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Palliative Care in Surgery: Defining the Research Priorities

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Abstract

Objective: To describe the existing science of palliative care in surgery within three priority areas and expose specific gaps within the field.

Background: Given the acute and often life-limiting nature of surgical illness, as well as the potential for treatment to induce further suffering, surgical patients have considerable palliative care needs. Yet these patients are less likely to receive palliative care than their medical counterparts and palliative care consultations often occur when death is imminent, reflecting poor quality end-of-life care.

Methods: The National Institutes of Health and the National Palliative Care Research Center convened researchers from several medical subspecialties to develop a national agenda for palliative care research. The surgeon work group reviewed the existing surgical literature to identify critical knowledge gaps.

Results: To date, evidence to support the role of palliative care in surgical practice is sparse and palliative care research in surgery is encumbered by methodological challenges and entrenched cultural norms that impede appropriate provision of palliative care. Priorities for future research on palliative care in surgery include: 1) measuring outcomes that matter to patients, 2) communication and decision making, and 3) delivery of palliative care to surgical patients.

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Conclusions: Surgical patients would likely benefit from early palliative care delivered alongside surgical treatment to promote goal-concordant decision making and to improve patients' physical, emotional, social and spiritual well-being and quality of life. We propose a research agenda to address major gaps in the literature and provide a road map for future investigation.

Keywords

palliative care; palliative surgery; surgical research

Palliative care is a multidisciplinary specialty which aims to relieve suffering and support quality of life for seriously ill patients and their families. In a statement on the principles of palliative care in surgery, the American College of Surgeons recognized the life-affirming role of palliative care in the management of surgical patients with serious illness, and emphasized the need to provide palliative care alongside life-prolonging and curative surgical treatments.[1] Despite the burdens of surgical treatment and frequently life-limiting nature of surgical illness, palliative care delivery remains insufficient for surgical patients.

In 2003, the American College of Surgeon Palliative Care Workgroup identified 7 priority areas to build the science around palliative care in surgery, including surgical decision making, patient-oriented decision making, end-of-life decision making, symptom management, communication, processes of care, and surgical education about palliative care.[2] A systematic review of the literature from 1994 to 2014, however, reveals only 25 studies focused on palliative care interventions for surgical patients.[3] Like other assessments of palliative care interventions for nonsurgical patients, these studies suggest that palliative care interventions for surgical patients may reduce healthcare utilization[4–10] and improve advance care planning[5,6,8,11–15] without increasing mortality.[4–6,8,9,13,16–23] Nonetheless, interventions to promote the alignment of surgical treatment decisions with patients' goals of care and research on how to integrate palliative care principles into rescue-oriented surgical culture are notably absent. Furthermore, existing research is difficult to interpret due to the array of heterogeneous outcomes targeted.[3] Additional methodological weaknesses include small sample size, single-center studies, and inadequate follow-up.

Recent reports from the Institute of Medicine and the National Institutes of Health (NIH) identify key contributions of palliative care for the management of seriously ill patients, including improved symptom management, better quality of life, reduced healthcare costs, and higher quality physician-patient communication.[24,25] In light of these benefits, the Institute of Medicine and NIH reports called for increased research and support for the unmet needs of patients and families.[24,25] The NIH and the National Palliative Care Research Center convened subspecialty work groups to develop a national agenda for palliative care research in several medical disciplines. Herein, we provide an overview of major gaps in the current evidence (Table 1) and identify 3 priority areas for research on palliative care in surgery targeted to fill these gaps (Table 2).

PRIORITY AREA 1: MEASURING OUTCOMES THAT MATTER TO PATIENTS

Defining Outcomes That Patients Value

A major pitfall in measurement to improve quality is that measured and reported outcomes, such as 30-day mortality, fall short of measuring outcomes most meaningful to patients and can impede patient access to palliative and end-of-life care.[26–30] Survival is frequently measured in surgical research, but reporting the quantity of days without concurrent reporting of quality of life does not attest to the patient experience. Furthermore, defining surgical quality and value based solely on survival duration incentivizes surgeons to prolong life, not improve it, and can impede integration of palliative care. Alternatively, measures of functional independence,[31] disability-free survival,[32] days spent at home,[33] or freedom from pain after surgery provide information on outcomes that are both clinically meaningful and important to patients. Likewise, measures of health-care utilization required to achieve specific outcomes [ie, surgical intensive care unit (SICU) admission, days on a ventilator, discharge to skilled nursing facilities, or long-term acute care hospitals] provide information regarding the burdens of treatment. In addition, survivors of postoperative complications, major trauma, and critical surgical illness are likely to have postacute palliative care needs; yet their long-term symptom burden, impairment, social concerns (ie, need for assistance at home), and overall well-being are not well described in the current literature. Future studies need to characterize patients' perspectives on the benefits, burdens, and tradeoffs associated with surgery and how best to measure the outcomes that are most meaningful to them.[34,35]

Existing patient-reported outcomes measures used in palliative care were designed for patients with chronic, progressive illnesses, such as cancer, and are not readily translated to surgical patients because they do not account for the expected pain and disability that frequently accompany surgical recovery, nor do they distinguish acute postoperative symptoms from those which are chronic or refractory. Furthermore, some instruments, such as the Edmonton Symptom Assessment Scale, have only been validated in cancer patients receiving palliative care who forego disease-directed treatment.[36] There are a few excellent examples of patient-reported outcomes measures developed for surgical problems in the literature; 1 study used qualitative data from adult trauma survivors and their caregivers to develop a questionnaire assessing aspects of quality of life that were specifically related to the trauma experience.[37] Additional examples of surgery-specific instruments have been developed to measure patient-reported outcomes after breast surgery,[38] bariatric surgery,[39] colorectal surgery,[40] and cosmetic surgery.[39,41] Recent studies have also used measures from the NIH Patient-Reported Outcomes Measurement System[42] to assess physical, mental, and social health in surgical patients.[43,44] Although there are several instruments, which are appropriate for measuring patient-reported outcomes after surgery, the evidence remains thin due to their underuse in research. Observational studies measuring patient-reported outcomes are needed for a broad range of surgical subspecialties, including surgical oncology, neurosurgery, vascular surgery, and trauma.

In addition to patient-reported outcomes measures, there are other clinically relevant measures that are more aligned with outcomes that patient value than 30-day morbidity and mortality, such as longer-term survival, SICU days, and postacute care needs.[26,27,31,32]

Future work will also need to determine the feasibility and validity of incorporating these metrics into assessment and reporting of surgical quality.

Measures to Evaluate High-quality Palliative Care in Surgery

Measures that reflect the timely and appropriate delivery of high-quality palliative care in surgery are needed to promote accountability and identify targets for improvement. These metrics within the scope of surgical practice should address 2 separate issues: (1) palliative care provision for seriously ill surgical patients and (2) management of patients undergoing palliative surgery.

Evaluating and improving processes of care, such as documentation of advance directives, and quality indicators for care at the end of life, such as hospice enrollment and death on life-sustaining treatments, are particularly pertinent for surgical patients at high risk of death. The National Quality Forum has endorsed 24 measures to assess the utilization and adequacy of palliative care in multiple settings.[45]These measures were, however, designed around the needs of patients afflicted with suffering as they approach the final stages of illness, and may not be relevant for the management of seriously ill surgical patients, many of whom have a high symptom burden and a high risk of mortality but are not clearly expected to die in the short term.

Efforts are underway to collect national data to analyze patterns and utilization of do-not-resuscitate orders, palliative care consultation, and hospice referral in older surgical patients.[46] These data, however, do not provide in-depth understanding of how and why these processes occur, nor whether they are beneficial from a patient's perspective; both are necessary to inform the development of surgery-specific indicators for high-quality palliative care (ie, quality of communication, adherence to treatment preferences, and quality of death and dying). Multi-institutional prospective cohort studies are needed to define and measure palliative care process measures for surgical practice and correlate them with patients' perceptions, experiences, and outcomes of care.

Palliative surgical procedures are intended to reduce suffering or support quality of life rather than prolong life or cure disease.[34,35,47] Prior studies have described the considerable risks of postoperative complications and mortality after palliative surgery, but few have measured the impact of palliative surgery on restoration of function and quality of life, or conversely, the occurrence of adverse outcomes that further threaten quality of life, function, and ability to achieve a good death.[26,48] Absence of a uniform system for designating and classifying procedures performed with palliative intent presents a barrier to studying outcomes of palliative surgery. Generation of standards for palliative surgery will permit future studies to assess the quality of palliative surgical care using criteria consistent with high-quality palliative care, rather than current metrics used in surgery, namely mortality and morbidity. Future comparative effectiveness trials are needed to compare the effectiveness of surgical procedures to non-surgical management on palliative outcomes for multiple surgical indications, including limb salvage, valve repair, and malignant obstruction.

PRIORITY AREA 2: COMMUNICATION AND DECISION MAKING

Aligning Surgical Treatments With Patient-oriented Outcomes

Surgeons and patients face high-stakes care decisions in the perioperative period, specifically whether to proceed with surgical intervention and associated, potentially burdensome, postoperative treatments. To support complex, in-the-moment decision making —often when the patient's clinical condition is changing or has changed rapidly—patients and their family members need to clearly understand the capacity and limitations of surgical intervention and the short- and long-term effects of surgery on their functional status and quality of life. Although patients frequently pursue surgery with the intent to cure disease, the trade-offs between cure and quality of life (ie, impaired functional status and prolonged pain and suffering) are typically value sensitive.[49,50] In cases in which surgery is directed toward palliation or ameliorating symptoms, evaluation of these trade-offs brings added complexity to decisions for surgery. Moreover, clinical decisions are severely hampered by the paucity of data comparing longer-term survival, quality of life, and function after operative and nonoperative management. This lack of data hinders the consideration of palliative care as an adjunct or alternative to surgery.

Although innovations to improve preoperative communication and decision making have been described,[7,20,49–51] whether these strategies improve the quality of surgical decisions (ie, better patient understanding of their disease and procedure, realistic expectations of recovery, reduced decisional regret) or other patient-oriented outcomes is unknown because assessment of these interventions is fraught with multiple serious methodological challenges.[26,52,53] Two single-institution cohort studies suggest that preoperative interventions to better clarify patients' disease understanding and treatment preferences are associated with a decrease in surgical procedures among frail older adults[7] and improved symptom control and reduced morbidity and mortality after palliative procedures in patients with cancer.[20] Both studies are, however, observational and lack a control group. Future randomized clinical trials and comparative effectiveness studies are needed to test structured communication interventions for surgical decision making that emphasize quality of life, long-term survival, and quality of death and dying. Valuable palliative care outcomes should include the alignment between patients' goals and the likely outcomes of surgery, reduction of burdensome, unwanted or nonbeneficial postoperative interventions, and improvement in physical and psychological outcomes after surgery.

Preoperative Advance Care Planning

Because patients who have surgery are at risk for losing decision-making capacity for prolonged periods, it is important to clarify—before surgery—the desired outcome from the patient's perspective, treatments patients are willing to endure to achieve those outcomes, and postoperative outcomes patients find unacceptable (ie, prolonged ventilator dependence). Patients who have major surgical procedures may also have desires to limit burdensome life-supporting treatments after surgery, and those with pre-existing directives restricting specific treatments may want to suspend these restrictions during the acute, perioperative period to achieve specific goals. Despite the importance of clarifying treatment preferences before surgery, some surgeons are resistant or reluctant to pursue preoperative

advance care planning[30,54,55] and data suggest that such conversations are often incomplete, or altogether absent, which can lead to unwanted postoperative treatment and conflict between surgeons and patients.[29,55] Unless preferences are clarified beforehand, surgeons and surrogates may presume that permission for surgery implies permission for all postoperative treatments necessary to avoid postoperative death.

Small studies of preoperative advance care planning conversations with high-risk surgical patients and their surrogates suggest that interventional strategies can improve surrogate understanding of patient preferences.[11,12,14] In these studies a total of only 28 patient-surrogate dyads, however, received an intervention, making it hard to draw definitive conclusions about intervention efficacy. Larger, hypothesis-driven studies are needed to determine the effect of preoperative advance care planning interventions to identify the patient's preferred surrogate decision maker before surgery; elicit and document patients' goals, expectations, and concerns about surgical treatment; and determine how much leeway patients might give to surgeons and surrogate decision makers to select the treatments needed to achieve these goals.[56]

Decision Making After Postoperative Complications or Critical Illness

In the setting of postoperative complications, additional barriers to communication have been described, including surgeons' heightened sense of duty[30,57–59] and belief in surgical buy-in; that in accepting surgical care, patients have also agreed to any postoperative treatment deemed necessary to survive.[29,55] Furthermore, in contrast to the more predictable decline in health and typical trajectory for patients with chronic, terminal illness, acutely ill surgical patients often experience minute-by-minute alterations in health status. When major complications occur, patients' previously stated goals and desired surgical outcomes may become unattainable. Insofar as treatment preferences are context specific and contingent upon patients' prognostic understanding, their priorities for treatment may change if the best possible outcome is no longer consistent with their individual values and judgments about quality of life. However, the combination of prognostic uncertainty, desire to rescue, and fear of extinguishing hope makes it difficult for surgeons and intensivists to communicate and provide accurate and precise information about outcomes for patients and their families.[29,30,55,57–59]

Surrogate decision making in the SICU differs from most other intensive care settings in that the sudden decline to critical illness after acute surgical illness, postoperative complications, or traumatic injury is unexpected and the appointed surrogate is often poorly prepared for decision making. Given the acute shift in trajectory, this is particularly challenging for family members who often do not discuss preferences with loved ones before hospitalization, or engage in preoperative conversations between the patient and surgeon. There is little evidence about how best to support these unprepared surrogates for their decision-making role in the SICU. At the same time, few studies have examined interventions to communicate prognosis amid uncertainty and re-evaluate patients' treatment preferences when postoperative complications or critical illness have altered the expected postoperative course. Future studies are needed to develop and refine communication tools to facilitate these conversations with patients and surrogates in the SICU and to evaluate

whether rescue treatments to manage complications align with patients' wishes in light of less desirable outcomes.

PRIORITY AREA 3: DELIVERY OF PALLIATIVE CARE TO SURGICAL PATIENTS

Integrating Palliative Care Principles Into Routine Surgical Practice

Surgical rescue culture and surgeons' deep-seated notions about error and responsibility are frequently cited as barriers to improving palliative care for surgical patients.[8,29,30,49,55,57–59] Interventions integrating elements of palliative care into routine surgical practice[6,9,18,60–63] and promoting cultural changes through peer review, specifically morbidity and mortality rounds,[6,8] have reported promising results. These single-institution studies, however, target high-risk patients at large academic medical centers. To establish durable improvements, dissemination and implementation studies are needed to develop scalable models of palliative care delivery and reproducible strategies for changing practice and culture. Large, multisite implementation studies of physician and systems-targeted interventions are needed to redirect treatment options so that surgery is not the default modality for patients known to have extremely poor survival due to baseline serious illness or acute surgical conditions. This requires a cultural shift promoting less aggressive treatments or comfort-directed care as reasonable adjuncts or alternatives to surgical management, rather than characterizing this high-quality care as ''doing nothing.''[49] Multidisciplinary, and multi-institutional, interventions are needed to educate surgical clinicians regarding the appropriateness of palliative care in the management of seriously ill patients. Studies will need to evaluate the adoption and maintenance of these interventions.

Palliative care education for surgeons is necessary to fully integrate palliative care into surgical care delivery; however, standardized and validated approaches for surgical palliative care education are lacking. In prior studies, surgical residents reported discomfort with conducting family meetings about end-of-life care.[64] Others have found deficiencies in residents' knowledge of palliative care and insufficient documentation of end-of-life care conversations.[65] Few studies have tested the effect of palliative care education interventions on surgical patients' outcomes.[3,10] Studies are needed to delineate robust methods for teaching surgeons basic palliative care skills (ie, thoroughly exploring patients' goals of treatment, managing acute and chronic symptoms, treating depression and anxiety), and to evaluate the effect of this training on patient outcomes. Innovative curriculum development, including simulation-based education, and competency-based assessment, is needed for surgeons in all stages of training. Incorporating core clinical and patient-reported outcomes and core processes (eg, documentation) in evaluating these interventions is essential.

Developing Scalable Models of Primary Palliative Care Delivery for Surgical Patients

Early integration of palliative care in the management of seriously ill nonsurgical patient populations is associated with improved quality of life, reduced healthcare costs, and longer survival.[24,25,66–69] In contrast with the longitudinal management of chronic, progressive disease, surgical care typically focuses on acute conditions, with broad variation in recovery outcomes. Moreover, surgeons must quickly establish relationships with their patients and

often have a finite role in their care. Thus, the approach used for integrating palliative care into other specialties does not translate into surgery specialties. There are no studies that have evaluated scalable models for delivering palliative care in the perioperative period and the optimal strategy for meeting complex palliative care needs in surgical populations. Large, multi-institutional interventional studies are needed to determine the effectiveness of palliative care interventions on patient and caregiver outcomes and healthcare cost.

Identifying Patients Who Would Benefit From Palliative Care Specialist Consultation

Patients with complex palliative care needs benefit from specialist consultations[70–72]; however, palliative care consultations are less common among surgical patients than other patients and are often delayed until patients are within days of death.[73–75] In the current treatment model, palliative care needs are typically unattended until the end of life. To attend to the palliative care needs of seriously ill surgical patients throughout all phases of care, especially as those needs gradually increase in intensity and complexity with illness progression, we need to shift our approach. Investigation is needed to identify seriously ill, but not imminently dying, surgical patients who would benefit from early palliative care intervention from surgeons with subsequent referral to palliative care specialists when their needs are beyond the scope of their primary surgical providers.

There are few studies that explore strategies for promoting timely palliative care consultation for surgical patients with unmet or complex needs.[3] Results of 2 single-institution studies suggest that screening surgical patients for frailty[17] and serious chronic illness[76] may increase palliative care consultation and improved clinical outcomes. A third study, however, found no difference in the number of palliative care consultations.[16]

Observational studies using qualitative, mixed methods and secondary dataset analyses, are needed to characterize patients with a large burden of suffering from symptoms, high postoperative morbidity and mortality, and those for whom surgery represents an inflection point in their health trajectory. Potential targets include a variety of patients with poor prognosis surgical illnesses, such as pancreatic cancer, peripheral vascular disease, and frail injured patients. Interventional studies are needed to examine whether targeted early palliative care has a similar effect on healthcare utilization, treatment intensity, symptom management, survival, and quality of life for high-needs surgical cohorts as it does in lung cancer, advanced heart failure, and end-stage renal disease.[68,77–79]

CONCLUSIONS

Seriously ill surgical patients have substantial palliative care needs that are often unrecognized and unaddressed. Although much has been accomplished since the first research agenda for palliative care in surgery was put forth in 2003, much more remains to be done. As the population ages and technical innovation advances, surgical patients will become increasingly complex as surgeons and patients navigate the blurred boundaries between technically feasible, clinically appropriate, and value-concordant care. Building the science around palliative care in surgery will require the engagement and support of stakeholders, interdisciplinary collaboration, and development of new, well-trained researchers with interest in this field. The proposed research priorities will provide evidence

to support lasting improvements and establish palliative care as a core tenet of high-quality surgical care.

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REFERENCES

1. American College of Surgeons Task Force on Surgical Palliative Care and Committee on Ethics. Statement of principles of palliative care. Bull Am Coll Surg. 2005;90:34–35.
2. Surgeons Palliative Care Workgroup. Office of Promoting Excellence in End-of-Life Care: Surgeon's Palliative Care Workgroup report from the field. J Am Coll Surg. 2003;197:661–686.14562800
3. Lilley EJ , Khan KT , Johnston FM , et al. Palliative care interventions for surgical patients: a systematic review. JAMA Surg. 2016;151:172–183.26606747
4. Axelsson B , Christensen SB . Evaluation of a hospital-based palliative support service with particular regard to financial outcome measures. Palliat Med. 1998;12:41–49.9616458
5. Hall RI , Rocker GM , Murray D . Simple changes can improve conduct of end-of-life care in the intensive care unit. Can J Anaesth. 2004;51:631–636.15197128
6. Lamba S , Murphy P , McVicker S , et al. Changing end-of-life care practice for liver transplant service patients: structured palliative care intervention in the surgical intensive care unit. J Pain Symptom Manage. 2012;44:508–519.22765967
7. Moorhouse P , Mallery LH . Palliative and therapeutic harmonization: a model for appropriate decision-making in frail older adults. J Am Geriatr Soc. 2012;60:2326–2332.23110462
8. Mosenthal AC , Murphy PA , Barker LK , et al. Changing the culture around end-of-life care in the trauma intensive care unit. J Trauma. 2008;64:1587–1593.18545128
9. Tan KY , Tan P , Tan L . A collaborative transdisciplinary ‘‘geriatric surgery service’’ ensures consistent successful outcomes in elderly colorectal surgery patients. World J Surg. 2011;35:1608–1614.21523500
10. Holloran SD , Starkey GW , Burke PA , et al. An educational intervention in the surgical intensive care unit to improve ethical decisions. Surgery. 1995;118:294–298. discussion 298–299.7638746
11. Briggs LA , Kirchhoff KT , Hammes BJ , et al. Patient-centered advance care planning in special patient populations: a pilot study. J Prof Nurs. 2004;20:47–58.15011193
12. Cooper Z , Corso K , Bernacki R , et al. Conversations about treatment preferences before high-risk surgery: a pilot study in the preoperative testing center. J Palliat Med. 2014;17:701–707.24832687
13. Grimaldo DA , Wiener-Kronish JP , Jurson T , et al. A randomized, controlled trial of advance care planning discussions during preoperative evaluations. Anesthesiology. 2001;95:43–50.11465582
14. Song MK , Kirchhoff KT , Douglas J , et al. A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. Med Care. 2005;43:1049–1053.16166875
15. Swetz KM , Freeman MR , AbouEzzeddine OF , et al. Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy. Mayo Clin Proc. 2011;86:493–500.21628614
16. Bradley C , Weaver J , Brasel K . Addressing access to palliative care services in the surgical intensive care unit. Surgery. 2010;147:871–877.20097397
17. Ernst KF , Hall DE , Schmid KK , et al. Surgical palliative care consultations over time in relationship to systemwide frailty screening. JAMA Surg. 2014;149:1121–1126.25207603

18. McCorkle R , Strumpf NE , Nuamah IF , et al. A specialized home care intervention improves survival among older post-surgical cancer patients. J Am Geriatr Soc. 2000;48:1707–1713.11129765
19. Meilink M , Van de Wetering K , Klip H . Discussing and documenting (do not attempt) resuscitation orders in a Dutch Hospital: a disappointing reality. Resuscitation. 2006;71:322–326.17064837
20. Miner TJ , Cohen J , Charpentier K , et al. The palliative triangle: improved patient selection and outcomes associated with palliative operations. Arch Surg. 2011;146:517–522.21576604
21. Ross L , Frederiksen K , Boesen SH , et al. No effect on survival of home psychosocial intervention in a randomized study of Danish colorectal cancer patients. Psychooncology. 2009;18:875–885.19137506
22. Ross L , Thomsen BL , Karlsen RV , et al. A randomized psychosocial intervention study on the effect of home visits on the well-being of Danish colorectal cancer patients—the INCA Project. Psychooncology. 2005;14:949–961.15669014
23. Young JM , Butow PN , Walsh J , et al. Multicenter randomized trial of centralized nurse-led telephone-based care coordination to improve outcomes after surgical resection for colorectal cancer: the CONNECT intervention. J Clin Oncol. 2013;31:3585–3591.24002519
24. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life The National Academies Press; 2014.
25. National Institute of Nursing Research. Building momentum: The science of end-of-life and palliative care—a review of research trends and funding 1997–2010. 2013 Available at: http://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR-Building-Momentum-508.pdf. Accessed January 18, 2015.
26. Badgwell BD . Palliative surgical research: challenges and solutions. J Palliative Care Med. 2012;S2:1–2.
27. Schwarze ML , Brasel KJ , Mosenthal AC . Beyond 30-day mortality: aligning surgical quality with outcomes that patients value. JAMA Surg. 2014;149:631–632.24897945
28. Kupfer JM . The morality of using mortality as a financial incentive: unintended consequences and implications for acute hospital care. JAMA. 2013;309:2213–2214.23736729
29. 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;38:843–848.20048678
30. Schwarze ML , Redmann AJ , Brasel KJ , et al. The role of surgeon error in withdrawal of postoperative life support. Ann Surg. 2012;256:10–15.22584696
31. Berian JR , Mohanty S , Ko CY , et al. Association of loss of independence with readmission and death after discharge in older patients after surgical procedures. JAMA Surg. 2016;151:e161689.27409710
32. Shulman MA , Myles PS , Chan MT , et al. Measurement of disability-free survival after surgery. Anesthesiology. 2015;122:524–536.25689757
33. Groff AC , Colla CH , Lee TH . Days spent at home—a patient-centered goal and outcome. N Engl J Med. 2016;375:1610–1612.27783911
34. Badgwell B , Bruera E , Klimberg SV . Can patient reported outcomes help identify the optimal outcome in palliative surgery? J Surg Oncol. 2014;109:145–150.24132785
35. Badgwell BD , Aloia TA , Garrett J , et al. Indicators of symptom improvement and survival in inpatients with advanced cancer undergoing palliative surgical consultation. J Surg Oncol. 2013;107:367–371.22886727
36. Richardson LA , Jones GW . A review of the reliability and validity of the Edmonton Symptom Assessment System. Curr Oncol. 2009;16:55.
37. Wanner JP , DeRoon-Cassini T , Kodadek L , et al. Development of a trauma-specific quality-of-life measurement. J Trauma Acute Care Surg. 2015;79:275–281.26218697
38. Howard MA , Sisco M , Yao K , et al. Patient satisfaction with nipple-sparing mastectomy: a prospective study of patient reported outcomes using the BREAST-Q. J Surg Oncol. 2016;114:416–422.27393183

39. Klassen AF , Cano SJ , Alderman A , et al. The BODY-Q: a patient-reported outcome instrument for weight loss and body contouring treatments. Plast Reconstr Surg Glob Open. 2016;4:e679.27200241
40. Wendel CS , Grant M , Herrinton L , et al. Reliability and validity of a survey to measure bowel function and quality of life in long-term rectal cancer survivors. Qual Life Res. 2014;23:2831–2840.24890826
41. Klassen AF , Cano SJ , Scott A , et al. Measuring patient-reported outcomes in facial aesthetic patients: development of the FACE-Q. Facial Plast Surg. 2010;26:303–309.20665408
42. Broderick JE , DeWitt EM , Rothrock N , et al. Advances in patient-reported outcomes: the NIH PROMIS((R)) measures. EGEMS (Wash DC). 2013;1:1015.25848562
43. Titsworth WL , Abram J , Guin P , et al. A prospective time-series quality improvement trial of a standardized analgesia protocol to reduce postoperative pain among neurosurgery patients. J Neurosurg. 2016;125:1523–1532.26967774
44. Beckmann JT , Hung M , Voss MW , et al. Evaluation of the patient-reported outcomes measurement information system upper extremity computer adaptive test. J Hand Surg Am. 2016;41:739e4–744.e4.27263986
45. National Quality Forum. NQF-Endorsed Palliative Care and End-of-Life Care Endorsement Maintenance Standards 2012 Available at: www.qualityforum.org/Publications/2012/04/Palliative_Final_Report.aspx. Accessed March 16, 2015.
46. Robinson TN , Rosenthal RA . The ACS NSQIP Geriatric Surgery Pilot Project: improving care for older surgical patients. Bull Am Coll Surg. 2014;99:21–23.
47. Collins LK , Goodwin JA , Spencer HJ , et al. Patient reasoning in palliative surgical oncology. J Surg Oncol. 2013;107:372–375.22806710
48. Miner TJ , Jaques DP , Tavaf-Motamen H , et al. Decision making on surgical palliation based on patient outcome data. Am J Surg. 1999;177:150–154.10204560
49. Cooper Z , Courtwright A , Karlage A , et al. 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;260:949–957.24866541
50. 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;63:1805–1811.26280462
51. Lilley EJ , Cauley CE , Cooper Z . Using a palliative care framework for seriously ill surgical patients: the example of malignant bowel obstruction. JAMA Surg. 2016;151:695–696.27096440
52. Easson AM , Lee KF , Brasel K , et al. Clinical research for surgeons in palliative care: challenges and opportunities. J Am Coll Surg. 2003;196:141–151.12517566
53. Volk ML , Lok AS , Ubel PA , et al. Beyond utilitarianism: a method for analyzing competing ethical principles in a decision analysis of liver transplantation. Med Decis Making. 2008;28:763–772.18725405
54. Burkle CM , Swetz KM , Armstrong MH , et al. Patient and doctor attitudes and beliefs concerning perioperative do not resuscitate orders: anesthesiologists' growing compliance with patient autonomy and self determination guidelines. BMC Anesthesiol. 2013;13:2.23320623
55. Schwarze ML , Redmann AJ , Alexander GC , et al. Surgeons expect patients to buy-in to postoperative life support preoperatively: results of a national survey. Crit Care Med. 2013;41:1–8.23222269
56. Sudore RL , Fried TR . Redefining the ''planning'' in advance care planning: preparing for end-of-life decision making. Ann Intern Med. 2010;153:256–261.20713793
57. Bosk CL . Forgive and Remember: Managing Medical Failure. Chicago: University of Chicago Press; 1979.
58. Cassell J Dismembering the image of God: surgeons, heroes, wimps and miracles. Anthropol Today. 1986;2:13–15.
59. Cassell J , Buchman TG , Streat S , et al. Surgeons, intensivists, and the covenant of care: administrative models and values affecting care at the end of life—updated. Crit Care Med. 2003;31:1551–1557. discussion 1557–1559.12771632

60. 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;18:62–70.18570223
61. Mosenthal AC , Murphy PA . Interdisciplinary model for palliative care in the trauma and surgical intensive care unit: Robert Wood Johnson Foundation Demonstration Project for Improving Palliative Care in the Intensive Care Unit. Crit Care Med. 2006;34(11 suppl):S399–S403.17057605
62. Olufajo OA , Tulebaev S , Javedan H , et al. Integrating geriatric consults into routine care of older trauma patients: one-year experience of a level I trauma center. J Am Coll Surg. 2016;222:1029–1035.26968324
63. Lauck S , Garland E , Achtem L , et al. Integrating a palliative approach in a transcatheter heart valve program: bridging innovations in the management of severe aortic stenosis and best end-of-life practice. Eur J Cardiovasc Nurs. 2014;13:177–184.24477655
64. Hutul OA , Carpenter RO , Tarpley JL , et al. Missed opportunities: a descriptive assessment of teaching and attitudes regarding communication skills in a surgical residency. Curr Surg. 2006;63:401–409.17084769
65. Kelley AS , Gold HT , Roach KW , et al. Differential medical and surgical house staff involvement in end-of-life decisions: a retrospective chart review. J Pain Symptom Manage. 2006;32:110–117.16877178
66. Morrison RS , Dietrich J , Ladwig S , et al. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. Health Aff (Millwood). 2011;30:454–463.21383364
67. Morrison RS , Penrod JD , Cassel JB , et al. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med. 2008;168:1783–1790.18779466
68. 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;363:733–742.20818875
69. Teno JM , Freedman VA , Kasper JD , et al. Is Care for the dying improving in the United States? J Palliat Med. 2015;18:662–666.25922970
70. Quill TE , Abernethy AP . Generalist plus specialist palliative care—creating a more sustainable model. N Engl J Med. 2013;368:1173–1175.23465068
71. Von Gunten CF . Secondary and tertiary palliative care in US hospitals. JAMA. 2002;287:875–881.11851580
72. Weissman DE , Meier DE . Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. J Palliat Med. 2011;14:17–23.21133809
73. Kross EK , Engelberg RA , Downey L , et al. Differences in end-of-life care in the ICU across patients cared for by medicine, surgery, neurology, and neurosurgery physicians. Chest. 2014;145:313–321.24114410
74. Olmsted CL , Johnson AM , Kaboli P , et al. Use of palliative care and hospice among surgical and medical specialties in the veterans health administration. JAMA Surg. 2014;149:1169–1175.25251601
75. Rodriguez KL , Barnato AE , Arnold RM . Perceptions and utilization of palliative care services in acute care hospitals. J Palliat Med. 2007;10:99–110.17298258
76. 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;42:672–675.22045371
77. Fassett RG , Robertson IK , Mace R , et al. Palliative care in end-stage kidney disease. Nephrology (Carlton). 2011;16:4–12.21175971
78. Yong DS , Kwok AO , Wong DM , et al. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care. Palliat Med. 2009;23:111–119.19153131
79. Adler ED , Goldfinger JZ , Kalman J , et al. Palliative care in the treatment of advanced heart failure. Circulation. 2009;120:2597–2606.20026792

TABLE 1.

Current Knowledge Gaps in Palliative Care in Surgery

Research Focus Area	Current Knowledge Limitations
Defining outcomes that matter to patients	
Defining outcomes that patients value	The scope of most surgical outcomes research is limited to short-term survival. Few studies have examined other outcomes (function, quality of life, time in ICU, etc) that patients value after surgery or defined the benefits and tradeoffs of surgery from the patient's perspective. Existing measures for palliative care outcomes have not been validated for surgical patients and are not readily translated to surgical care.
Measures to evaluate high-quality palliative care in surgery	Processes of care that are common in palliative care, including communication about goals of care and documentation of a surrogate decision maker, have not been used as quality indicators in surgical care. There is a lack of appropriate quality metrics that align with the goals of palliative surgery, such as quality of life, functional status, and relief from symptoms. There is no uniform system for classifying palliative versus curative intent of surgery.
Communication and decision making	
Aligning surgical treatments with patient-oriented outcomes	Prior studies have described communication strategies for surgical decisions, but little is known about whether they lead to treatment decisions that are concordant with patients' preferences.
Preoperative advance care planning	Evidence for preoperative advance care planning conversations is limited to small, single-institution studies, and impact on patient- oriented outcomes is lacking.
Decision making after postoperative complications or critical illness	Studies have not examined communication strategies with patients and surrogate decision makers about postoperative care after complications or critical illness.
Delivery of palliative care to surgical patients	
Integrating palliative care principles into routine surgical practice	Few studies have examined the feasibility or efficacy of integrating primary palliative care into surgical practice and culture, including strategies for process change and workforce education.
Developing scalable models of primary palliative care delivery for surgical patients	No studies have evaluated models for surgical palliative care that can be scaled to populations in the perioperative setting.
Identifying patients who would benefit from palliative care specialist consultation	Studies using various criteria for screening palliative needs in surgical patient populations have reported mixed results from interventions to increase palliative care consultation.

TABLE 2.

Research Priorities for Palliative Care in Surgery

Research Priority	Study Objective	Study Setting	Sample	Study Design
Defining outcomes that matter to patients				
Develop and validate instruments for patientreported measures of palliative out omes relevant to surgical patient populations	Evaluate patient-reported outcome measures that reflect palliative care in surgery	Outpatient, inpatient, ICU,home	Patients who have major surgery and their caregivers	Qualitative and mixed method studies; psychometric research
Develop and validate palliative care process measures for surgeryspecific palli tive care delivery and ACP	Develop measurable processes of care to deliver high quality palliative care to surgical patients	Outpatient, inpatient, ICU	Seriously ill surgical patients and their caregivers	Randomized controlled trials; quasiexperimental studies; cohort studies
Communication and decision making				
Determine the effectiveness and comparative effectiveness of communication interventions versus usual care	Evaluate interventions to improve perioperative decision making and align surgical treatments with outcomes patients value	Outpatient, inpatient,emergency room	Patients with serious illness and caregivers who are considering major surgery	Randomized controlled trials; Prospective and retrospective studies; quasiexperimental designs
Design and conduct large, multicenter trials assessing effectiveness of communication tools to disclose prognosis in the perioperative period.	Reduce conflict (between clinical team and family and among the clinical team) and burdensome interventions that are not aligned with patients' goals for care in the postoperative period	Inpatient, emergency room, ICU	Patients who experience complications and their families	Randomized controlled trials; prospective and retrospective studies; quasiexperimental designs
Delivery of palliative care to surgical patients				
Develop and test models for integrating palliative care into routine management of seriously ill surgical patients	Increase acceptance and utilization of palliative care in surgical culture and practice	Academic centers and community hospitals	Surgical clinicians (ie, surgeons, nurses, anesthesiologists)	Randomized controlled trials; prospective and retrospective studies; quasi-experimental designs
Determine effectiveness and comparative effectiveness of targeted early versus late palliative care on healthcare cost, symptom management, quality of life, and caregiver burden	Increase timeliness of palliative care interventions for surgical patients with complex palliative care needs	Community, outpatient, inpatient	Surgical patients with poor prognosis and their caregivers	Randomized controlled trials; prospective and retrospective studies; quasi-experimental designs
Design and conduct large, multisite studies to compare palliative surgery versus medical management on symptom burden and quality of life.	Examine the effect of palliative surgical procedures on patientreported outcomes	Outpatient, inpatient	Patients with oncologic, vascular, cardiac surgical problems, and their caregivers	Mixed-methods studies; randomized controlled trials; prospective and retrospective studies; quasiexperimental designs

ACP indicates advance care planning; DNR, do-not-resuscitate; ICU, intensive care unit; LST, life-sustaining treatment.