Surg.* 2018;267(1):66-72.

Elle L. Kalbfell, MD is a resident physician in general surgery at the University of Wisconsin-Madison. She is also a graduate of the MacLean Clinical Ethics Fellowship. Her interests include surgical ethics and palliative care.

Margaret L. Schwarze, MD, MPP is the Morgridge Endowed Professor in Vascular Surgery at the University of Wisconsin-Madison. She is a health service researcher and medical ethicist with expertise in surgical decision making, informed consent, advance directives, and end-of-life care. Her research focuses on improving communication between older patients and clinicians so that patients can avoid unwanted treatments and make decisions that align with their values, preferences, and goals.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation AMA J Ethics. 2021;23(10):E772-777.

DOI

10.1001/amajethics.2021.772.

Acknowledgements

This work was supported by grant KL2TR000428 from the National Center for Advancing Translational Sciences of the National Institutes of Health and by a Faculty Scholars Program grant from the Greenwall Foundation (Dr Schwarze).

Conflict of Interest Disclosure

Dr Schwarze reported that her spouse has ownership interest outside the submitted work. Dr Kalbfell had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E778-782

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE How Should Surgical Palliative Success Be Defined?

Pringl Miller, MD, Preeti R. John, MD, MPH, and Sabha Ganai, MD, PhD, MPH

Abstract

Palliative surgery is often defined as surgical intervention with intent to improve a patient's quality of life by relieving suffering secondary to symptoms of advanced disease. In the context of shared decision making about palliative surgery intervention, tensions can arise between patient (or surrogate) and surgeon, who might not share goals and values. This article suggests that a surgeon's clinical and ethical duty is to identify goals of care, including those related to quality of life, from a patient's perspective and to consider how to achieve them.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Case

"All I want from life is the opportunity to have sex with my wife, and without this," said Mr J, tearful and despondent, pointing to an ostomy appliance attached to his abdominal wall. Following initial diagnosis of rectal cancer several years ago, Mr J underwent chemoradiation followed by proctectomy and ileorectal anastomosis, with a "protective" diverting ileostomy to reduce risk of anastomotic leak. Mr J felt initially led to believe that the ileostomy was temporary. Despite assistance from enterostomal therapists, Mr J was extremely distressed about ostomy leakage during sex and felt dismissed when someone told him he needed to learn to live with it.

After developing bilateral pulmonary metastases, Mr J chose to undergo palliative systemic chemotherapy. During that time, his disease remained stable, and he felt frustrated by not being able to convince his 2 prior surgeons to reverse his ileostomy. The first surgeon, Dr S, performed the protectomy and ileostomy and told Mr J that temporary suspension of chemotherapy to treat metastatic disease for the sake of reversing his ileostomy was not a good idea. After much discussion with Mr J, Dr S sympathized and sought to help Mr J adapt to life with the ileostomy but could not agree to reverse it. The second surgeon, Dr T, agreed with Dr S that there was no clinical indication to reverse his ileostomy, given that he was adequately hydrated and had no electrolyte imbalances, and agreed with Dr S that reversal would not be a good decision.

Mr J sought the opinion of a third surgeon, Dr Q, to whom he was referred by his primary care clinician. Dr Q and Mr J had a lengthy conversation. Dr Q saw no reason to question Mr J's capacity to make health decisions for himself; felt Mr J had a solid understanding of an ileostomy takedown procedure's prospective benefits and risks for complications and how possible complications could compromise his survival; and felt that ileostomy reversal expressed Mr J's values and quality-of-life (QOL) priorities. Dr Q is aware of Dr T's and Dr S's refusals to reverse Mr J's ileostomy and considers how to respond.

Commentary

Surgeons' roles in patient-surgeon relationships have evolved from exercising paternalistic authority to partnering in decision making,¹ trending over time toward expressing respect for patients' autonomy and practicing patient-centered care. The Institute of Medicine defines decision making in patient-centered care as "responsive to individual patient preferences, needs, and values."² Surgeons aiming to practice patient-centered care, however, can still struggle sometimes to see therapeutic goals through the eyes of a patient, especially when a patient's goals or priorities are not seen by surgeons as promoting optimal care or outcomes, and this can generate tension that needs ethical and clinical attention.

Patient-Centered Surgery

An ideal for patient-centered surgery, articulated in the fourth principle of the 2005 American College of Surgeons Statement on Principles of Palliative Care, states that "primary goals of care from the patient's perspective" should guide a surgeon's care of that patient.³ While palliative surgery has various definitions, it is often defined as surgical intervention with intent to improve a patient's QOL by relieving suffering secondary to symptoms of advanced disease.⁴ Most importantly, effectiveness of palliative surgery is judged in terms of whether, to what extent, and how durably it improves QOL and resolves symptoms⁴ from the point of view of the patient, not according to traditional metrics (ie, absence of complications, reduced morbidity, or prolonged survival) of surgical success. In Mr J's case, Drs S and T seem to take a surgeon-centered approach to assessing risks and benefits of reversing Mr J's ileostomy, which focuses more on outcomes (eg, prolonging survival, maintaining homeostasis) and less on Mr J's views of his QOL, specifically the value of sexual intimacy with his wife in what remains of his life. The surgeons' initial decision not to reverse Mr J's ileostomy during his illness' progression to metastatic disease was clinically justifiable. But when Mr J's disease stabilized after chemotherapy, we argue that it's reasonable, particularly after several years, to reconsider Mr J's request and persistent desire for ileostomy reversal. Mr J accepts known risks of this procedure and certainly seeks a surgeon who will adopt a patient-centered and palliative approach to his goals; he turns to Dr Q.

Also important to note from an ethics standpoint is that Mr J feels dismissed and that he must acquiesce to Dr S's and Dr T's denials of his requests for ileostomy reversal. This is an important feature of this case, as many surgeons tend to privilege physical problems' influences on patients' lives. Mr J's deeply held desire for ileostomy reversal reflects key psychosocial and spiritual dimensions of his QOL and deserves close attention in his surgical care (see Figure).⁵

Figure. Quality of Life Dimensions Key to Patient-Centered Care of Mr Ja

Physical Well-Being	Psychological Well-Being
Functioning, independence	Managing anxiety, depression, fear, anger
Managing pain, relieving symptoms	Coping with loss of control
Social Well-Being Interpersonal connection, intimacy, sexuality	Spiritual Well-Being Sense of meaning, purpose, hope

^a Adapted from Ferrell, Dow, Leigh, Ly, Gulasekaram.⁶

Palliative Surgical Goal Setting

Surgical palliative care requires a patient-focused approach and preserving palliation as a goal. Standard global QOL assessments include social, emotional, and family wellbeing, so Dr Q might engage in conversation with Mr J about how palliation should be prioritized by probing how Mr J would define success of ileostomy reversal. Particularly during an informed consent process that precedes ileostomy reversal, key questions to ask Mr J are these: How do you see ileostomy reversal as helping you improve sex and intimacy with your wife and contributing to enriching your relationship and your emotional well-being? Would you consider ileostomy reversal a success if sex is improved only temporarily, perhaps if your malignancy progresses due to chemotherapy cessation?

Deciding whether to perform surgery a patient requests and deciding whether to give informed consent or informed refusal to a procedure a surgical team recommends are both complex and require discussion about expectations. A "palliative triangle" has been proposed by Miner et al as a model to help clinicians, patients, and their surrogates share decisions,⁷ facilitating discussion of QOL and relevant factors for each stakeholder.^{7,8}

Applying the palliative triangle to Mr J's case, perhaps Mr J, his wife, and Dr Q could consider the questions posed above, compare the status quo against hypothetical recovery scenarios and scenarios about sex without Mr J's ileostomy, and imagine possible outcomes of and feelings about those possibilities.

Palliative Surgical Success

As discussed, surgeons are generally trained to focus on physical, measurable outcomes (ie, physiologic responses, intervention side effects, morbidity, and mortality) and measures of palliative surgical success from patients' perspectives are not well defined or documented.⁹ Nevertheless, patients' QOL estimates and self-reports about QOL improvement¹⁰ should play key roles in decision making, goal formation, and definition of success. Patients selected to receive palliative surgery for oncologic indications might have improved survival and improved morbidity,⁶ and the finding that patients demonstrate increased overall satisfaction regardless of outcome is also important.¹¹ In the case, if we assume that Mr J underwent ileostomy reversal and recovered well under Dr Q's care—and if we further assume that he and his wife had more satisfying sex, which generated improved QOL reports from Mr J—we likely would have good reason to call the goals of his ileostomy reversal palliative, to call the surgery a success, and to feel that we've done what we could as surgeons to not overlook his needs.

References

1. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patientcentered care. *N Engl J Med*. 2012;366(9):780-781.

- 2. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. National Academy Press; 2001.
- 3. Statement of principles of palliative care. American College of Surgeons. Accessed November 11, 2021. https://www.facs.org/about-acs/statements/50palliative-care
- 4. Hanna J, Blazer DG, Mosca PJ. Overview of palliative surgery: principles and priorities. *J Palliat Care Med*. 2012;2(7):1-6.
- 5. National Consensus Project. *Clinical Practice Guidelines for Quality Palliative Care*. 4th ed. National Coalition for Hospice and Palliative Care; 2018.
- 6. Ferrell BR, Dow KH, Leigh S, Ly J, Gulasekaram P. Quality of life in long-term cancer survivors. *Oncol Nurs Forum*. 1995;22(6):915-922.
- 7. Miner TJ, Cohen J, Charoentier K, et al. The palliative triangle: improved patient selection and outcomes associated with palliative operations. *Arch Surg.* 2011;146(5):517-522.
- 8. Thomay AA, Jaques DP, Miner TJ. Surgical palliation: getting back to our roots. *Surg Clin North Am*. 2009;89(1):27-41, vii-viii.
- 9. Cady B, Easson A, Aboulafia AJ, et al. Part I: surgical palliation of advanced illness— what's new, what's helpful. *J Am Coll Surg*. 2005;200(1):115-127.
- 10. Badgwell B, Bruera E, Klimberg SV. Can patient reported outcomes help identify the optimal outcome in palliative surgery? *J Surg Oncol*. 2014;109(2):145-150.
- 11. Miner TJ, Brennan MF, Jaques DP. A prospective, symptom related, outcomes analysis of 1022 palliative procedures for advanced cancer. *Ann Surg.* 2004;240(4):719-727.

Pringl Miller, MD is board certified in general surgery and hospice and palliative medicine with fellowship training in clinical medical ethics. She is an associate member of the American College of Surgeon's Academy of Master Surgeon Educators and the founder and executive director of the nonprofit organization Physician Just Equity.

Preeti R. John, MD, MPH practices at the Veterans Affairs Maryland Health Care System. She is triple board certified in general surgery, surgical critical care, and hospice and palliative medicine. Certified as a health care ethics consultant by the American Society for Bioethics and Humanities, she has interests in narrative medicine, end-of-life care, and pain management.

Sabha Ganai, MD, PhD, MPH is board certified in general surgery and complex general surgical oncology with fellowship training in clinical medical ethics from the University of Chicago MacLean Center for Clinical Medical Ethics. She is a member of the American College of Surgeon's Commission on Cancer and is an associate professor of surgery at University of North Dakota School of Medicine and Health Sciences in Grand Forks.

Citation

AMA J Ethics. 2021;23(10):E778-782.

DOI

10.1001/amajethics.2021.778.

Conflict of Interest Disclosure

Dr Ganai serves on the advisory board of Castle Biosciences. The other authors had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E783-793

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

When Should Neuroendovascular Care for Patients With Acute Stroke Be Palliative?

Michael J. Young, MD, MPhil, Robert W. Regenhardt, MD, PhD, Leonard L. Sokol, MD, and Thabele M. Leslie-Mazwi, MD

Abstract

Noncurative surgeries intended to relieve suffering during serious illness or near end of life have been analyzed across palliative settings. Yet sparse guidance is available to inform clinical management decisions about whether, when, and which interventions should be offered when ischemic stroke and other neurological complications occur in patients whose survival is extended by other novel disease-modifying interventions. This case commentary examines key ethical and clinical considerations in palliative neuroendovascular care of patients with acute stroke.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit[™] available through the AMA Ed Hub[™]. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Case

Mr J is a 64-year-old man with metastatic non-small cell lung cancer (NSCLC), who, while eating, abruptly developed right hemiplegia and aphasia. He had been diagnosed 10 months earlier with NSCLC; his estimated life expectancy was approximately 1 year. After a course of chemotherapy with pemetrexed and carboplatin, Mr J started pembrolizumab, an antiprogrammed death-1 immune checkpoint inhibitor offered possibly to extend his life but not as a cure for his cancer.^{1,2} Since diagnosis, Mr J has suffered multiple hematologic complications, including thrombosis and hemorrhage. When brought to an emergency department, he was confirmed as full code and intubated on arrival due to poor mental status and aspiration risk. Computed tomography (CT) imaging of his head and neck revealed normal brain parenchyma and occlusion of the proximal left middle cerebral artery (MCA), which supplies blood to most of the brain's left hemisphere, including areas critical for language and right-side sensorimotor function.³ The mechanism of Mr J's left MCA occlusion was presumed to be thromboembolism, to which he was predisposed by hypercoagulability of malignancy, pembrolizumab,^{4,5,6} and intracardiac hemostasis, given his known low left ventricular ejection fraction.

After discussion of acute stroke as a likely a complication of Mr J's cancer, Mr J's health care proxy, GG, consented to Mr J undergoing an emergent thrombectomy. This neuroendovascular procedure is a minimally invasive alternative to more invasive interventions and is the standard method for thrombectomy for acute ischemic stroke with large-vessel occlusion using an endovascular approach. Emergent thrombectomy utilizes femoral artery access to position an intracranial catheter system that permits intracerebral thrombus removal, with the goals of reestablishing blood flow to vascular territory downstream from an occlusion and enabling salvage of the ischemic penumbra to restore neurological function and prevent further impairment.⁷ If thrombectomy is not performed, a large proximal-vessel stroke typically occurs, potentially leading to extended brain tissue infarction, cerebral edema, and other symptoms of elevated intracranial pressure (eg, nausea, vomiting, headache, visual changes, and cranial neuropathies) that can exacerbate a patient's impairment and suffering.^{8,9,10,11}

Mr J's thrombectomy was uncomplicated and resulted in rapid and successful left MCA territory reperfusion. A subsequent brain magnetic resonance (MR) image, however, revealed multifocal infarcts affecting the left and the right hemisphere of Mr J's brain and bilateral cerebellar hemispheres, consistent with his presumed cardioembolic etiology. Mr J was unable to communicate or meaningfully interact. After neurological examination, Dr N informed GG of key findings, including bilateral infarcts expected to produce long-term bilateral weakness, disordered speech, and cognitive impairment. Dr N also explained to GG that Mr J would likely need life support, including tracheostomy, gastrostomy, and rehabilitation if he survived much longer. GG expressed understanding and asked the team to prioritize Mr J's comfort.

Commentary

More than 1 in 10 patients who present with acute ischemic stroke are estimated to have comorbid cancer.^{12,13} As the median survival of patients with cancer improves with novel targeted therapies, the frequency of acute stroke and other neurologic complications in this expanding population is expected to rise.^{14,15,16,17,18} Malignancy can predispose patients to ischemic stroke through hypercoagulability, nonbacterial thrombotic endocarditis, systemic treatment effects, or, rarely, tumor embolism or angioinvasion.^{14,19} Since many patients seeking emergency evaluation of acute stroke symptoms might have comorbid cancer, clarifying ethical questions in these patients' stroke care, especially for patients near the end of life, is key. Should clinicians try to preempt or reverse neurological dysfunction when the end of a patient's life is near? When, to what extent, and according to whom should thrombectomy for patients with terminal illness be considered palliative? How should palliative or comfort care goals be set in order to guide appropriate neuroendovascular management decisions in the context of end-of-life care?

Palliative Thrombectomy Goals

Palliative care is defined by the World Health Organization (WHO) as "active total care of patients whose disease is not responsive to curative treatment" that aims to achieve "the best quality of life for patients and their families."²⁰ The Center to Advance Palliative Care (CAPC) conceives of the field as "specialized medical care for people with serious illnesses [that is] focused on providing patients with relief from the symptoms, pain, and stress of a serious illness.... The goal is to improve quality of life ... and [palliative care] can be provided along with curative treatment."²¹ Noncurative surgery intended to relieve symptoms in patients with serious illness or near the end of life has been analyzed in a range of contexts, particularly in surgical

oncology.^{22,23,24,25,26,27,28,29,30,31} However, invasive neurological procedures intended to address indirect complications of terminal illnesses (eg, thrombosis due to hypercoagulability of malignancy) have received little clinical or ethical attention. Especially in clinical neuroscience, little evidence is available to guide neuroendovascular intervention decisions with patients who develop ischemic stroke or other neurological complications near the end of life.

Although in Mr J's case, thrombectomy did not appreciably reduce disability near the end of his life, we argue that Dr N's team's decision to perform thrombectomy was ethically justifiable based on its concordance with Mr J's goals that the team gleaned through conversations with GG. As highlighted by the WHO and CAPC definitions, appropriate palliative care consists not merely of pain control but of the active total care of a patient who strives for the best quality of life. To the extent that neurological symptoms, including sensorimotor dysfunction (eg, weakness and numbness), headache, delirium, aphasia, dysarthria, imbalance, gait disturbance, and cranial neuropathies can detract from quality of life, it is incumbent upon clinicians to diligently address symptoms throughout a patient's illness.^{32,33,34,35} Among patients who experience acute ischemic stroke, more severe neurological impairment has been linked with significantly lower quality of life.^{35,36}

Neuroendovascular approaches, such as thrombectomy, are specifically intended to attenuate or prevent accumulated neurological disability^{37,38,39} and are supported by randomized clinical trials.^{40,41} The location and type of stroke and the extent of salvageable ischemic penumbra must be considered case by case in terms of whether foreseeable benefits of thrombectomy outweigh its risks. Eligibility criteria for late endovascular treatment trials for patient-subjects with acute ischemic stroke have included occlusion of proximal MCA or internal carotid artery on CT imaging or MR angiography, a score greater than 6 on the National Institutes of Health Stroke Scale up to 24 hours from the time the patient was last seen well, significant ischemic penumbra, and factors such as age, baseline modified Rankin Scale score, and life expectancy. Exclusion criteria have varied by trial and have been a source of practice variation across centers.⁴² Another source of complexity is that treatment decisions are typically made emergently.

Minimally invasive neuroendovascular interventions can aptly be considered palliative for a patient with limited life expectancy and should not be withheld based solely on a patient's terminal comorbidity. Even if a patient is expected to live only a few weeks or months, any additional stroke-related neurological impairment could exacerbate their suffering near the end of life. Many patients who undergo thrombectomy experience reversal of neurologic impairment or return to functional independence due to their reduced risk of ischemic penumbra.⁴⁰ Successful reperfusion of ischemic penumbra might forestall development of malignant cerebral edema, cerebral herniation, or other symptoms of increased intracranial pressure, as evidenced by lower rates of decompressive hemicraniectomy since the advent of mechanical thrombectomy.^{43,44,45,46} Following the ethical principles of doing good and avoiding harm^{47,48,49} likely requires clinicians to offer palliative thrombectomy, even when a patient has incurable comorbidity.

Decision Sharing

Patient-centered care requires assessing (1) a patient's functional status at baseline; (2) their preferences, values, and goals, perhaps as expressed by surrogates; and (3) their

prospects for recovery.^{50,51,52,53} Interpreting each stroke not as a discrete new disease but in the context of a patient's broader health state, relevant comorbidities, and illness narrative can foster holistic, goal-concordant intervention and might help avoid unnecessary discontinuity or fragmentation in a patient's care.^{54,55,56,57} Clinicians' conversations with patients and surrogates should emphasize that estimates of an intervention's effects are extrapolated from studies in which subjects were drawn not from the unique population of patients with terminal illnesses but from a general population with minimal preexisting disability. Decision sharing and informed consent require conveying uncertainty about how well the available evidence applies to a particular patient.

Equity and Evolving Therapies

Further research on the efficacy of palliative neuroendovascular care is essential, although the practical and ethical problems of conducting clinical research in patient-subjects with advanced illnesses deserve careful consideration.^{58,59,60,61} In one study of persons with metastatic NSCLC, newly diagnosed patients whose care plans integrated early palliative care experienced improved quality of life and mood,⁶² and the challenges of ensuring goal-concordant palliative care given the growth of novel interventions in the past decade are actively being studied.^{63,64} Equity as an organizational ethical value requires inclusion of all key stakeholders' perspectives and goals—curative and palliative—when crafting policy and evaluating downstream implications of decisions to administer or withhold neuroendovascular interventions in individual cases.

In the case, Mr J had an acceptable health-related quality of life and—assuming his comparability to otherwise healthy patients with acute stroke—a higher chance of making a functional recovery with treatment than without it, at very low procedural risk.⁶⁵ While caution must be exercised in generalizing from studies of acute stroke patients who did not have cancer, the data indicate that patients treated with thrombectomy for acute proximal MCA occlusion stroke lived the remainder of their lives with fewer neurologic impairments than if untreated and with reduced need for aggressive care and institutionalization following a sentinel cerebrovascular event.^{64,66,67,68}

While not a factor in this Mr J's case, do-not-intubate (DNI) orders are common and worthy of mention here. DNI orders should not independently influence stroke care decisions "unless otherwise explicitly indicated," as emphasized by an American Heart Association/American Stroke Association statement (Class IIa recommendation).⁶⁹ Generally, clinicians should express respect for patients' right to decline interventions⁷⁰ but should recognize that such interventions can have palliative roles by preventing debilitating neurological impairment and concomitant end-of-life suffering.^{71,72} Palliative radiotherapy, including stereotactic radiosurgery for patients with advanced cancer with brain metastases, has been pursued,^{73,74,75,76} as have deep brain stimulation for Parkinson disease management near the end of life⁷⁷ and palliative decompressive spinal surgery for patients with metastatic spinal cord compression.^{78,79,80,81}

Care Planning

Unlike decisions about specific palliative interventions, decisions about stroke care are typically made quickly, given the urgency of acute stroke, its impact on patients' capacity to participate in decision making, and the exquisite time sensitivity of implementing acute stroke interventions. Although outcomes data for specific palliative neuroendovascular interventions are limited, advance care planning should include surrogate designation and discussion of minimally invasive intervention preferences, which could help safeguard value-concordant goal setting and decision sharing later.^{71,82}

Ethically appropriate palliative neuroendovascular care for patients with acute stroke includes more than pain control and extends to management of distressing physical, spiritual, emotional, and psychosocial symptoms.^{83,84} Recognizing the relatively high frequency of neurological complications among patients with terminal illnesses,^{12,85,86,87,88,89} clinicians can implement patient-centered palliative neuroendovascular care with guidance from the ideas in the Table.

Table. Elements of Ethically Appropriate Palliative Neuroendovascular Care

Recognize palliative care as more than pain control; extend it to management of potentially disabling, distressing neurologic symptoms.^{83,84,90}

Clarify the patient's (or surrogate's) values and goals of care.⁹¹

Avoid assumptions about a patient's values, preferences, or goals.92

Discuss intended aims, prospective benefits, and possible risks of a neuroendovascular intervention with a patient or surrogate.

Explain the range of possible postprocedural outcomes to motivate transparency.

Discuss likely outcomes of no neuroendovascular intervention or alternative interventions.

Ensure that decision making is sensitive to patient preferences, values, and goals.

Clearly document and communicate decisions to colleagues and care team members.

References

- Garon EB, Rizvi NA, Hui R, et al; KEYNOTE-001 Investigators. Pembrolizumab for the treatment of non-small-cell lung cancer. *N Engl J Med*. 2015;372(21):2018-2028.
- 2. Gandhi L, Rodríguez-Abreu D, Gadgeel S, et al; KEYNOTE-189 Investigators. Pembrolizumab plus chemotherapy in metastatic non-small-cell lung cancer. *N Engl J Med.* 2018;378(22):2078-2092.
- 3. Caplan LR. Caplan's Stroke: A Clinical Approach. 5th ed. Cambridge University Press; 2016.
- 4. Horio Y, Takamatsu K, Tamanoi D, et al. Trousseau's syndrome triggered by an immune checkpoint blockade in a non-small cell lung cancer patient. *Eur J Immunol.* 2018;48(10):1764-1767.
- 5. Moik F, Chan WSE, Wiedemann S, et al. Incidence, risk factors and outcomes of venous and arterial thromboembolism in immune checkpoint inhibitor therapy. *Blood*. 2021;137(12):1669-1678.
- 6. Ando Y, Hayashi T, Sugimoto R, et al. Risk factors for cancer-associated thrombosis in patients undergoing treatment with immune checkpoint inhibitors. *Invest New Drugs*. 2020;38(4):1200-1206.
- 7. Regenhardt RW, Das AS, Stapleton CJ, et al. Blood pressure and penumbral sustenance in stroke from large vessel occlusion. *Front Neurol*. 2017;8:317.
- 8. Friedman DI. Headaches due to low and high intracranial pressure. *Continuum* (*Minneap Minn*). 2018;24(4, Headache):1066-1091.

- 9. Koenig MA. Cerebral edema and elevated intracranial pressure. *Continuum* (*Minneap Minn*). 2018;24(6):1588-1602.
- 10. Pandhi A, Krishnan R, Goyal N, Malkoff M. Increased intracranial pressure in critically ill cancer patients. In: Nates J, Price K, eds. *Oncologic Critical Care*. Springer; 2020:395-407.
- 11. Arch AE, Sheth KN. Malignant cerebral edema after large anterior circulation infarction: a review. *Curr Treat Options Cardiovasc Med*. 2014;16(1):275.
- 12. Bang OY, Chung JW, Lee MJ, Seo WK, Kim GM, Ahn MJ; OASIS-Cancer Study Investigators. Cancer-related stroke: an emerging subtype of ischemic stroke with unique pathomechanisms. *J Stroke*. 2020;22(1):1-10.
- 13. Zaorsky NG, Zhang Y, Tchelebi LT, Mackley HB, Chinchilli VM, Zacharia BE. Stroke among cancer patients. *Nat Commun.* 2019;10(1):5172.
- 14. Dearborn JL, Urrutia VC, Zeiler SR. Stroke and cancer—a complicated relationship. *J Neurol Transl Neurosci*. 2014;2(1):1039.
- 15. Kitano T, Sasaki T, Gon Y, et al. The effect of chemotherapy on stroke risk in cancer patients. *Thromb Haemost*. 2020;120(4):714-723.
- 16. Zhang J, Zhao J. Clinical characteristics and analysis of lung cancer-associated acute ischemic stroke. *J Stroke Cerebrovasc Dis*. 2020;29(10):105164.
- 17. Sands JM, Daly ME, Lee EQ. Neurologic complications of lung cancer. *Cancer*. 2020;126(20):4455-4465.
- Abdelsalam M, Abu-Hegazy M, El-Hadaad HA, Wahba H, Egila H, Esmael A. Pathophysiology, mechanism, and outcome of ischemic stroke in cancer patients. J Stroke Cerebrovasc Dis. 2020;29(11):105299.
- 19. Bang OY, Seok JM, Kim SG, et al. Ischemic stroke and cancer: stroke severely impacts cancer patients, while cancer increases the number of strokes. *J Clin Neurol.* 2011;7(2):53-59.
- 20. World Health Organization. *Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee*. World Health Organization; 1990. Accessed August 6, 2021.

http://apps.who.int/iris/bitstream/handle/10665/39524/WHO_TRS_804.pdf? sequence=1

- 21. About palliative care. National Palliative Care Research Center. Accessed July 6, 2021. http://www.npcrc.org/content/15/About-Palliative-Care.aspx
- 22. McCahill LE, Krouse RS, Chu DZ, et al. Decision making in palliative surgery. *J Am Coll Surg.* 2002;195(3):411-422.
- 23. Hallissey MT, Allum WH, Roginski C, Fielding JW. Palliative surgery for gastric cancer. *Cancer*. 1988;62(2):440-444.
- 24. Hirabayashi H, Ebara S, Kinoshita T, et al. Clinical outcome and survival after palliative surgery for spinal metastases: palliative surgery in spinal metastases. *Cancer*. 2003;97(2):476-484.
- 25. McCahill LE, Krouse R, Chu D, et al. Indications and use of palliative surgery– results of Society of Surgical Oncology survey. *Ann Surg Oncol.* 2002;9(1):104-112.
- 26. Hofmann B, Håheim LL, Søreide JA. Ethics of palliative surgery in patients with cancer. *Br J Surg*. 2005;92(7):802-809.
- 27. Ferguson HJM, Ferguson CI, Speakman J, Ismail T. Management of intestinal obstruction in advanced malignancy. *Ann Med Surg (Lond)*. 2015;4(3):264-270.
- Sigurdsson HK, Kørner H, Dahl O, Skarstein A, Søreide JA; Norwegian Rectal Cancer Group. Palliative surgery for rectal cancer in a national cohort. *Colorectal Dis.* 2008;10(4):336-343.

- 29. Perinel J, Adham M. Palliative therapy in pancreatic cancer—palliative surgery. *Transl Gastroenterol Hepatol.* 2019;4:28.
- 30. Lindvall C, Lilley EJ, Zupanc SN, et al. Natural language processing to assess end-of-life quality indicators in cancer patients receiving palliative surgery. *J Palliat Med.* 2019;22(2):183-187.
- 31. Kobayashi K, Ando K, Nakashima H, et al. Prognostic factors in the new Katagiri scoring system after palliative surgery for spinal metastasis. *Spine (Phila Pa* 1976). 2020;45(13):E813-E819.
- 32. Wong AWK, Lau SCL, Fong MWM, Cella D, Lai JS, Heinemann AW. Conceptual underpinnings of the Quality of Life in Neurological Disorders (Neuro-QoL): comparisons of core sets for stroke, multiple sclerosis, spinal cord injury, and traumatic brain injury. *Arch Phys Med Rehabil*. 2018;99(9):1763-1775.
- 33. Jonkman EJ, de Weerd AW, Vrijens NL. Quality of life after a first ischemic stroke. Long-term developments and correlations with changes in neurological deficit, mood and cognitive impairment. *Acta Neurol Scand*. 1998;98(3):169-175.
- 34. Katzan IL, Thompson NR, Uchino K, Lapin B. The most affected health domains after ischemic stroke. *Neurology*. 2018;90(16):e1364-e1371.
- 35. Asaithambi G, Tipps ME. Quality of life among ischemic stroke patients eligible for endovascular treatment: analysis of the DEFUSE 3 trial. *J Neurointerv Surg.* 2021;13(8):703-706.
- 36. Askew RL, Capo-Lugo CE, Sangha R, Naidech A, Prabhakaran S. Trade-offs in quality-of-life assessment between the Modified Rankin Scale and Neuro-QoL measures. *Value Health*. 2020;23(10):1366-1372.
- 37. Regenhardt RW, Young MJ, Etherton MR, et al. Toward a more inclusive paradigm: thrombectomy for stroke patients with pre-existing disabilities. *J Neurointerv* Surg. 2021;13(10):865-868.
- 38. Young MJ, Regenhardt RW, Leslie-Mazwi TM, Stein MA. Disabling stroke in persons already with a disability: ethical dimensions and directives. *Neurology*. 2020;94(7):306-310.
- 39. Fargen KM, Leslie-Mazwi TM, Chen M, Hirsch JA. Physician, know thyself: implicit and explicit decision-making for mechanical thrombectomy in stroke. *J Neurointerv* Surg. 2020;12(10):952-956.
- 40. Martinez-Gutierrez JC, Leslie-Mazwi T, Chandra RV, et al. Number needed to treat: a primer for neurointerventionalists. *Interv Neuroradiol*. 2019;25(6):613-618.
- 41. Powers WJ, Rabinstein AA, Ackerson T, et al. Guidelines for the early management of patients with acute ischemic stroke: 2019 update to the 2018 guidelines for the early management of acute ischemic stroke: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2019;50(12):e344-e418.
- 42. Nannoni S, Strambo D, Sirimarco G, et al. Eligibility for late endovascular treatment using DAWN, DEFUSE-3, and more liberal selection criteria in a stroke center. *J Neurointerv Surg.* 2020;12(9):842-847.
- 43. Rumalla K, Ottenhausen M, Kan P, Burkhardt JK. Recent nationwide impact of mechanical thrombectomy on decompressive hemicraniectomy for acute ischemic stroke. *Stroke*. 2019;50(8):2133-2139.
- 44. Göttsche J, Flottmann F, Jank L, et al. Decompressive craniectomy in malignant MCA infarction in times of mechanical thrombectomy. *Acta Neurochir (Wien)*. 2020;162(12):3147-3152.

- 45. Khattar NK, Ugiliweneza B, Fortuny EM, et al. Inverse national trends in decompressive craniectomy versus endovascular thrombectomy for stroke. *World Neurosurg.* 2020;138:e642-e651.
- 46. Mouchtouris N, Saiegh FA, Baldassari M, et al. Decompressive hemicraniectomy in the modern era of acute ischemic stroke: the impact of mechanical thrombectomy. *Neurosurgery*. 2020;67(suppl 1):nyaa447_292.
- 47. Purves D. Harming as making worse off. *Philos Stud*. 2019;176(10):2629-2656.
- 48. Carlson E, Johansson J, Risberg O. Well-being counterfactualist accounts of harm and benefit. *Australas J Philos*. 2021;99(1):164-174.
- 49. Johansson J, Risberg O. Harming and failing to benefit: a reply to Purves. *Philos Stud.* 2020;177(6):1539-1548.
- 50. Regenhardt RW, Takase H, Lo EH, Lin DJ. Translating concepts of neural repair after stroke: structural and functional targets for recovery. *Rest Neurol Neuroscience*. 2020;38(1):67-92.
- 51. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284(19):2476-2482.
- 52. Nair KPS, Chandler B, Lee M, et al. Rehabilitation medicine in palliative care of chronic neurological conditions. *BMJ Support Palliat Care*. Published online August 24, 2020.
- 53. Creutzfeldt CJ, Holloway RG, Walker M. Symptomatic and palliative care for stroke survivors. *J Gen Intern Med*. 2012;27(7):853-860.
- 54. Creutzfeldt CJ, Holloway RG, Curtis JR. Palliative care: a core competency for stroke neurologists. *Stroke*. 2015;46(9):2714-2719.
- 55. Creutzfeldt CJ, Kluger B, Kelly AG, et al. Neuropalliative care: priorities to move the field forward. *Neurology*. 2018;91(5):217-226.
- 56. Connolly T, Coats H, DeSanto K, Jones J. The experience of uncertainty for patients, families and healthcare providers in post-stroke palliative and end-of-life care: a qualitative meta-synthesis. *Age Ageing*. 2021;50(2):534-545.
- 57. Visvanathan A, Mead GE, Dennis M, Whiteley WN, Doubal FN, Lawton J. The considerations, experiences and support needs of family members making treatment decisions for patients admitted with major stroke: a qualitative study. *BMC Med Inform Decis Mak*. 2020;20:98.
- 58. Abernethy AP, Capell WH, Aziz NM, et al. Ethical conduct of palliative care research: enhancing communication between investigators and institutional review boards. *J Pain Symptom Manage*. 2014;48(6):1211-1221.
- 59. Bloomer MJ, Hutchinson AM, Brooks L, Botti M. Dying persons' perspectives on, or experiences of, participating in research: an integrative review. *Palliat Med.* 2018;32(4):851-860.
- 60. Oriani A, Fusi-Schmidhauser T, Guo P. Should end-of-life patients be enrolled as participants in clinical research? A best-fit framework synthesis. *J Adv Nurs*. 2021;77(4):1656-1666.
- 61. Vinches M, Neven A, Fenwarth L, et al. Clinical research in cancer palliative care: a metaresearch analysis. *BMJ Support Palliat Care*. 2020;10(2):249-258.
- 62. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-742.
- 63. Temel JS, Shaw AT, Greer JA. Challenge of prognostic uncertainty in the modern era of cancer therapeutics. *J Clin Oncol*. 2016;34(30):3605-3608.
- 64. Tokunboh I, Vales Montero M, Zopelaro Almeida MF, et al. Visual aids for patient, family, and physician decision making about endovascular thrombectomy for acute ischemic stroke. Stroke. 2018;49(1):90-97.

- 65. Goyal M, Menon BK, van Zwam WH, et al; HERMES collaborators. Endovascular thrombectomy after large-vessel ischaemic stroke: a meta-analysis of individual patient data from five randomised trials. *Lancet*. 2016;387(10029):1723-1731.
- 66. Moshayedi P, Liebeskind DS, Jadhav A, et al. Decision-making visual aids for late, imaging-guided endovascular thrombectomy for acute ischemic stroke. *J Stroke*. 2020;22(3):377-386.
- 67. Kamal N, Rogers E, Stang J, et al. One-year healthcare utilization for patients that received endovascular treatment compared with control. *Stroke*. 2019;50(7):1883-1886.
- 68. Zerna C, Rogers E, Rabi DM, et al. Comparative effectiveness of endovascular treatment for acute ischemic stroke: a population-based analysis. *J Am Heart* Assoc. 2020;9(7):e014541.
- 69. Holloway RG, Arnold RM, Creutzfeldt CJ, et al; American Heart Association Stroke Council; Council on Cardiovascular and Stroke Nursing; Council on Clinical Cardiology. Palliative and end-of-life care in stroke: a statement for healthcare professionals from the American Heart Association/American Stroke Association. Stroke. 2014;45(6):1887-1916.
- 70. Rehmann-Sutter C. When a patient refuses life-sustaining treatments. In: Emmerich M, Malia P, Gordijn B, Pistoia F, eds. *Contemporary European Perspectives on the Ethics of End of Life Care*. Springer; 2020:297-314.
- 71. Sokol LL, Hauser JM, Lum HD, et al. Goal-concordant care in the era of advanced stroke therapies. *J Palliat Med*. 2021;24(2):297-301.
- 72. VanKerkhoff TD, Viglianti EM, Detsky ME, Kruser JM. Time-limited trials in the intensive care unit to promote goal-concordant patient care. *Clin Pulm Med*. 2019;26(5):141-145.
- 73. Caron JL, Souhami L, Podgorsak EB. Dynamic stereotactic radiosurgery in the palliative treatment of cerebral metastatic tumors. *J Neurooncol*. 1992;12(2):173-179.
- 74. Harrison RA, Bruera E. The palliative care of patients with brain metastases. In: Ahluwalia M, Metellus P, Soffietti R, eds. *Central Nervous System Metastases*. Springer; 2020:705-718.
- 75. Hong AM, Waldstein C, Shivalingam B, et al. Management of melanoma brain metastases: evidence-based clinical practice guidelines by Cancer Council Australia. *Eur J Cancer*. 2021;142:10-17.
- 76. Hatiboglu MA, Akdur K, Sawaya R. Neurosurgical management of patients with brain metastasis. *Neurosurg Rev.* 2020;43(2):483-495.
- 77. Sankary LR, Ford PJ, Machado AG, Hoeksema LJ, Samala RV, Harris DJ. Deep brain stimulation at end of life: clinical and ethical considerations. *J Palliat Med*. 2020;23(4):582-585.
- 78. Akram H, Allibone J. Spinal surgery for palliation in malignant spinal cord compression. *Clin Oncol (R Coll Radiol)*. 2010;22(9):792-800.
- 79. Kakutani K, Sakai Y, Maeno K, et al. Prospective cohort study of performance status and activities of daily living after surgery for spinal metastasis. *Clin Spine Surg.* 2017;30(8):E1026-E1032.
- 80. Miyazaki S, Kakutani K, Sakai Y, et al. Quality of life and cost-utility of surgical treatment for patients with spinal metastases: prospective cohort study. *Int Orthop.* 2017;41(6):1265-1271.
- 81. Tao F, Shi Z, Tao H, et al. Comparison of subtotal vertebral resection with reconstruction and percutaneous vertebroplasty for treatment of metastasis in the lumbar spine. *Br J Neurosurg*. 2020;34(3):308-312.

- Sokol LL, Young MJ, Paparian J, et al. Advance care planning in Parkinson's disease: ethical challenges and future directions. *NPJ Parkinsons Dis*. 2019;5:24.
- 83. Bindu B, Rath GP. Palliative care for neurologically injured patients: why and how? J Neuroanaesth Crit Care. 2019;6(1):5-12.
- 84. Creutzfeldt CJ, Kluger BM, Holloway RG. Neuropalliative care: an introduction. In: Creutzfeldt C, Kluger B, Holloway R, eds. *Neuropalliative Care: A Guide to Improving the Lives of Patients and Families Affected by Neurologic Disease*. Springer; 2019:1-8.
- 85. DeAngelis LM, Posner JB. *Neurologic Complications of Cancer*. 2nd ed. Oxford University Press; 2009. *Contemporary Neurology*; vol 73.
- 86. Haugh AM, Probasco JC, Johnson DB. Neurologic complications of immune checkpoint inhibitors. *Expert Opin Drug Saf*. 2020;19(4):479-488.
- 87. Lee EQ. Neurologic complications in patients with cancer. *Continuum (Minneap Minn)*. 2020;26(6):1629-1645.
- 88. Krishnan AV, Kiernan MC. Neurological complications of chronic kidney disease. *Nat Rev Neurol.* 2009;5(10):542-551.
- 89. Zhang F, Wang K, Du P, et al. Risk of stroke in cancer survivors: a meta-analys of population-based cohort studies. *Neurology*. 2021;96(4):e513-e526.
- 90. Sokol LL, Lum HD, Creutzfeldt CJ, et al. Meaning and dignity therapies for psychoneurology in neuropalliative care: a vision for the future. *J Palliat Med*. 2020;23(9):1155-1156.
- 91. Young MJ. Compassionate care for the unconscious and incapacitated. *Am J Bioeth*. 2020;20(2):55-57.
- Chesney TR, Schwarze ML. Patient-centered surgical decision making. In: Rosenthal RA, Zenilman NE, Katlic MR, eds. *Principles and Practice of Geriatric Surgery*. 3rd ed. Springer; 2020:81-93.

Michael J. Young, MD, MPhil is a fellow in neurology at Massachusetts General Hospital and Brigham and Women's Hospital in Boston. His research examines frameworks underlying standards of care in clinical neuroscience and improving novel neurotechnology applications for care of patients with neurological disorders.

Robert W. Regenhardt, MD, PhD is a neuroendovascular fellow and stroke scientist at Massachusetts General Hospital in Boston. His research interests include translation, white matter infarction, and improving stroke care.

Leonard L. Sokol, MD is a neurology resident physician at Northwestern University in Evanston, Illinois, who plans to continue fellowship training in hospice and palliative medicine. His research interests include adaptation and development of novel, meaning-centered models of palliative care for patients with neurodegenerative diseases.

Thabele M. Leslie-Mazwi, MD directs endovascular stroke services at Massachusetts General Hospital in Boston. He has practiced in state, regional, and national systems of stroke care and is passionate about improving thrombectomy access for patients with large vessel occlusions.

Citation

AMA J Ethics. 2021;23(10):E783-793.

DOI

10.1001/amajethics.2021.783.

Acknowledgements

This work was supported by Northwestern University Feinberg School of Medicine Department of Neurology's Physician-Scientist Training Program, National Institutes of Health R25 CA190169 for Meaning-Centered Psychotherapy research and training at Memorial Sloan Kettering Cancer Center, National Institute of Neurological Disorders and Stroke of the National Institutes of Health Cooperative Agreement F32MH123001, the Tiny Blue Dot Foundation, and a Scientific Projects to Accelerate Research and Collaboration award from the Henry and Allison McCance Center for Brain Health, Massachusetts General Hospital.

Conflict of Interest Disclosure

Dr Sokol serves as an ad hoc consultant for Tikvah for Parkinson and is an ad hoc reviewer for the *Journal of Geriatric Psychiatry and Neurology, Pilot and Feasibility Studies,* and *Palliative Medicine Reports.* The other authors had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. This article is the sole responsibility of the author(s) and does not necessarily represent the views of the National Institutes of Health, the Tiny Blue Dot Foundation, or the Henry and Allison McCance Center for Brain Health. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E794-799

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Surgeons Communicate About Palliative and Curative Intentions, Purposes, and Outcomes?

Charles E. Binkley, MD

Abstract

How surgeons describe procedures should be accurate, precise, and concordant with patients' values. By focusing on intention rather than realistic goals, terms like *curative* and *palliative*, when applied to highstakes operations, such as a Whipple pancreaticoduodenectomy, can be confusing to patients. This case commentary argues that surgeons' language choices can influence patients' decisions and experiences.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit[™] available through the AMA Ed Hub[™]. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Case

LL is a 66-year-old patient with a pancreatic head adenocarcinoma. In consultation, Dr B recommended that LL undergo a Whipple pancreaticoduodenectomy and indicated that his "intention in doing this procedure is to cure your cancer." There were no postoperative complications, and LL completed adjuvant chemotherapy. But 18 months later, surveillance computed tomography imaging revealed a 3 cm mass in LL's right liver. Metastatic pancreatic cancer was confirmed by biopsy.

LL returned to see Dr B and asked why her operation wasn't curative. Dr B explained that most often pancreatic cancer recurs and that the operation was palliative.

Commentary

In 1978, C. Gardner Child, former chairman of surgery at the University of Michigan, published a summary of 55 Whipple pancreaticoduodenectomies (PDs) he had performed from 1960 to 1978, mostly for malignancy. Child observed that the operation was "primarily a palliative surgical procedure."¹ More than 40 years later, the same operation is still being referred to in many cases as palliative.² However, the basis of the current designation is much different than what Child meant by *palliative*. Given advances in addressing major symptoms of malignancies treated by a PD, the role of true surgical palliation is significantly limited.^{3,4} *Palliative Whipple* is thus a description that should be used with precision, as imprecise usage can compromise patient autonomy, informed consent, and physician truthfulness.

PD as Palliative

Currently, PD is most commonly performed to treat periampullary malignancies of the head and neck of the pancreas, distal common bile duct, ampulla of Vater, and duodenum. These malignancies share common symptoms and an overall poor prognosis.⁵ Tumors in this region cause biliary obstruction in over 80% of patients, gastric outlet or duodenal obstruction in 10% to 25% of patients, and severe pain in 80% of patients.^{4,6,7,8,9} PD can effectively relieve these symptoms by removing the obstructing tumor and restoring biliary and gastric continuity directly with the proximal jejunum. Moreover, because these tumors characteristically infiltrate along nerves of the celiac plexus, resection might provide some pain relief.¹⁰

Child held that, as long as there is no evidence of distant disease or tumor encasement of vital structure, PD should be performed on patients with a periampullary malignancy.¹ Although he recognized that most patients would develop recurrent disease and die within a few months or a few years of surgery, he believed that "death from metastatic disease is more humane than death with a painful cancer in place."¹ Thus, Child was able to accurately describe the operation he performed as *palliative* in that it relieved obstructive symptoms and pain. Recognizing that overall survival was poor, Child identified palliation as the primary justification for performing a PD.

Advances in endoscopic techniques during the 1990s made stent placement in the bile duct to relieve biliary obstruction a routine procedure. This was followed by endoscopic stenting of malignant obstructions in the pyloric channel and duodenum.^{4,6,7,8,9} At the same time, percutaneous and endoscopic chemical splanchnicectomy and celiac plexus block were introduced in order to relieve pain and decrease the need for opioids.^{11,12,13} Combined, these 3 minimally invasive procedures have largely supplanted PD in providing palliative benefit, except in limited situations.⁴ Thus, indications and contraindications justifying PD have shifted from improving symptoms to improving survival.^{2,10,14,15,16}

Misnomers

Despite advances in surgery, neoadjuvant and adjuvant chemotherapy, and radiation therapy, survival after PD for periampullary malignancies remains dismal.⁵ Most of the uncertainty about PD for periampullary malignancies, particularly for pancreatic cancer, involves preoperative predictions about which patients are likely to experience long-term postsurgical survival (ie, 5 years or more).¹⁷ The only current justification for most PDs is the prospect of long-term survival, so the operation is performed by a surgeon with *curative* intention. If it becomes clear that the surgeon's intention was not realized, either because of residual microscopic or macroscopic disease found at the cut margin of the pancreas or actual cancer recurrence before the 5-year mark and often within the first 2 years after surgery, the operation is described post hoc as palliative.^{2,10,14,15,16} The term *palliative Whipple* therefore evolved as a post hoc description of a curative surgery for which the original curative purpose was unrealized.^{2,10,14,15,16}

Language

The language physicians use to communicate with patients is clinically and ethically relevant,¹⁸ so ambiguous language should be eliminated when describing the Whipple procedure or any other intervention. Confusion generated by linguistic ambiguity can undermine patients' self-determination and patients' and surrogates' decision making, informed consent, or informed refusal.

The word *curative* should be reserved for procedures for which the probable outcome is long-term postsurgical survival. Thus, use of the term *curative* to describe PD misses the mark for informed consent because it focuses on a surgeon's intention rather than the expected outcome.¹⁹ What is further misleading is that PD does not lead to long-term survival in over 95% of cases.¹⁷ The American College of Surgeons specifically stipulates that potential benefits of a proposed operation should not be "exaggerate[d]."²⁰ Describing PD as curative arguably violates this principle. *Cure* is also a value-laden term, particularly in cancer care, and patients often do not comprehend fully the details of their surgical informed consent.^{21,22} As such, imprecise use of the term can confuse patients about expected outcomes and undermine shared decision making.

Ad hoc use of the term *palliative Whipple* in the context of either unfavorable pathology or recurrence in less than 5 years is also misleading. Palliative surgery should be goaldirected with a reasonable expectation of symptom control.²³ While technically the operation may relieve biliary and gastroduodenal obstruction and potentially it might reduce pain, this is not the goal the patient and surgeon set out to achieve. The disconnect between goals and outcomes is particularly evident when preoperatively the patient is either asymptomatic or has had their symptoms effectively controlled endoscopically.²⁰ Even if the patient were symptomatic at the time of surgery, in most cases the patient's symptoms could have been effectively addressed either endoscopically or through a biliary or gastroduodenal bypass—procedures that are truly palliative—without requiring a PD.^{6,7,8,9} This is not to say that the term *palliative Whipple* is oxymoronic. There are instances, such as intractable bleeding, in which the only way to relieve a patient's symptoms is to perform a PD.¹⁴ In these instances, a PD is performed to achieve a reasonable goal, palliation, and the term *palliative Whipple* accurately describes the procedure.

In placing primacy on cure when describing PD, surgeons do not fully consider other benefits the operation is more likely to confer (ie, prolonged survival and improved quality of life). Using the term *curative* assumes the operation is all or nothing and that patients would refuse the operation if its benefit were limited to prolonged survival or improved quality of life. This narrow perspective unjustifiably presumes that patients would not value noncurative outcomes and ostensibly overlooks patient autonomy and patient-centered values and outcomes.^{22,24,25} Yet this criticism does not imply that surgeons act maliciously when communicating with patients or that surgeons should stop offering PD to eligible patients. Most surgeons performing PDs take seriously their duty to inform patients about risks and benefits but also value "optimistic honesty"²⁶ by focusing on the positive aspects of a planned PD to the exclusion of negative aspects.²⁶ While surgeons might intend to give a patient hope, this intention does not justify the use of inaccurate, ambiguous, and misleading terms. Truth and optimism need not be at odds.

In sum, I recommend abandoning the ambiguous terms *curative* and *palliative* to describe PD. Patients should be informed of predictable outcomes and realistic goals of PD. In personalized medicine, clinical and multiomic tumor data can aid surgeons in more accurately predicting the benefits that PD might offer individual patients,^{27,28} which they can then communicate to patients and use to facilitate informed decision making about PD based on outcomes rather than intentions. Surgeons who alter the language they use to inform patients during consent discussions might not influence poor prognoses for patients with periampullary malignancies, but they will likely improve honest communication, more fully informed consent, and patient-centered care.

References

- 1. Child CG III, Hinerman DL, Kauffman GL Jr. Pancreaticoduodenectomy. Surg Gynecol Obstet. 1978;147(4):529-533.
- 2. Wang SE, Shyr YM, Su CH, Chen TH, Wu CW. Palliative pancreaticoduodenectomy in pancreatic and periampullary adenocarcinomas. *Pancreas*. 2012;41(6):882-887.
- 3. Maire F, Sauvanet A. Palliation of biliary and duodenal obstruction in patients with unresectable pancreatic cancer: endoscopy or surgery? *J Visc Surg.* 2013;150(3)(suppl):S27-S31.
- 4. Perone JA, Riall TS, Olino K. Palliative care for pancreatic and periampullary cancer. *Surg Clin North Am.* 2016;96(6):1415-1430.
- 5. Kamarajah SK. Pancreaticoduodenectomy for periampullary tumours: a review article based on Surveillance, End Results and Epidemiology (SEER) database. *Clin Transl Oncol.* 2018;20(9):1153-1160.
- 6. Kneuertz PJ, Cunningham SC, Cameron JL, et al. Palliative surgical management of patients with unresectable pancreatic adenocarcinoma: trends and lessons learned from a large, single institution experience. *J Gastrointest Surg*. 2011;15(11):1917-1927.
- 7. Stark A, Hines OJ. Endoscopic and operative palliation strategies for pancreatic ductal adenocarcinoma. *Semin Oncol.* 2015;42(1):163-176.
- 8. Crippa S, Domínguez I, Rodríguez JR, et al. Quality of life in pancreatic cancer: analysis by stage and treatment. *J Gastrointest Surg*. 2008;12(5):783-793.
- 9. Nakakura EK, Warren RS. Palliative care for patients with advanced pancreatic and biliary cancers. *Surg Oncol.* 2007;16(4):293-297.
- 10. Lillemoe KD, Cameron JL, Yeo CJ, et al. Pancreaticoduodenectomy. Does it have a role in the palliation of pancreatic cancer? *Ann Surg.* 1996;223(6):718-725.
- 11. Lillemoe KD, Cameron JL, Kaufman HS, Yeo CJ, Pitt HA, Sauter PK. Chemical splanchnicectomy in patients with unresectable pancreatic cancer. A prospective randomized trial. *Ann Surg.* 1993;217(5):447-455.
- 12. Wong GY, Schroeder DR, Carns PE, et al. Effect of neurolytic celiac plexus block on pain relief, quality of life, and survival in patients with unresectable pancreatic cancer: a randomized controlled trial. *JAMA*. 2004;291(9):1092-1099.
- 13. Puli SR, Reddy JB, Bechtold ML, Antillon MR, Brugge WR. EUS-guided celiac plexus neurolysis for pain due to chronic pancreatitis or pancreatic cancer pain: a meta-analysis and systematic review. *Dig Dis Sci*. 2009;54(11):2330-2337.
- 14. Gouma DJ, Nieveen van Dijkum EJ, van Geenen RC, van Gulik TM, Obertop H. Are there indications for palliative resection in pancreatic cancer? *World J Surg.* 1999;23(9):954-959.
- 15. Kuhlmann K, de Castro S, van Heek T, et al. Microscopically incomplete resection offers acceptable palliation in pancreatic cancer. *Surgery*. 2006;139(2):188-196.
- 16. Schniewind B, Bestmann B, Kurdow R, et al. Bypass surgery versus palliative pancreaticoduodenectomy in patients with advanced ductal adenocarcinoma of the pancreatic head, with an emphasis on quality of life analyses. *Ann Surg Oncol.* 2006;13(11):1403-1411.
- 17. Kardosh A, Lichtensztajn DY, Gubens MA, Kunz PL, Fisher GA, Clarke CA. Longterm survivors of pancreatic cancer: a California population-based study. *Pancreas*. 2018;47(8):958-966.
- 18. Luks AM, Goldberger ZD. Watch your language!—misusage and neologisms in clinical communication. *JAMA Intern Med*. 2021;181(1):5-6.

- 19. Hofmann B, Håheim LL, Søreide JA. Ethics of palliative surgery in patients with cancer. *Br J Surg*. 2005;92(7):802-809.
- 20. Statements on principles. American College of Surgeons. September 2016. Accessed November 27, 2020. https://www.facs.org/About-ACS/Statements/stonprin
- 21. Cocanour CS. Informed consent—it's more than a signature on a piece of paper. *Am J Surg.* 2017;214(6):993-997.
- 22. Cooper Z, Courtwright A, Karlage A, Gawande A, Block S. Pitfalls in communication that lead to nonbeneficial emergency surgery in elderly patients with serious illness: description of the problem and elements of a solution. *Ann Surg.* 2014;260(6):949-957.
- 23. Cohen JT, Miner TJ. Patient selection in palliative surgery: defining value. *J Surg Oncol*. 2019;120(1):35-44.
- 24. Kruser JM, Nabozny MJ, Steffens NM, et al. "Best Case/Worst Case": qualitative evaluation of a novel communication tool for difficult in-the-moment surgical decisions. *J Am Geriatr Soc*. 2015;63(9):1805-1811.
- 25. Lilley EJ, Cooper Z, Schwarze ML, Mosenthal AC. Palliative care in surgery: defining the research priorities. *Ann Surg.* 2018;267(1):66-72.
- 26. Blakely K, Karanicolas PJ, Wright FC, Gotlib Conn L. Optimistic honesty: understanding surgeon and patient perspectives on hopeful communication in pancreatic cancer care. *HPB (Oxford)*. 2017;19(7):611-619.
- 27. Truty MJ, Kendrick ML, Nagorney DM, et al. Factors predicting response, perioperative outcomes, and survival following total neoadjuvant therapy for borderline/locally advanced pancreatic cancer. *Ann Surg.* 2021;273(2):341-349.
- 28. Turanli B, Yildirim E, Gulfidan G, Arga KY, Sinha R. Current state of "omics" biomarkers in pancreatic cancer. *J Pers Med*. 2021;11(2):127.

Charles E. Binkley, MD is the director of bioethics at the Markkula Center for Applied Ethics at Santa Clara University in California, where he leads the Health Care Ethics Internship. He is a surgeon whose research interests include surgical ethics and the just application of technology particularly clinical decision support systems, in health care.

Citation

AMA J Ethics. 2021;23(10):E794-799.

DOI

10.1001/amajethics.2021.794.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E800-805

MEDICAL EDUCATION: PEER-REVIEWED ARTICLE Teaching Palliative Care in Surgical Education

Jessica H. Ballou, MD, MPH and Karen J. Brasel, MD, MPH

Abstract

Without training in how to identify and relieve pain and suffering, surgeons miss opportunities to offer palliative services to patients. Despite explicit calls for expanding palliative care education since the 1990s, palliative care training in surgical curricula is often limited to end-of-life discussions. A growing consensus among palliative care experts suggests that formal palliative care education during surgical training should include structured communication and prognostication tools, strategies for symptom management, and an understanding of palliative care specialists' role in treating patients at all disease stages.

The physician should not treat the disease but the patient who is suffering from it. **Moses Maimonides**, *Treatise on Asthma*

Stop Avoiding Difficult Conversations

Surgical palliative care refers to efforts "to relieve physical pain and psychological, social, and spiritual suffering while supporting the patient's treatment goals and respecting the patient's racial, ethnic, religious, and cultural values."¹ Surgeons have practiced palliative care for patients for centuries. Coronary bypass, for example, relieved chest pain before physicians fully understood its life-sustaining role.² Although the relief of suffering has motivated surgical developments and innovations, clinicians' ability to communicate palliative intent to their patients has not always been a priority in US medical and surgical education. A study of Chicago physicians in the 1960s found that nearly 90% of clinicians surveyed preferred not to disclose a cancer diagnosis for fear that the information would have "disturbing psychological effects."³ Because clinicians did not acknowledge the reality of death in terminal cases, patients and their families were unable to receive the support they needed. To confront this history of avoidance and integrate palliative care appropriately into surgical practice, the American College of Surgeons released its 2005 Statement of Principles of Palliative Care,¹ which states: "the tradition and heritage of surgery emphasize that the control of suffering is of equal importance to the cure of disease [italics added]." Training to help clinicians identify and meet their patients' palliative needs at all stages of disease must be robustly integrated into a system that has too long avoided or minimized them.

Curriculum Development

The Accreditation Council for Graduate Medical Education (ACGME) and the Surgical Council on Resident Education (SCORE) have included palliative care material and educational requirements in residency training since the early 2000s.⁴ These requirements aim to address needs of patients at all stages of disease, not just at the end of life. 2020 ACGME requirements state: "residents must learn to communicate with patients and families to partner with them to assess their care goals, including, when appropriate, end-of-life goals."⁵ Similarly, the 2020 SCORE autodidactic module on Geriatric Surgery and End of Life Care broadens palliative care to include (1) advance directives and do-not-resuscitate and power of attorney orders, (2) frailty, (3) goal setting with elderly patients and families, (4) palliative and hospice care, and (5) perioperative management of geriatric patients.⁶ The American College of Surgeons also produced a workbook for surgical residents,⁷ and hospice and palliative care is now a recognized subspecialty of the American Board of Surgery.⁸

These initiatives aimed to create a common educational foundation, but their adoption has been inconsistent and has left many surgical trainees ill-prepared to palliate symptoms of advanced illnesses.⁹ Some institutions limit palliative care training to self-instructed or classroom-based curricula, while others have dedicated multidisciplinary palliative care rotations.¹⁰ Barriers to implementation vary but are likely limited by institutional expertise, absence of interdisciplinary partnerships, and the misperception that palliative care is limited to the end of life.¹¹ As a result, data on palliative care training's efficacy tend to derive from single-site studies.¹² Nonetheless, even one multisite survey of surgery residents and faculty demonstrates a need for education that is specific, practical, and appropriate because "while many residents felt that they had appropriate clinical exposure to palliative care principles, over half of the residents felt that their education had not been appropriate for their level of training."¹³ Training in communicating outcomes and prognoses, symptom management, and consultation prepare clinicians to identify and address a patient's palliative needs.

Communicating Outcomes and Prognosis

Clinicians who are unable or unwilling to discuss potential outcomes with patients or families might unwittingly practice medicine incongruently with patients' care goals.¹⁴ Incongruence results in unwanted procedures and generates emotional and psychological trauma. A classic example is a frail elder who requires emergent surgical intervention. While a procedure is technically possible, operating presents a high likelihood of prolonged intubation, intensive care, rehabilitation, or death. Focus groups of elders facing these scenarios reveal that maintaining independence and quality of life are paramount values in their decision making.¹⁵

Although it is impossible to predict a patient's course exactly, clinician experience and prognostic tools, such as the American College of Surgeons' NSQIP Surgical Risk Calculator, can help facilitate potential outcome discussions.¹⁶ Regardless of prognostic data availability, how clinicians communicate outcomes matters. For example, in one study, patients presented with a choice between "life or death" often agreed with aggressive treatments, even if the most likely outcome was severe disability or death.¹⁵ Nevertheless, many patients asserted that quality of life should inform medical decision making for elderly patients.¹⁵ Eliciting goals of care and communicating potential outcomes can be especially challenging in situations in which there is no preexisting therapeutic relationship between a patient and surgeon. In these circumstances, best-and worst-case scenario planning offers a framework for high-stakes discussion and

decision making.¹⁷ Applying this framework helps clinicians identify and uphold patient and caregiver goals of care, but it requires practice, empathy, patience, and time.

One option to address surgeon time constraints is to include surgical palliative care in clinic settings where there can be more interaction, engagement, and discussion. However, outpatient palliative discussions are rare in surgical training.¹³ Incorporating palliative care into the clinic has its own obstacles (eg, financial compensation, resource allocation, and clinicians' willingness to engage), which can cause clinicians to bypass palliative needs altogether or directly refer patients to palliative care specialists. Recently, however, initiatives such as sending patients palliative care-based questions prior to their clinic visits have been shown to increase the number of questions patients ask their surgeon during the consultation.¹⁸

Current data on training residents in communication skills suggest that passive written or oral presentations are valuable in supporting in-person role-playing, feedback, and small-group discussion.¹⁰ When part of a palliative care curriculum, rotations with a palliative care team or on services with a high demand for palliative care—such as intensive care units, trauma, or surgical oncology—allow for case-based practice. Currently, however, palliative care-specific rotations are neither mandated nor universally offered in surgical training programs.

Symptom Management

According to *Surgical Palliative Care: A Resident's Guide*, comprehensive palliative care education means cultivating comfort in managing common distressing physical and psychological symptoms (eg, pain, dyspnea, delirium, depression, nausea, and constipation).⁷ Surgical trainees should also be familiar with fatigue and with inadequate oral nutrition intake and the role of artificial nutrition in its rectification. Although workbooks and other initiatives can improve clinician familiarity with these symptoms and conditions, there is little consensus about how to incorporate lessons into clinical practice.^{10,12}

In addition to medical and pharmaceutical interventions for symptom management, surgical palliative care training should include procedures that relieve symptoms, minimize distress, and improve quality of life. Surgeons play central roles in interdisciplinary approaches to advanced illness by broadening palliative options available to patients. From removing painful spinal metastases to bypassing an obstructive intestinal tumor, surgeons can alleviate suffering in persons with advanced illnesses.^{19,20,21}

Surgical residency should also include training in palliative procedures done with intent to relieve symptoms, minimize patient distress, and improve quality of life.²² A 2002 survey of surgical oncologists noted that patient reluctance to undergo a procedure, health insurance limitations, and lack of referrals from nonsurgical clinicians were key barriers to surgeons offering procedures.²³ Additionally, depending on patient selection, palliative procedures can have high complication rates that might deter some surgeons from including them in their practice.²² Measuring surgical procedural success in terms of symptom relief and defining which patients benefit from specific interventions remain research priorities.²⁴

When to Consult a Specialist

Because specialty palliative care involves learning to manage refractory symptoms and to coordinate complex care demands, distinguishing between primary and specialty palliative care is essential. First, this distinction acknowledges that there are not enough palliative care specialists to address all surgical patients' unmet needs for palliative care. Second, surgeons are less likely than other clinicians to refer patients to palliative care specialists, even though many patients would likely benefit.^{24,25} Surgeons' reasons for waiting too long to integrate palliative care or not integrating palliative care at all range from a surgical rescue culture—inspired by the apparent desire to do everything possible to maintain biological life—to concerns about error and responsibility.²⁴ When a surgeon's goal should transition from cure to palliation is a source of reasonable disagreement among reasonable clinicians, but, in all cases, a surgeon's ability to communicate prognoses and palliative options, manage symptoms, and identify and meet patients' palliative needs can significantly influence patients' lives and the quality of their care.

References

- 1. Task Force on Surgical Palliative Care; Committee on Ethics. Statement of principles of palliative care. *Bull Am Coll Surg*. 2005;90(8):34-35.
- 2. Melly L, Torregrossa G, Lee T, Jansens JL, Puskas JD. Fifty years of coronary artery bypass grafting. *J Thorac Dis.* 2018;10(3):1960-1967.
- 3. Oken D. What to tell cancer patients. A study of medical attitudes. *JAMA*. 1961;175:1120-1128.
- 4. Mosenthal AC, Weissman DE, Curtis JR, et al. Integrating palliative care in the surgical and trauma intensive care unit: a report from the Improving Palliative Care in the Intensive Care Unit (IPAL-ICU) Project Advisory Board and the Center to Advance Palliative Care. *Crit Care Med*. 2012;40(4):1199-1206.
- 5. Accreditation Council for Graduate Medical Education. ACGME common program requirements (residency). Updated 2020. Accessed Nov 2, 2020. https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/CPRReside ncy2020.pdf
- 6. Surgical Council on Resident Education. Curriculum outline for general surgery, 2020-2021. Accessed November 20, 2020. http://files.surgicalcore.org/2020-2021_GS_CO_Booklet_v3editsfinal.pdf
- Dunn GP, Martensen R, Weissman D. Surgical Palliative Care: A Resident's Guide. American College of Surgeons; 2009. Accessed July 6, 2021. https://www.facs.org/~/media/files/education/palliativecare/surgicalpalliativec areresidents.ashx
- 8. Definitions of ABS specialties. American Board of Surgery. Accessed March 20, 2021. https://www.absurgery.org/default.jsp?public_definitions
- 9. Wancata LM, Hinshaw DB, Suwanabol PA. Palliative care and surgical training: are we being trained to be unprepared? *Ann Surg.* 2017;265(1):32-33.
- 10. Kapadia MR, Lee E, Healy H, Dort JM, Rosenbaum ME, Newcomb AB. Training surgical residents to communicate with their patients: a scoping review of the literature. *J Surg Educ*. 2021;78(2):440-449.
- 11. Aldridge MD, Hasselaar J, Garralda E, et al. Education, implementation, and policy barriers to greater integration of palliative care: a literature review. *Palliat Med*. 2016;30(3):224-239.
- 12. Bakke KE, Miranda SP, Castillo-Angeles M, et al. Training surgeons and anesthesiologists to facilitate end-of-life conversations with patients and

families: a systematic review of existing educational models. *J Surg Educ*. 2018;75(3):702-721.

- 13. Bonanno AM, Kiraly LN, Siegel TR, Brasel KJ, Cook MR. Surgical palliative care training in general surgery residency: an educational needs assessment. *Am J Surg.* 2019;217(5):928-931.
- 14. Cooper Z, Courtwright A, Karlage A, Gawande A, Block S. Pitfalls in communication that lead to nonbeneficial emergency surgery in elderly patients with serious illness: description of the problem and elements of a solution. *Ann Surg.* 2014;260(6):949-957.
- 15. Nabozny MJ, Kruser JM, Steffens NM, et al. Constructing high-stakes surgical decisions: it's better to die trying. *Ann Surg.* 2016;263(1):64-70.
- 16. Surgical Risk Calculator. National Surgical Quality Improvement Program, American College of Surgeons. Accessed March 20, 2021. https://riskcalculator.facs.org/RiskCalculator/
- 17. Kruser JM, Taylor LJ, Campbell TC, et al. "Best Case/Worst Case": training surgeons to use a novel communication tool for high-risk acute surgical problems. *J Pain Symptom Manage*. 2017;53(4):711-719.e5.
- 18. Schwarze ML, Buffington A, Tucholka JL, et al. Effectiveness of a question prompt list intervention for older patients considering major surgery: a multisite randomized clinical trial. *JAMA Surg.* 2019;155(1):6-13.
- 19. Hirabayashi H, Ebara S, Kinoshita T, et al. Clinical outcome and survival after palliative surgery for spinal metastases: palliative surgery in spinal metastases. *Cancer*. 2003;97(2):476-484.
- 20. Paul Olson TJ, Pinkerton C, Brasel KJ, Schwarze ML. Palliative surgery for malignant bowel obstruction from carcinomatosis: a systematic review. *JAMA Surg*. 2014;149(4):383-392.
- 21. Roland NJ, Bradley PJ. The role of surgery in the palliation of head and neck cancer. *Curr Opin Otolaryngol Head Neck Surg*. 2014;22(2):101-108.
- 22. Miner TJ, Cohen J, Charpentier K, McPhillips J, Marvell L, Cioffi WG. The palliative triangle: improved patient selection and outcomes associated with palliative operations. *Arch Surg.* 2011;146(5):517-522.
- 23. McCahill LE, Krouse RS, Chu DZ, et al. Decision making in palliative surgery. J Am Coll Surg. 2002;195(3):411-413.
- 24. Lilley EJ, Cooper Z, Schwarze ML, Mosenthal AC. Palliative care in surgery: defining the research priorities. *Ann Surg*. 2018;267(1):66-72.
- 25. Bateni SB, Canter RJ, Meyers FJ, Galante JM, Bold RJ. Palliative care training and decision-making for patients with advanced cancer: a comparison of surgeons and medical physicians. *Surgery*. 2018;164(1):77-85.

Jessica H. Ballou, MD, MPH is completing advanced training in plastic surgery at Johns Hopkins University in Baltimore, Maryland, and previously completed general surgery residency at Oregon Health and Science University.

Karen J. Brasel, MD, MPH is a professor in the Division of Trauma, Critical Care and Acute Care Surgery at Oregon Health and Science University in Portland, where she also serves as the general surgery program director as well as the assistant dean for graduate medical education.

Citation

AMA J Ethics. 2021;23(10):E800-805.

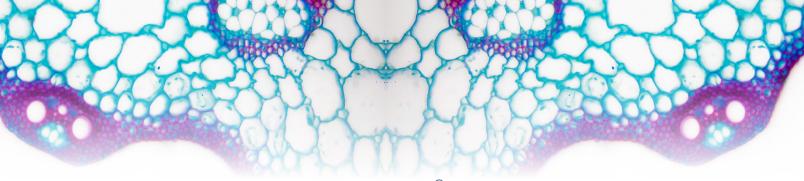
DOI 10.1001/amajethics.2021.800.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980



AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E806-810

IN THE LITERATURE: PEER-REVIEWED ARTICLE Which Priorities Should Guide Palliative Surgical Research?

Zara Cooper, MD, MSc and Christy Cauley, MD

Abstract

Research priorities in surgical palliative care should go beyond generating data from traditional surgical morbidity or mortality metrics. Surgical researchers can seek to better understand care management complexities of surgical patients with serious illnesses in order to gather high-quality, patient-centered data; improve surgical patients' experiences; and motivate surgical palliative care as a field.

Higher Risk for latrogenic Harm

More than 1 million patients with serious illnesses (ie, illnesses that are time limiting, negatively influence quality of life, and involve interventions that are burdensome to patients and families¹) undergo major surgery annually.² It is widely known that palliative care—focused on relieving pain, managing distressing symptoms, and improving quality of life^{3,4,5,}—reduces health care costs⁶ and promotes better patient-physician communication.⁷ Yet seriously ill surgical patients are less likely than other seriously ill patients to receive palliative care.⁸ Two reasons for this disparity are a rescue-based cultural bias in surgery⁹ and an inability to accurately measure surgical palliative care quality solely with traditional surgical metrics (eg, morbidity and mortality). We argue here that failure to incorporate measures of seriously ill patients' experiences¹⁰ undermines care that accords patients' goals and exacerbates iatrogenic harm to patients.

Palliative Surgical Research

Measuring palliative surgical quality is complex. Surgical patients with serious illness often have competing conditions and priorities, making appropriate research outcomes difficult to identify.⁷ Patients with serious illness often prioritize health recovery outcomes (eg, time at home, relationships with loved ones)¹¹ and are unable or unwilling to participate in research. Consequently, surgical palliative care research has used proxy outcome measures to capture key features of patients' experiences when direct patient report is unavailable. For example, in a national study of Medicare beneficiaries with advanced cancer, patients' end-of-life care intensity and quality was measured by health care utilization.¹² Older patients who received a venting gastrostomy during their first hospital admission for a malignant bowel obstruction had fewer readmissions, less intensive unit care during their last 30 days of life, and greater hospice enrollment prior to death than patients receiving medical management.¹²

Data sources and analysis. Currently, national and quality program (eg, Medicare and the American College of Surgeons National Surgical Quality Improvement Program) data sets do not classify procedures based on surgeons' intentions, which greatly limits researchers' capacity to evaluate palliative surgery efficacy. Documenting surgeons' intentions (eg, as curative or palliative) in patients' health records provides critical data about surgical decision making and a procedure's purpose so that appropriate metrics can be used to measure surgical performance, procedural success, and quality outcomes. Collecting longitudinal data about procedures having a palliative purpose from data registries and billing codes and then measuring associations between procedures and outcomes from patients' perspectives (eg, symptom alleviation, pain relief, postoperative quality of life^{13,14}) and from clinical viewpoints (eg, infection, death, prolonged hospitalization) would provide robust assessments of procedures' quality and value to stakeholders.

Patient-centered priorities. Outcomes that express whether and to what extent patients' postoperative experiences accord with their values (eg, symptom alleviation, pain relief, postoperative quality of life, time at home, relationships with loved ones) must be prioritized in palliative surgical research. In one such study of 106 patients with advanced incurable cancer who underwent palliative surgery (ie, to control gastrointestinal obstruction, tumor-related symptoms, and jaundice), 90.7% reported symptom resolution or improvement.² Another study of surgical patients with gynecologic malignancy found that 6 months of postoperative palliative care from advanced practice nurses resulted in patients experiencing less distress and better guality of life.¹⁵ Other metrics of guality outcomes from patients' perspective include improvements in physical and psychological outcomes, functional independence, disability-free survival, social well-being, and numbers of days at home.^{13,16,17} For example, patients with symptomatic incurable cancer who received home-based postoperative palliative support had 5.5 more days at home in the last 2 months of their lives.¹⁸ Other researchers have evaluated guality in terms of patients' postoperative recovery (eg, duration of postoperative mechanical ventilation, intensive care unit stay, and inpatient status in the last 6 months of their lives).¹⁹

Communication. Communication between surgeons and patients with serious illness should be regarded as a palliative surgery quality research priority,¹⁰ since linguistic and cultural differences between patients and clinicians can influence patients' experiences.²⁰ Clinicians' clear communication about patients' prognosis, underlying illness, and changes in health states is foundational to establishing and nourishing relationships, disclosing possible benefits and risks, promoting patients' or surrogates' informed consent to or informed refusal of procedures, and affirming clinicians' ongoing support of patients and their loved ones.^{21,22} Communication is just one feature of surgeons', patients', or surrogates' understanding²³ that inform shared decision making about palliative surgical interventions. Little is known, for example, about how surgical patients with serious illnesses evaluate trade-offs (eg, between quality of life and survival duration). An abundance of literature evaluates improving communication interactions and improving documentation about advanced care planning,^{24,25,26} but patients' or surrogates' family perceptions about communication quality have been neglected.

The American College of Surgeons Geriatric Surgery Verification Quality Improvement Program to improve elders' surgical care requires that preoperative documentation include a patient's quotation about their overall health goals and goals of surgery and a surgeon's description of how a surgical care plan is informed by the quoted goals.²⁷ Measuring adherence to this practice standard will help assess perioperative communication and palliative surgical quality and help motivate goal-concordant care.

References

- 1. Kelley AS. Defining "serious illness." J Palliat Med. 2014;17(9):985-985.
- 2. Kelly MT, Sturgeon D, Harlow AF, Jarman M, Weissman JS, Cooper Z. Using Medicare data to identify serious illness in older surgical patients. *J Pain Symptom Manage*. 2020;60(2):e101-e103.
- 3. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-742.
- 4. Rummans TA, Clark MM, Sloan JA, et al. Impacting quality of life for patients with advanced cancer with a structured multidisciplinary intervention: a randomized controlled trial. *J Clin Oncol*. 2006;24(4):635-642.
- 5. Morrison RS, Penrod JD, Cassel JB, et al; Palliative Care Leadership Centers' Outcomes Group. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168(16):1783-1790.
- 6. Morrison RS, Dietrich J, Ladwig S, et al. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff (Millwood)*. 2011;30(3):454-463.
- 7. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press; 2015.
- 8. Olmsted CL, Johnson AM, Kaboli P, Cullen J, Vaughan-Sarrazin MS. Use of palliative care and hospice among surgical and medical specialties in the Veterans Health Administration. *JAMA Surg*. 2014;149(11):1169-1175.
- 9. Mehtsun WT, Zheng J, Orav EJ, Lillemoe KD, Jha AK. Unintended consequences of the 30-day mortality metric: fact or fiction. *Ann Surg.* 2017;266(6):962-967.
- 10. Sanders JJ, Curtis JR, Tulsky JA. Achieving goal-concordant care: a conceptual model and approach to measuring serious illness communication and its impact. *J Palliat Med*. 2018;21(suppl 2):S17-S27.
- 11. Cooper Z, Courtwright A, Karlage A, Gawande A, Block S. Pitfalls in communication that lead to nonbeneficial emergency surgery in elderly patients with serious illness: description of the problem and elements of a solution. *Ann Surg*. 2014;260(6):949-957.
- 12. Lilley EJ, Scott JW, Goldberg JE, et al. Survival, healthcare utilization, and end-oflife care among older adults with malignancy-associated bowel obstruction: comparative study of surgery, venting gastrostomy, or medical management. *Ann Surg.* 2018;267(4):692-699.
- 13. Myles PS, Shulman MA, Heritier S, et al. Validation of days at home as an outcome measure after surgery: a prospective cohort study in Australia. *BMJ Open*. 2017;7(8):e015828.
- Schwarze ML, Brasel KJ, Mosenthal AC. Beyond 30-day mortality: aligning surgical quality with outcomes that patients value. *JAMA Surg.* 2014;149(7):631-632.
- 15. McCorkle R, Dowd M, Ercolano E, et al. Effects of a nursing intervention on quality of life outcomes in post-surgical women with gynecological cancers. *Psychooncology*. 2009;18(1):62-70.
- 16. Lilley EJ, Cooper Z, Schwarze ML, Mosenthal AC. Palliative care in surgery: defining the research priorities. *Ann Surg.* 2018;267(1):66-72.
- 17. Chesney TR, Haas B, Coburn NG, et al; Recovery After Surgical Therapy for Older Adults Research–Cancer (RESTORE-Cancer) Group. Patient-centered time-at-

home outcomes in older adults after surgical cancer treatment. *JAMA Surg.* 2020;155(11):e203754.

- 18. Axelsson B, Christensen SB. Evaluation of a hospital-based palliative support service with particular regard to financial outcome measures. *Palliat Med*. 1998;12(1):41-49.
- 19. Nabozny MJ, Barnato AE, Rathouz PJ, et al. Trajectories and prognosis of older patients who have prolonged mechanical ventilation after high-risk surgery. *Crit Care Med*. 2016;44(6):1091-1097.
- 20. Sanders JJ, Berrier AI, Nshuti L, Tulsky JA, Lindvall C. Differences by race, religiosity, and mental health in preferences for life-prolonging treatment among Medicare beneficiaries. *J Gen Intern Med*. 2019;34(10):1981-1983.
- 21. Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol*. 2007;25(36):5748-5752.
- 22. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014;174(12):1994-2003.
- 23. Nabozny MJ, Kruser JM, Steffens NM, et al. Constructing high-stakes surgical decisions: it's better to die trying. *Ann Surg.* 2016;263(1):64-70.
- 24. Lamba S, Murphy P, McVicker S, Harris Smith J, Mosenthal AC. Changing end-oflife care practice for liver transplant service patients: structured palliative care intervention in the surgical intensive care unit. *J Pain Symptom Manage*. 2012;44(4):508-519.
- 25. Mosenthal AC, Murphy PA, Barker LK, Lavery R, Retano A, Livingston DH. Changing the culture around end-of-life care in the trauma intensive care unit. *J Trauma*. 2008;64(6):1587-1593.
- 26. Udelsman BV, Lilley EJ, Qadan M, et al. Deficits in the palliative care process measures in patients with advanced pancreatic cancer undergoing operative and invasive nonoperative palliative procedures. *Ann Surg Oncol.* 2019;26(13):4204-4212.
- 27. Geriatric Surgery Verification Quality Improvement Program. Optimal Resources for Geriatric Surgery: 2019 Standards. American College of Surgeons; 2019. Accessed July 31, 2021. https://www.facs.org/-/media/files/qualityprograms/geriatric/geriatricsv_standards.ashx

Zara Cooper, MD, MSc is an associate professor of surgery at Harvard Medical School in Boston, Massachusetts. She is also a trauma critical care surgeon, the Kessler Director for the Center for Surgery and Public Health, and the director of the Center for Geriatric Surgery at Brigham and Women's Hospital. Her research focuses on the intersection of surgery, palliative care, and geriatrics with the intent to integrate palliative and geriatric processes into routine surgical care to improve surgical outcomes for seriously ill patients and their families.

Christy Cauley, MD is an assistant professor of surgery at Harvard Medical School in Boston, Massachusetts. She is also a colon and rectal surgeon at Massachusetts General Hospital and a researcher at Ariadne Labs. Her research focuses on patientcentered outcomes assessment to inform surgical shared decision making in patients with serious illness.

Citation

AMA J Ethics. 2021;23(10):E806-810.

DOI

10.1001/amajethics.2021.806.

Acknowledgements

Dr Cooper is supported by the American Federation for Aging Research and a Paul B. Beeson Leadership Award K76AG054859.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E811-813

AMA CODE SAYS

AMA *Code of Medical Ethics*' Opinions Related to Palliative Surgical Care Shreya Budhiraja

Abstract

The AMA Code of Medical Ethics offers guidance on the significance of palliative surgical care in Opinion 5.6, "Sedation to Unconsciousness in End-of-Life Care," and Opinion 5.5, "Medically Ineffective Interventions." The American Medical Association's House of Delegates policies further outline ways in which physicians should navigate palliative care intervention through spreading awareness of and advancing research on palliative care and improving reimbursement practices. This article defines *palliative care*, examines the risks associated with palliative surgery, and discusses AMA Code guidance.

Introduction

Roughly 12.5% of all surgeries are palliative.¹ Palliative surgery aims to alleviate psychological, physical, emotional, and spiritual suffering of patients. Palliative surgical risks illuminate the importance of ethical questions about the nature and scope of palliation's role in a care plan and how to balance respect for patient autonomy and physicians' duties to uphold the principles of beneficence and nonmaleficence. American Medical Association (AMA) *Code of Medical Ethics*' opinions recognize the significance of palliative care. AMA House policies, which support AMA opinions, also describe physicians' role in motivating palliative approaches to practice.

Defining Palliative Care

Ideally, patients, their loved ones, and clinicians share understandings of what palliative care means. To be clear, noncurative surgical interventions aim to prevent symptoms in asymptomatic patients (eg, preventive mastectomy); palliative surgery aims not to cure but to relieve symptoms in symptomatic patients. Palliation can occur alongside recovery and is not just reserved for patients at the end of life.

End-of-Life Palliative Care

The AMA Code recognizes death as a risk of palliative surgery, especially in patients with late-stage cancer. Opinion 5.6, "Sedation to Unconsciousness in End-of-Life Care," states that a "duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients."² The AMA Code also emphasizes a physician's duty to "balance obligations to respect patient autonomy and

not to abandon the patient with obligations to be compassionate, yet candid, and to preserve the integrity of medical judgment" when dealing with palliative care requests.³ In the case of palliation, it is important to note that a palliative intervention is not futile, as the "meaning of the term 'futile' depends on the values and goals of a particular patient in specific clinical circumstances."³

Roles of Physicians

The AMA House of Delegates "support[s] efforts to clarify coding guidance or development of codes to capture 'comfort care,' 'end-of-life care,' and 'hospice care'" in house policy H-70.915, "Good Palliative Care."⁴ House policy H-70.915 also recognizes some clinicians' lack of awareness of palliative care in encouraging clinician education programs. One study found that some surgeons believe palliative care is "irrelevant to quality of life or symptom relief."⁵ Such bias might reflect inadequate training, as one study, for example, noted that 76.1% of colorectal surgeons received no formal training in palliative care in *all* clinical specialties, stating that "all physicians [should] become skilled in palliative medicine" and encouraging "education programs for all appropriate health care professionals, and the public."⁴ The AMA *Code* further supports "consult[ing] with a multi-disciplinary team (if available), including an expert in the field of palliative care, to ensure that symptom-specific interventions have been sufficiently employed."²

Palliative Practice

The AMA *Code* guidance on informed consent to palliative surgery suggests the importance of making patients aware of consequences of inappropriate treatment. Opinion 5.5, "Medically Ineffective Interventions," urges physicians to "discuss with the patient the individual's goals for care, including desired quality of life, and seek to clarify misunderstandings."³ The AMA *Code* also recommends including a patient's surrogate in conversations "even when the patient retains decision-making capacity" in case the patient loses capacity.³

AMA House of Delegates policies also encourage "research in the field of palliative medicine to improve treatment of unpleasant symptoms that affect quality of life for patients" and "research into the needs of dying patients and how the care system could better serve them."⁴ One example could be "examining the degree to which palliative care reduces the requests for euthanasia or assisted suicide."⁷ With research shedding light on how palliation can be "integrated into the overall provision of care and services,"⁸ House policy H-140.966, "Decisions Near the End of Life," endorses efforts to improve palliative practice.⁷ House policy H-70.915 also urges more palliative care reimbursement, promotes "coordination and continuity of care, 'maintenance' level services, counseling for patient and family, use of multidisciplinary teams, and effective palliation of symptoms."⁴ The policy looks to extend reimbursement for physicians' "prolonged time spent on patients' care outside of the face-to-face encounter in nonhospital settings."⁴

Physical, emotional, psychological, and spiritual benefits of palliative care are recognized in both AMA *Code of Medical Ethics*' opinions and AMA House of Delegates policies that can be used to guide physicians' incorporation of palliative care into their practices.

References

- 1. Krouse RS, Nelson RA, Farrell BR, et al. Surgical palliation at a cancer center: incidence and outcomes. *Arch Surg.* 2001;136(7):773-778.
- 2. American Medical Association. Opinion 5.6 Sedation to unconsciousness in endof-life care. Code of Medical Ethics. Accessed December 8, 2020. https://www.ama-assn.org/delivering-care/ethics/sedation-unconsciousnessend-life-care
- 3. American Medical Association. Opinion 5.5 Medically ineffective interventions. Code of Medical Ethics. Accessed December 8, 2020. https://www.amaassn.org/delivering-care/ethics/medically-ineffective-interventions
- American Medical Association. Good palliative care H-70.915. Accessed July 31, 2021. https://policysearch.amaassn.org/policyfinder/search/palliative%20care/relevant/1/
- 5. Suwanabol PA, Kanters AE, Reichstein AC, et al. Characterizing the role of US surgeons in the provision of palliative care: a systematic review and mixed-methods meta-synthesis. *J Pain Symptom Manage*. 2018;55(4):1196-1215.e5.
- 6. Suwanabol PA, Reichstein AC, Suzer-Gurtekin ZT, et al. Surgeons' perceived barriers to palliative and end-of-life care: a mixed methods study of a surgical society. *J Palliat Med*. 2018;21(6):780-788.
- American Medical Association. Decisions near the end of life H-140.966. Accessed December 8, 2020. https://policysearch.amaassn.org/policyfinder/detail/H-140.966%20Decisions%20Near%20the%20End%20of%20Life?uri=%2FAMADo c%2FH0D.xml-0-497.xml
- 8. National Academies of Sciences, Engineering, and Medicine. *Models and* Strategies to Integrate Palliative Care Principles Into Care for People With Serious Illness: Proceedings of a Workshop. National Academies Press; 2017.

Shreya Budhiraja was an intern for the American Medical Association Council on Ethical and Judicial Affairs in Chicago, Illinois, in the fall of 2020. A student at Northwestern University's Feinberg School of Medicine, she is in the Honors Program in Medical Education.

Citation

AMA J Ethics. 2021;23(10):E811-813.

DOI

10.1001/amajethics.2021.811.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E814-822

MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Where's the Value in Preoperative Covenants Between Surgeons and Patients?

Robert Ledbetter and Buddy Marterre, MD, MDiv

Abstract

Values, preferences, and goals all affect patient autonomy. Their meanings are often conflated, so this article clarifies them and also distinguishes between *hope* and *wish*. Ethical investigation of preoperative and postoperative clinician-family communication in surgical intensive care units is needed to help mitigate valueincongruent, nonbeneficial operations and postoperative treatments as clinical scenarios unfold.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit[™] available through the AMA Ed Hub[™]. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Communication as Covenant

Patients value having a sense of purpose, functional independence, meaningful interactions with family, spirituality, and avoiding burdening their loved ones.^{1,2,3,4,5} Surgeons are often more technique-oriented than people-oriented "fixers"^{6,7,8} who feel an intense sense of duty to their patients^{9,10} and strive for technical excellence.¹¹ Preoperative communication in high-risk surgical scenarios has been described as a kind of covenant,¹² with patients (and perhaps their loved ones) often assuming that a surgeon can fix any ailment and respond to complications^{13,14} and with surgeons assuming that patients agree to any postoperative surgical intensive care unit (SICU) interventions.^{5,15,16,17} This article considers how continuing to see patient-surgeon communication as a covenant requires deeper ethical investigation into both surgeons' and patients' assumptions and into sources of dissonance between surgeons' and patients' values and goals.

The Nature of the Covenant

In his memoir, *Do No Harm:* Stories of Life, Death, and Brain Surgery, British neurosurgeon Henry Marsh states: "informed consent' sounds so easy in principle—the surgeon explains the … risks and benefits, and the calm and rational patient decides what he or she wants—just like … choosing from the vast array of toothbrushes on offer." He continues: "The reality is very different. Patients are both terrified and ignorant … [and] will try to overcome their fear by investing the surgeon with superhuman abilities."¹⁸ Here Marsh contrasts evidence-based reasoning, which he attributes only to

surgeons, and a fear-based approach to decisions, which he attributes to patients. Marsh's characterization of surgeons as reasonable and patients as emotional might be too stark a contrast. Regardless, one ethical upshot is that, in most clinical encounters, information exchange in patient-surgeon communication is value laden on both sides and that the transformational potential of those values must be richly contextualized¹⁹ if informed consent is to be a process that expresses a surgeon's respect for a patient's autonomy²⁰ and through which the covenantal nature of patient-surgeon communication can be upheld.

Keeping the Covenant

The actual process of respecting patient autonomy is messier than clinicians would like,²⁰ devoid of neat risk calculations or tidy formulas for approaching clinician-patient communication,²¹ particularly when medical-surgical care pathway preferences are overshadowed by the enormous influence that existential fear has on human behavior and decision making.²² The high clinical and ethical stakes of postoperative SICU settings can intensify conscious and subconscious fears—of surgeons as well as families—regarding the implementation or foregoing of life-sustaining interventions and magnify the critical, life-or-death nature of these decisions.^{2,22} When patients' loved ones look to withdraw life-extending interventions, prioritize patients' comfort, or emphasize making their death as peaceful as possible, a surgeon might be reluctant to acquiesce.^{8,9,13,22} In such cases, it is critical for surgeons to clearly distinguish between their own and their particular patient's values, preferences, and goals.²³ The following working definitions can be helpful:

- Values can be understood as stable, fundamental meaning-based concepts (eg, ethical, aesthetic, spiritual) that have broad control over moral agents' (eg, surgeons', patients', patients' loved ones') motivations^{2,23} and actions.
- *Preferences* can be understood as informed by values and as expressing moral agents' inclinations to prioritize one circumstance-specific course of action over another.
- Goals can be understood as the objects, aims, or desired *results* that direct moral agents' preferred courses of action.² Importantly, some goals are feasible, others are not.

In informed consent and all perioperative communication for surgical and palliative care, clarifying the suffering that patients are willing to endure for the *possibility* of achieving their goals²⁴ is key to success, since many patients prefer their dying process not to be prolonged, especially if other values (ie, self-sufficiency, dignity, enjoyment, or comfort) are compromised.^{2,3,4,25}

Falling Short

Physician and health care analyst David Eddy first applied a mathematical model to health decision making and concluded that 2 fundamental factors are (1) thoughtful analysis of evidence and (2) value judgments about risks and benefits of medical or surgical courses of action.^{26,27} Acceptable trade-offs (eg, willingness to extend life with specific procedures that will clearly diminish the quality of one's remaining time) and unacceptable burdens^{24,25} are also key features of informed consent and should be clarified, particularly when mortality risk is significant. Patients and their families value clear, compassionate communication that focuses on patients' preferences, goals, and values, as well as patient care that promotes comfort, dignity, and preservation of personhood.^{25,28} Yet, both preoperatively and postoperatively, surgeon-patient-family

discussion is frequently inadequate for imagining end-of-life scenarios, much less for eliciting patients' values about *meaning* in life or *how* they might prefer to die.^{29,30} Physicians regularly fail to consider what matters most to patients. Even though spirituality is a highly prevalent value that becomes more pressing near the end of life,^{31,32} spiritual concerns are rarely addressed by clinicians when patients are in a critical condition.^{30,33} Moreover, when surrogates initiate religious or spiritual discussions in the ICU, the topic is frequently buried by clinicians, who might redirect conversations to medical considerations.³³

Well-meaning surgeons might mistakenly believe that when they lay out treatment options along with intervention-associated risk predictions they are respecting patient autonomy.³⁴ This type of "independent informed choice,"^{35,36,37} however, is seldom beneficent, nonmaleficent, or patient centered.³⁸ As Ezekiel Emanuel and Linda Emanuel explain: "Freedom and control over medical decisions alone do not constitute patient autonomy."³⁵ True autonomy requires critical introspection on one's values prior to exercising one's freedom to act on those values.³⁵ Furthermore, as Daniela Lamas and Lisa Rosenbaum note: "Patients may be asked to choose from a bewildering array of medical options."³⁷ Paradoxically, although freedom and autonomy might be logically thought to promote greater well-being, psychologist Barry Schwartz reminds us that such "choice overload" frequently does not lead to empowerment and emotional health, but rather to greater distress.³⁹ In a recent and novel study undertaken by Leslie Scheunemann et al, family conferences rarely generated value-centered recommendations and fewer than half contained discussion of prolonged physical, cognitive, or emotional impairment among seriously ill patients.²⁹ Soliciting appropriate surrogates' substituted judgment^{40,41} during family meetings can relieve survivors' guilt, anxiety, depression, and posttraumatic stress^{42,43} and mitigate complex grief,^{44,45} but substituted judgment conversations happened in only 13.5% of meetings that Scheunemann and colleagues analyzed.29

Values, preferences, and feasible goals—understood by all parties in the context of either acceptable trade-offs or unacceptable levels of suffering^{24,25}—are needed for substituted judgment and shared decision making^{23,46} and are key to generating preoperative covenants and maintaining ongoing, collaborative postoperative communication in SICU settings as clinical scenarios unfold.^{2,30,47}

Hope and Wish

As previously discussed, assumptions should be articulated and explicitly addressed in patient-surgeon communication; deeply held attitudes and beliefs about uncertain futures should, too. Surveyed cancer surgeons reported their most common ethical strivings were "providing patients with honest information without destroying hope" and "preserving patient choice."⁴⁸ Withholding honest (if not accurate) prognostic estimates, however, can deprive families of much-needed context and thwart planning, preventing families from focusing on what matters most to their loved one. Accuracy and realism are key features of trustworthy professionalism.^{49,50} In one study, 93% of 179 interviewed surrogate decision makers "felt that avoiding discussions about prognosis is an unacceptable way to maintain hope."⁵¹ Honest prognostic estimates also allow families a space for meaningful communication⁴⁵ (eg, saying goodbye and expressing love, gratitude, and forgiveness).⁵² Because *hope* and *wish*—like values, preferences, and goals—are commonly conflated concepts that are often used to describe the value-laden future orientations and expectations of surgeons, patients, and their loved ones, another set of working definitions could help facilitate clear, covenantal communication.

- *Hope* is a positive, empowering, transcendent attitude, which reveals the underpinnings of deep-meaning construction that are based on acceptance of *realistic* prognostication,^{32,53,54,55} no matter how foreboding.
- Wishes are distinctly more anxiety oriented and reality denying than hope, as they derive from imagined *unrealistic* outcomes or outcomes for which no feasible pathway exists.³²

False hopes—such as patients' belief that if they die from surgery, they will do so peacefully in the operating room⁵⁶ or beliefs that death itself can somehow be defeated—are therefore better termed wishes. False beliefs and fantastical wishes⁵⁷ are commonly encountered in end-of-life scenarios—among both families⁵⁸ and surgeons^{9,12,13,16,59,60,61}—and might upend ethical collaborative communication processes,⁵⁷ particularly when grieving family members (and surgeons?) are asked to assess health information with realism and offer accurate preference-based substituted judgments.^{62,63,64} True hope, paradoxically, is not outcome based, but rather transcends outcomes, as it is the meaning-based substratum of one's goals.^{32,53,55} As Balfour Mount, the father of palliative care states:

Hope is not the same as wishing. Hope is a perspective on reality, a point of view.... It reflects a degree of inner peace. *Hope* is a child of the human spirit. It arises from an experience of personal meaning. *Wishing*, however, arises from a sense of need, dissatisfaction and unrest. It reflects a sense of incompleteness. Hope is the product of adversity transcended, wishing of adversity denied.³²

A Word About Wants

We caution against clinicians inquiring about what patients *want*, since, in our experience and the experience of other palliative care communication experts,⁶⁵ this word prompts many patients and surrogates to think in terms of their wishes rather than in terms of their values, preferences, or realistic and meaningful goals. Value-congruent decisions require reflective—rather than reactive—thinking.^{1,20,46} Asking patients or surrogates whether they *want* surgery or *want* potentially value-discordant postoperative treatments, consistent with the "independent informed choice" communication style (what one noteworthy palliative care ethicist terms "radical autonomy"),⁴¹ can shift the decision-making power locus toward the patient^{41,48,65} even as it might invite the patient's immediate—and possibly fear-based—dichotomous decision⁶⁵ rather than support the patient's reflection and deliberation about values^{1,14,23,29,36,45,48,66,67,68} that can be expressed in a surgeon's patient-centered actions.

Overall, we suggest that surgeons looking to establish and nourish covenantal communication with their patients, especially preoperatively but also in SICU settings, do the following: identify surrogates early; clearly explain to surrogates what substituted judgment is and promote it by eliciting and helping to clarify patient values and preferences with all 3 parties; and articulate value-congruent care pathway recommendations while deliberating about why alternative paths are value incongruent or fantastical, along the lines we have suggested here. To facilitate patient-centered surgical care and good end-of-life contingency planning, we also suggest inviting patients and their surrogates to imagine and articulate unacceptable levels of suffering and possible acceptable death process scenarios before patients are incapacitated with operative anesthesia, postoperative sedation, or delirium or before they lose the ability to express their values in nuanced terms (eg, after intubation), particularly in high-risk cases. Creating and maintaining actionable, value-congruent, feasible, patient-focused

action pathways is ethically and clinically necessary to making good on our covenants with those for whom we owe duties to care.

References

- 1. Scheunemann LP, Arnold RM, White DB. The facilitated values history: helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care Med.* 2012;186(6):480-486.
- Naik AD, Martin LA, Moye J, Karel MJ. Health values and treatment goals of older, multimorbid adults facing life-threatening illness. *J Am Geriatr Soc.* 2016;64(3):625-631.
- 3. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284(19):2476-2482.
- 4. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. 1999;281(2):163-168.
- 5. Nabozny MJ, Kruser JM, Steffens NM, et al. Patient-reported limitations to surgical buy-in: a qualitative study of patients facing high-risk surgery. *Ann Surg.* 2017;265(1):97-102.
- 6. Borges NJ, Osmon WR. Personality and medical specialty choice: technique orientation versus people orientation. *J Vocat Behav*. 2001;58(1):22-35.
- 7. Kruser JM, Pecanac KE, Brasel KJ, et al. "And I think that we can fix it": mental models used in high-risk surgical decision making. *Ann Surg.* 2015;261(4):678-684.
- Lee CW, Vitous CA, Silveira MJ, et al. Delays in palliative care referral among surgical patients: perspectives of surgical residents across the state of Michigan. *J Pain Symptom Manage*. 2019;57(6):1080-1088.
- 9. Little M. The fivefold root of an ethics of surgery. *Bioethics*. 2002;16(3):183-201.
- 10. Angelos P. Responding to patient requests to withdraw life support: surgical ethics and responsibility. *Ann Surg.* 2012;256(1):16-17.
- 11. Katz P. The Scalpel's Edge: The Culture of Surgeons. Allyn & Bacon; 1999.
- 12. Cassell J, Buchman TG, Streat S, Stewart RM. Surgeons, intensivists, and the covenant of care: administrative models and values affecting care at the end of life-updated. *Crit Care Med*. 2003;31(5):1551-1559.
- 13. Buchman TG, Cassell J, Ray SE. Who should manage the dying patient?: rescue, shame, and the surgical ICU dilemma. *J Am Coll Surg*. 2002;194(5):665-673.
- 14. Schwarze ML. 2019 John J. Conley Ethics and Philosophy Lecture: what we talk about when we talk about surgery. American College of Surgeons. Accessed August 7, 2021. https://www.facs.org/education/academy/namedlectures/2019-conley
- 15. Schwarze ML, Redmann AJ, Alexander GC, Brasel KJ. Surgeons expect patients to buy-in to postoperative life support preoperatively: results of a national survey. *Crit Care Med.* 2013;41(1):1-8.
- 16. Schwarze ML, Bradley CT, Brasel KJ. Surgical "buy-in": the contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy. *Crit Care Med.* 2010;38(3):843-848.
- 17. Pecanac KE, Kehler JM, Brasel KJ, et al. It's big surgery: preoperative expressions of risk, responsibility, and commitment to treatment after high-risk operations. *Ann Surg.* 2014;259(3):458-463.
- 18. Marsh H. Do No Harm: Stories of Life, Death, and Brain Surgery. Thomas Dunne Books; 2015.

- 19. Haidt J. The new synthesis in moral psychology. Science. 2007;316(5827):998-1002.
- 20. Fagan A. How autonomous is medical decision making? *AMA J Ethics*. 2009;11(8):631-635.
- 21. Morris RS, Ruck JM, Conca-Cheng AM, Smith TJ, Carver TW, Johnston FM. Shared decision-making in acute surgical illness: the surgeon's perspective. *J Am Coll Surg.* 2018;226(5):784-795.
- 22. Solomon S, Greenberg J, Pyszczynski T. *The Worm at the Core: On the Role of Death in Life*. Penguin Random House; 2016.
- 23. Baldt B. The influence of values in shared (medical) decision making. *Ethik Med*. 2020;32(1):37-47.
- 24. Gawande A. How to Talk End-of-Life Care With a Dying Patient. FORA.tv; 2010. Accessed January 29, 2019. https://www.youtube.com/watch?v=45b2QZxDd_o
- 25. Rubin EB, Buehler A, Halpern SD. Seriously ill patients' willingness to trade survival time to avoid high treatment intensity at the end of life. *JAMA Intern Med.* 2020;180(6):907-909.
- 26. Eddy DM. Anatomy of a decision. JAMA. 1990;263(3):441-443.
- 27. Tunis SR. Reflections on science, judgment, and value in evidence-based decision making: a conversation with David Eddy. *Health Aff (Millwood)*. 2007;26(4):w500-w515.
- 28. Nelson JE, Puntillo KA, Pronovost PJ, et al. In their own words: patients and families define high-quality palliative care in the intensive care unit. *Crit Care Med*. 2010;38(3):808-818.
- 29. Scheunemann LP, Ernecoff NC, Buddadhumaruk P, et al. Clinician-family communication about patients' values and preferences in intensive care units. *JAMA Intern Med.* 2019;179(5):676-684.
- 30. Nabozny MJ, Kruser JM, Steffens NM, et al. Constructing high-stakes surgical decisions: it's better to die trying. *Ann Surg.* 2016;263(1):64-70.
- 31. Balboni TA, Balboni MJ. The spiritual event of serious illness. *J Pain Symptom Manage*. 2018;56(5):816-822.
- 32. Mount BM. Existential suffering and the determinants of healing. *Eur J Palliat Care*. 2003;10(2)(suppl):40-42.
- 33. Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB. Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions. *JAMA Intern Med.* 2015;175(10):1662-1669.
- 34. Taylor LJ, Johnson SK, Nabozny MJ, et al. Barriers to goal-concordant care for older patients with acute surgical illness: communication patterns extrinsic to decision aids. *Ann Surg.* 2018;267(4):677-682.
- 35. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267(16):2221-2226.
- 36. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med*. 1996;125(9):763-769.
- 37. Lamas D, Rosenbaum L. Freedom from the tyranny of choice—teaching the endof-life conversation. *N Engl J Med*. 2012;366(18):1655-1657.
- 38. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns*. 2014;94(3):291-309.

- 39. Schwartz B. Choice, freedom, and autonomy. In: Shaver PR, Mikulincer M, eds. *Meaning, Mortality, and Choice: The Social Psychology of Existential Concerns.* American Psychological Association; 2012:271-287.
- 40. Buchanan AE, Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge University Press; 2008.
- 41. Macauley RC. *Ethics in Palliative Care: A Complete Guide*. Oxford University Press; 2018.
- 42. Pochard F, Darmon M, Fassier T, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *J Crit Care*. 2005;20(1):90-96.
- 43. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med*. 2005;171(9):987-994.
- 44. Tyrie LS, Mosenthal AC. Care of the family in the surgical intensive care unit. *Surg Clin North Am.* 2011;91(2):333-342.
- 45. Otani H, Yoshida S, Morita T, et al. Meaningful communication before death, but not present at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients. *J Pain Symptom Manage*. 2017;54(3):273-279.
- 46. Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff (Millwood)*. 2013;32(2):276-284.
- 47. Rubin MA. The collaborative autonomy model of medical decision-making. *Neurocrit Care*. 2014;20(2):311-318.
- 48. McCahill LE, Krouse RS, Chu DZJ, et al. Decision making in palliative surgery. *J Am Coll Surg.* 2002;195(3):411-422.
- 49. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol*. 2005;23(6):1278-1288.
- 50. Bernat JL. Ethical aspects of determining and communicating prognosis in critical care. *Neurocrit Care*. 2004;1(1):107-117.
- 51. Apatira L, Boyd EA, Malvar G, et al. Hope, truth, and preparing for death: perspectives of surrogate decision makers. *Ann Intern Med.* 2008;149(12):861-868.
- 52. Byock I. *The 4 Things That Matter Most*. Canadian Virtual Hospice; 2011. Accessed January 1, 2019. https://www.youtube.com/watch?v=vcMmx-6RIUY
- 53. Feldman DB, Snyder CR. Hope and the meaningful life: theoretical and empirical associations between goal-directed thinking and life meaning. *J Soc Clin Psychol*. 2005;24(3):401-421.
- 54. Eliott JA, Olver IN. Hope and hoping in the talk of dying cancer patients. Soc Sci *Med.* 2007;64(1):138-149.
- 55. Dufault K, Martocchio BC. Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *Nurs Clin North Am*. 1985;20(2):379-391.
- 56. Nabozny MJ, Kruser JM, Steffens NM, et al. Constructing high-stakes surgical decisions: it's better to die trying. *Ann Surg.* 2016;263(1):64-70.
- 57. Chaet DH. AMA Code of Medical Ethics' opinions related to false beliefs in health care. AMA J Ethics. 2018;20(11):1049-1051.
- 58. Zier LS, Burack JH, Micco G, Chipman AK, Frank JA, White DB. Surrogate decision makers' responses to physicians' predictions of medical futility. *Chest*. 2009;136(1):110-117.

- 59. Olson TJP, Brasel KJ, Redmann AJ, Alexander GC, Schwarze ML. Surgeonreported conflict with intensivists about postoperative goals of care. *JAMA Surg*. 2013;148(1):29-35.
- 60. Olson TJP, Schwarze ML. Failure-to-pursue rescue: truly a failure? *Ann Surg*. 2015;262(2):e43-e44.
- 61. Sorella MC, Sakakushev B, Coccolini F, et al. Ethical decisions and dilemmas in the ACS patients requiring ICU: understanding when to start and when to stop. In: Picetti E, Pereira BM, Razek T, Narayan M, Kashuk JL, eds. *Intensive Care for Emergency Surgeons*. Springer International Publishing; 2019:321-329.
- 62. Sulmasy DP, Terry PB, Weisman CS, et al. The accuracy of substituted judgments in patients with terminal diagnoses. *Ann Intern Med.* 1998;128(8):621-629.
- 63. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med.* 2006;166(5):493-497.
- Fagerlin A, Ditto PH, Danks JH, Houts RM, Smucker WD. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol*. 2001;20(3):166-175.
- 65. Schwarze ML, Campbell TC, Cunningham TV, White DB, Arnold RM. You can't get what you want: innovation for end-of-life communication in the intensive care unit. *Am J Respir Crit Care Med.* 2016;193(1):14-16.
- 66. Abhyankar P, Bekker HL, Summers BA, Velikova G. Why values elicitation techniques enable people to make informed decisions about cancer trial participation. *Health Expect*. 2011;14(suppl 1):20-32.
- 67. Marterre B, Shin J, Terzian WTH. Shared decision-making in the context of uncertain care goals and outcomes: dissecting a penetrating abdominal trauma case complicated by enterocutaneous fistulae. *Am Surg.* 2020;86(11):1456-1461.
- Cooper Z, Courtwright A, Karlage A, Gawande A, Block S. Pitfalls in communication that lead to nonbeneficial emergency surgery in elderly patients with serious illness: description of the problem and elements of a solution. *Ann* Surg. 2014;260(6):949-957.

Robert Ledbetter is a fourth-year medical student at Wake Forest University School of Medicine in Winston-Salem, North Carolina, and serves on the Public Relations Committee for Delivering Equal Access to Care Clinic, a student-run charitable medical clinic that provides high-quality care for local underserved communities. He received his BA degree in philosophy with a concentration in science and medicine from the University of Tennessee. His professional interests include emergency medicine as well as medical advocacy for equitable and just health care access for all.

Buddy Marterre, MD, MDiv is an assistant professor of surgery and internal medicine at Wake Forest University School of Medicine in Winston-Salem, North Carolina, where he serves as co-director of the fourth-year medical student clinical clerkship in geriatrics and palliative care as well as the third-year clerkship in surgery and where he recently completed a master of divinity degree that included a hospital chaplaincy internship. He is a founding councilor of the Surgical Palliative Care Society.

Citation

AMA J Ethics. 2021;23(10):E814-822.

DOI

10.1001/amajethics.2021.814.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E823-825

MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

"Aren't Surgery and Palliative Care Kind of Opposites?"

Myrick C. Shinall Jr, MD, PhD

Abstract

Surgery is often considered one of the most aggressive forms of medical care. Palliative care, on the other hand, usually focuses on eliminating aggressive forms of medical care in the name of patient comfort. This article explores the seeming incongruity between surgery and palliative care, conditions in which surgery and palliation coexist, and further integration of surgery and palliation.

Glad You Asked!

When I was a general surgery chief resident, I scrubbed a concurrent case with one of my orthopedic surgery colleagues. We chatted, discussing our postresidency plans. When I told him that I was enrolling in a fellowship in hospice and palliative medicine, he asked, "Aren't surgery and palliative care kind of opposites?" This was a reasonable question. After all, surgery is typically intensive and invasive, and palliative care typically seeks to eliminate unwanted, ineffective, intensive, and invasive interventions. So how to explain to my friend (and myself) that I wanted to practice surgery and palliative care?

Before addressing how palliation fits with surgery or other intensive or invasive interventions, a few terms need clarification. *Palliative* is derived from a Latin word meaning "to cloak" and refers to interventions that aim to mitigate symptoms without curing underlying disease.¹ *Palliative care* involves alleviating suffering and improving quality of life for patients with serious underlying diseases.² Palliative care is a necessary skill set for anyone caring for patients with serious illnesses, and some physicians, like me, train and become board-certified in hospice and palliative medicine so that we can bring expert palliation to patients whose cases are especially complex. Expert palliation involves helping patients avoid intensive interventions that do not serve their goals and that are accompanied by unpleasant side effects (eg, pain, fatigue, or other demands on patients' remaining time). Importantly, however, there is no single definition of *intensive*, nor is it always the case that effective palliation means foregoing some intensive interventions.

This opposition between palliation and surgery is not intrinsic but rather is coincidental in situations in which palliation is most routinely deployed. *Intensity* describes the nature of an intervention, specifically how it affects a patient receiving it. *Palliation* describes an intervention's aim not to cure but to reduce suffering. In short, palliation is an end, and intensity is a means. Although the ends of surgery suggest which means are

appropriate for achieving those ends, so do particular circumstances of a patient's case. Surgery and other intensive interventions are usually inappropriate means for end-of-life palliation because there is simply not enough time for a patient to recover or to benefit. A surgery likely to reduce suffering in a month is not useful to a patient likely to die this week.

Intensive Palliation

End-of-life scenarios can appear deceptively simple to some clinicians, particularly if their understanding of palliation is that it eliminates intensive therapies from a patient's care plan. But, in any given case, moving backward in time from the end of life to the inception of a condition requiring palliation can confound this limited understanding. Consider a patient who is living with, say, peripheral arterial disease that constricts his distal leg blood flow such that walking becomes nearly impossible due to claudication. A vascular surgeon who performs an endarterectomy or lower extremity bypass to relieve such life-limiting claudication does not cure this patient's underlying peripheral arterial disease but does help him walk without pain.³ Similarly, the absence of effective esophageal peristalsis renders a patient with achalasia miserable with dysphagia. A surgeon who performs a Heller myotomy for this patient does not restore normal peristalsis but helps her to swallow more comfortably.⁴ Neither surgery cures the underlying disease, but both alleviate disabling symptoms and restore some function: they are palliative surgeries and should be discussed in those terms, even if only to augment explanation of these surgeries as treatments for these incurable diseases. The upshot of these examples is that surgical palliation is not an oxymoron.

Although it's true that intensive surgical intervention cannot effectively palliate in some cases, the trick is to judge in which circumstances it will do so. As in the cases just described, when we move further back in time from the end of life to a time when a patient with a fatal, incurable disease (such as a malignant bowel obstruction) still has time to live, making judgments about whether a patient will live long enough to recover from an operation and enjoy its benefits is fraught with uncertainties—about survivability, the possibility of life extension or risk of death hastening, and the degree to which symptoms can be managed surgically or medically—that certainly justify the need for fellowship-level training. Deciding whether and when to offer a palliative surgical option also requires having good data to inform the decision⁵ and the skill to apply that data and to discuss possible outcomes with a patient in a given case.

Palliative Surgical Metrics

The lack of data is only one challenge in palliative surgical practice. Another is that typical measures of success and failure in both surgery and palliative care can make it harder to apply surgical solutions to palliative problems.⁶ Surgical success has typically been measured in terms of the absence of complications and their consequences, including postoperative death. Patient-reported outcomes (eg, about symptom burden and function) have not counted for much until recently.⁷ Yet traditional morbidity and mortality metrics are not well-suited to evaluate palliative surgical interventions' success. What is more, palliative care is typically evaluated in terms of the degree to which intensive, expensive interventions are eliminated from patients' care plans. But for patients like those just described, surgical palliation will increase the cost and intensity of care. Surgery entails incursion of operating room fees, costs of postoperative hospitalization, and payment to clinical staff. In sum, successful palliation of a terminally ill patient will likely appear as a failure until metrics are developed, integrated into practice, and updated to meet the needs of the field and of patients.

Conclusion

We can now see why my orthopedic colleague's assumption of a conflict between palliative care and surgery was well-founded. The ways that both specialties have conceived of their roles and what constitutes success and failure make it natural to see them as opposites. Nevertheless, I hope to have shown here how palliation can be surgical and intensive, even aggressive. Recognizing when surgery is the best means for alleviating a patient's suffering should be a major priority in both surgery and palliative care.

References

- 1. Stevenson A, Waite M. Concise Oxford English Dictionary. 12th ed. Oxford University Press; 2011.
- 2. Dunn GP. Surgical palliative care: recent trends and developments. *Anesthesiol Clin.* 2012;30(1):13-28.
- 3. Campbell WB, Birchley DW. What is the place of surgery for intermittent claudication? *Eur J Vasc Endovasc Surg*. 2010;39(6):745-746.
- 4. Schlottmann F, Luckett DJ, Fine J, Shaheen NJ, Patti MG. Laparoscopic Heller myotomy versus peroral endoscopic myotomy (POEM) for achalasia: a systematic review and meta-analysis. *Ann Surg.* 2018;267(3):451-460.
- 5. Lilley EJ, Cooper Z, Schwarze ML, Mosenthal AC. Palliative care in surgery: defining the research priorities. *Ann Surg*. 2018;267(1):66-72.
- 6. Dunn GP. Palliative surgical outcomes: are we looking through a keyhole? *Ann Surg Oncol.* 2012;19(12):3637-3638.
- 7. Waljee JF, Dimick JB. Do patient-reported outcomes correlate with clinical outcomes following surgery? *Adv Surg.* 2017;51(1):141-150.

Myrick C. Shinall Jr, MD, PhD is an assistant professor of surgery and medicine at Vanderbilt University Medical Center in Nashville, Tennessee, where he is also a faculty member in Vanderbilt's Center for Biomedical Ethics and Society. Board-certified in surgery and palliative and hospice medicine, Dr Shinall practices general surgery and palliative care consultation, and his research focuses on palliative interventions for surgical patients.

Citation AMA J Ethics. 2021;23(10):E823-825.

DOI

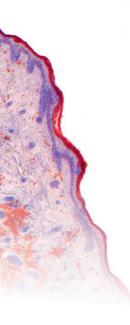
10.1001/amajethics.2021.823.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980



AMA Journal of Ethics[®]

October 2021, Volume 23, Number 10: E826-831

VIEWPOINT

Whoever Does Image-Guided Palliative Care Needs to Be Properly Trained to Do So

Jay A. Requarth, MD

Abstract

Vascular and interventional radiologists (VIRs) often offer image-guided palliative care procedures, despite having little training in clinical medicine, let alone in palliative medicine. Informed consent tends to be inadequate, as does postprocedure patient care. This article proposes that VIRs who perform image-guided palliative procedures be sufficiently trained in palliative care or that surgeons or internists subspecialized in palliative care be sufficiently trained to provide image-guided techniques.

Image-Guided Palliation

Although hospice and palliative medicine is a recognized subspecialty, palliative and end-of-life care is provided by many different specialties. End-of-life and palliative care in the United States is fragmented, expensive, and often inconsistent with the patient's wishes.¹ In my experience, nowhere are these limitations more apparent than in the image-guided palliative procedures provided by vascular and interventional radiologists (VIRs), many of whom have little training in clinical medicine, let alone in palliative medicine.² Although historically, VIRs have championed new image-guided procedures such as angiography, endovascular stenting, embolotherapy, and endovascular thrombolysis, it wasn't until these procedures were adopted by specialties like cardiology and vascular surgery that they became mainstream. It is long past time either for VIRs to add palliative medicine to their armamentarium or to have physicians who provide palliative care by specialists, similar to how care for atherosclerotic cardiovascular disease is provided by cardiologists, would substantially improve end-of-life and palliative care in the United States.

What Went Wrong

Over the years, much of my practice in surgery and interventional radiology gravitated toward palliative care procedures, and, having practiced hospice and palliative medicine (HPM), I used my HPM knowledge nearly every day. As examples of how diverse vascular and interventional radiological image-guided palliative procedures can be, I saw patients with liver failure and portal hypertension referred for transjugular intrahepatic portosystemic shunts, pelvic and bladder cancers referred for nephrostomy drain

placement, biliary and pancreatic cancers referred for biliary drainage, and bleeding thoracic, abdominal, and pelvic cancers referred for embolotherapy. Furthermore, when I worked in hospice, I frequently saw patients who had undergone image-guided palliative procedures or should have undergone image-guided palliative procedures prior to their hospice referral.

During my decade as a surgeon working in vascular and interventional radiology, I was finally able to see inside the field's black box, and it was enlightening. Most, if not all, procedures performed in vascular and interventional radiology involve image-guided palliative care,² which can benefit frail patients, patients with complex or hostile anatomy, or patients with advanced malignancies. However, in my experience, image-guided palliative procedures provided by VIRs are often painful and sometimes fail to achieve the desired clinical endpoint.

As a now-retired hospice and palliative care specialist, surgeon, and provider of VIR services, I also found the lack of pre- and postprocedural interactions distressing. I am not alone. About the then-new Practice Guideline for Interventional Clinical Practice,³ one reviewer stated:

It is bad medicine to perform an invasive therapeutic procedure on a patient without establishing the history, performing a physical examination, and developing or confirming a treatment plan with the patient ahead of time. It is unconscionable to perform that service and not follow the patient over time to see if it worked and if the patient is healthy and satisfied.⁴

VIRs' lack of patient interaction contributes to the public's impression that they are not physicians. In a 2018 survey, Heister and colleagues found that 83% of patients identified a urologist as a physician, but only 28% identified an interventional radiologist as a physician.⁵ Many VIRs have lamented this problem and urged their colleagues to become more visible by maintaining an inpatient practice, but this is not the norm.

VIR Training

As I have argued elsewhere, adding palliative care to VIR training would improve patient care and provide VIRs with necessary clinical skills to protect their turf.^{2,6,7} Despite recent changes in VIR training,⁸ however, I have not seen progress toward adding palliative care education. Indeed, one qualitative study of 16 VIR fellows found that though they were more likely to be clinically oriented than their predecessors, 81% still did not consider clinical care to extend beyond the periprocedural period, and fellows who went into private practice found their clinical initiatives unsupported.⁹

Since VIRs refuse or are unable to provide comprehensive palliative care, perhaps one solution is for physicians already familiar with diagnostic and palliative care to develop skill in image-guided procedures. Radiologists do not own the X-ray part of the electromagnetic spectrum. In fact, the transfer of image-guided procedures from VIRs to other clinicians is common and likely benefits patients. Coronary angiography, peripheral vascular angioplasty, dialysis access maintenance, and acute ischemic stroke treatment were all started by—or have been championed by—VIRs. But because VIRs failed to provide pre- and postprocedural care, skill in doing these procedures was developed by cardiologists, vascular surgeons, nephrologists, neurosurgeons, and neurologists.^{10,11,12,13,14,15} For example, between 1996 and 2007, the number of therapeutic endovascular procedures performed by vascular surgery resident physicians

increased from an average of 7.2 to 103.6.¹² Most or all of these endovascular procedures were at one time performed by VIRs; now, they are almost exclusively performed by vascular surgeons and cardiologists uniquely qualified to provide the appropriate procedure and postprocedural care until a patient's death.

Improving VIR Practice

During informed consent, the burdens of an image-guided palliative procedure—not just the risks and benefits—need to be reviewed with a patient and his or her family by a skilled physician who will perform the procedure. Since quality of life should be a significant focus, postprocedural pain should be discussed and pain management options reviewed. Finally, discussion of a patient's do-not-resuscitate (DNR) order, if one exists, needs to be facilitated by the physician performing the procedure.

Informed consent. The physician has a duty to provide the patient with enough information for a reasonable patient to make an informed consent.^{16,17,18} Necessary components of informed consent include the name of the physician performing the procedure, diagnosis, intervention options, prospective risks and benefits, prognosis after the intervention or alternative interventions (including no intervention), chances of success, and recovery time.^{16,17,18} Two informed consent cases adjudicated by state supreme courts, but not tested by the Supreme Court of the United States, suggest informed consent needs to be facilitated by the physician performing the procedure and given by a patient or appropriate surrogate before any intervention.^{19,20} To maximize palliative potential of an image-guided procedure, informed consent should be tailored to a specific patient at a specific point in time.

Informed consent should not be thought of as a process in which patient and physician set goals of care once and for all. Goals can change, and physicians need to ask about them every time they see a patient. For example, informed consent for percutaneous transhepatic drainage of unresectable obstructive jaundice should include informing a patient about how long the drain will be in place; pain associated with it; the possibility of hepatic artery injury; the need for frequent drain changes, if and when the drain can be removed; and, most importantly, the chance that the patient's serum bilirubin level will fall to a point at which palliative chemotherapy can start. Furthermore, the physician needs to understand the patient's wishes if complications develop. As objectionable as it might be to some physicians, there may be a day when the physician should allow the patient to die in the procedure room if things go terribly wrong.

Pain management. Informed consent should also include pain control. Even if a procedure is performed under general anesthesia or intravenous sedation, patients sometimes suffer from severe pain associated with follow-up procedures, such as drain changes. VIRs can ameliorate this pain, and they have an obligation to do so as best they can. Even if a patient is referred for a subcutaneous infusion port-catheter, VIRs can educate a patient about image-guided pain relief procedures, such as celiac plexus blocks for pancreatic cancer pain, during informed consent. For all patients, and especially for palliative care patients, if a procedure causes pain, sedation and intravenous opiates should be offered.

In my experience, pseudoaddiction—manifest when patients complain about pain before a procedure because they did not receive adequate pain control in prior procedural experiences—was common in drain exchange patients. As every palliative care specialist knows, pseudoaddiction is an iatrogenic problem caused by physicians undertreating severe pain.²¹ Often these patients are labeled as drug seekers or addicts, but they are not. Pseudoaddicts rarely ask for a prescription for pain medications for postprocedural pain control; they just want pain control during a procedure. Despite its importance in clinical care and despite the high likelihood of encountering patients with pseudoaddiction in vascular and interventional radiology, pseudoaddiction is not referenced in otherwise excellent textbooks or in Society of Interventional Radiology guidelines.^{3,22,23}

DNR protocols. In my experience, VIRs often neither understand nor follow proper DNR protocols.¹⁶ Patients are not required to suspend their DNR order before a procedure. If significant complications occur during the procedure, a patient's death on the fluoroscopy table could be clinically and ethically appropriate. In my view, it is improper for VIRs (and anesthesiologists) to refuse to perform a procedure if patients choose not to suspend their DNR order during a procedure. In my experience, a patient's DNR order is routinely revoked by an anesthesiologist before a procedure because some anesthesiologists consider intravenous vasopressors to be a type of resuscitation. For this reason, I usually asked patients who did not want to suspend their DNR order to let me decide when resuscitation should stop. Obviously, this requires a significant amount of patient-physician trust, and I felt my palliative care knowledge helped me with these discussions. Finally, after surgery, when a patient is fully awake and can make decisions, the physician who performed the image-guided procedure should have another DNR discussion with the patient that includes information obtained during the procedure. This is also an excellent time to plan follow-up and pain management.

What Palliative Patients Deserve

Image-guided palliative procedures are performed by interventional radiologists, surgeons, pulmonologists, gastroenterologists, urologists, and other specialists, but follow-up with patients receiving these procedures is haphazard and often erroneously referred to interventional radiology. Many procedures non-VIRs now perform were pioneered by VIRs and appropriated by non-VIRs when the technique was perfected and billing problems resolved. In my experience, VIRs provide many procedures to palliative care patients but do not offer adequate informed consent, preprocedural care, and postprocedural care. Too often, a decision to offer image-guided palliative procedures and postprocedural care is left up to a referring physician.

Improving palliative and end-of-life care in the United States requires either that VIRs add palliative medicine to their training and take care of their patients before and after the procedure or that general surgeons and internists subcertified in HPM follow the cardiology model and learn to provide VIR skillfully. Patients deserve better than the status quo.

References

- 1. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. National Academies Press; 2015.
- 2. McCullough HK, Bain RM, Clark HP, Requarth JA. The radiologist as a palliative care subspecialist: providing symptom relief when cure is not possible. *AJR Am J Roentgenol*. 2011;196(2):462-467.
- 3. American College of Radiology; American Society of Interventional and Therapeutic Neuroradiology; Society of Interventional Radiology. Practice guideline for interventional clinical practice. *J Vasc Interv Radiol*. 2005;16(2, pt 1):149-155.

- 4. Murphy TP. American College of Radiology practice guideline for interventional clinical practice: a commitment to patient care. *J Vasc Interv Radiol*. 2005;16(2, pt 1):157-159.
- 5. Heister D, Jackson S, Doherty-Simor M, Newton I. An evaluation of trends in patient and public awareness of IR. *J Vasc Interv Radiol*. 2018;29(5):661-668.
- 6. Requarth JA. IR and palliative care: a good match. *J Vasc Interv Radiol*. 2015;26(11):1740-1741.
- 7. Requarth JA. Thinking very far outside the box: providing improved clinical care while ensuring admitting privileges by adding a clinical training experience in hospice and palliative medicine. *J Vasc Interv Radiol*. 2015;26(2)(suppl):S167-S168.
- IR residency and fellowship: becoming an interventional radiologist. Society of Interventional Radiology. Accessed November 30, 2020. https://www.sirweb.org/learning-center/ir-residency/
- 9. Keller EJ, McGee KA, Resnick SA, et al. Who we are and what we can become: an analysis of professional identity formation in IR. *J Vasc Interv Radiol*. 2017;28(6):850-856.
- 10. Levin DC. The bygone era of interventional radiologists' involvement in coronary angiography. *J Vasc Interv Radiol*. 2019;30(11):1876-1877.
- 11. Hurks R, Ultee KHJ, Buck DB, et al. The impact of endovascular repair on specialties performing abdominal aortic aneurysm repair. *J Vasc Surg.* 2015;62(3):562-568.e3.
- 12. Mills JL Sr. Vascular surgery training in the United States: a half-century of evolution. *J Vasc Surg.* 2008;48(6)(suppl):90S-97S.
- 13. Murphy TP. Society of Interventional Radiology 2012 presidential address. J Vasc Interv Radiol. 2012;23(8):987-988.
- 14. Moossavi S, Regan JD, Pierson ED, et al. Non-surgical salvage of thrombosed arterio-venous fistulae: a case series and review of the literature. *Semin Dial*. 2007;20(5):459-464.
- 15. Pierot L, Jayaraman MV, Szikora I, et al; Asian-Australian Federation of Interventional and Therapeutic Neuroradiology (AAFITN); Australian and New Zealand Society of Neuroradiology (ANZSNR); American Society of Neuroradiology (ASNR), et al. Standards of practice in acute ischemic stroke intervention: international recommendations. *J Neurointerv Surg.* 2018;10(11):1121-1126.
- 16. Requarth JA. Informed consent challenges in frail, delirious, demented, and donot-resuscitate adult patients. *J Vasc Interv Radiol*. 2015;26(11):1647-1651.
- 17. Ripley BA, Tiffany D, Lehmann LS, Silverman SG. Improving the informed consent conversation: a standardized checklist that is patient centered, quality driven, and legally sound. *J Vasc Interv Radiol*. 2015;26(11):1639-1646.
- 18. Berlin A, Kunac A, Mosenthal AC. Perioperative goal-setting consultations by surgical colleagues: a new model for supporting patients, families, and surgeons in shared decision making. *Ann Palliat Med*. 2017;6(2):178-182.
- 19. Annas GJ. Informed consent, cancer, and truth in prognosis. *N Engl J Med*. 1994;330(3):223-225.
- 20. Robeznieks A. Informed-consent ruling may have "far-reaching, negative impact." American Medical Association. August 8, 2017. Accessed November 28, 2020. https://www.ama-assn.org/practice-management/sustainability/informed-consent-ruling-may-have-far-reaching-

management/sustainability/informed-consent-ruling-may-have-far-reachingnegative-impact

- 21. Weinstein S, Portenoy RK, Harrington SE, Bial A. *UNIPAC 3: Assessing and Treating Pain.* 4th ed. American Academy of Hospice and Palliative Medicine; 2012.
- 22. Kaufman EJ, Lee MJ. Vascular and Interventional Radiology: The Requisites. 2nd ed. Saunders Elsevier; 2014.
- 23. Valji K. Vascular and Interventional Radiology. 2nd ed. Saunders Elsevier; 2006.

Jay A. Requarth, MD is retired but maintains board certification by the American Board of Surgery and the American Board of Thoracic Surgery and is subcertified in hospice and palliative medicine by the American Board of Surgery. Following a fellowship year in vascular and interventional radiology (VIR), he worked over a decade in an academic VIR program.

Citation AMA J Ethics. 2021;23(10):E826-831.

DOI 10.1001/amajethics.2021.826.

Conflict of Interest Disclosure The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2021 American Medical Association. All rights reserved. ISSN 2376-6980