

# Surgeon Perspectives Regarding Death and Dying

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## Abstract

**Background:** Surgical patients most commonly receive palliative care services within 24–48 hours of death, and reasons for this delay are poorly understood. Research with nonsurgeons suggests that physician characteristics and beliefs about death and dying may contribute to late referral.

**Objective:** To describe surgeon perspectives related to death and dying, and their relationship with delayed referrals to palliative care.

**Design:** Using a previously validated survey instrument supplemented by open-ended questions, deductive content analysis was used to describe surgeon preferences for end-of-life care.

**Settings:** Participants were all current nonretired members of the American Society of Colon and Rectal Surgeons.

**Main Outcome Measures:** Surgeon descriptions of a “good death” and how personal experiences influence care provided.

**Results:** Among 131 survey respondents (response rate 16.5%), 117 (89.3%) completed all or part of the qualitative portion of the survey. Respondents consistently reported their personal preferences for end-of-life care, and four central themes emerged: (1) *pain and symptom management*, (2) *clear decision making*, (3) *avoidance of medical care*, and (4) *completion*. Surgeons also reflected on both good and bad experiences with patients and family members dying, and how these experiences impact practice.

**Limitations:** The small sample size inherent to Internet surveys may limit generalizability and contribute to selection bias.

**Conclusion:** This study reveals surgeon preferences for end-of-life care, which may inform initiatives aimed at surgeons who may underuse or delay palliative care services. Future studies are needed to better understand how surgeon preferences may directly impact treatment recommendations for their patients.

**Keywords:** death; end-of-life care; palliative care; perspective; surgeon; surgery

## Introduction

EVERY YEAR, 100,000 patients die after inpatient surgery in the United States,<sup>1</sup> and most never receive palliative care services.<sup>2–4</sup> Less than one-third of patients who undergo surgery in the last year of life are referred to palliative care.<sup>2</sup> Similarly, only 25% of vascular surgery patients who died during their hospitalization were seen by palliative care,<sup>3</sup> and in another study, only 10% of palliative care referrals were for trauma or burn patients.<sup>4</sup> Furthermore, when surgical

patients do receive palliative care services, it is often within 24–48 hours of death.<sup>2,5,6</sup> Late referral is associated with aggressive interventions, poorer symptom control, and fewer hospice days,<sup>7,8</sup> whereas earlier referral may improve quality of dying and reduce rates of prolonged grief for family members.<sup>9</sup>

Studies demonstrate that physician attitudes about death and dying may be related to their willingness to refer to palliative care and hospice.<sup>10–14</sup> A survey of oncologists found that those who report more comfort with end-of-life care are more likely

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to provide primary palliative care and refer to specialty palliative care than those who report less comfort.<sup>10</sup> Similar studies have examined nonsurgeons in specialties such as internal medicine, family medicine, and emergency medicine.<sup>11–14</sup>

However, it is unclear whether surgeons, as a physician subgroup, share similar views when compared to nonsurgeons. Surgeons may have differing opinions on advance directives due to the frequent need for life-sustaining therapies in the perioperative and postoperative periods to permit patient recovery.<sup>15</sup> If surgeons prefer more aggressive interventions near the end of life, this may drive the observed discrepancies in palliative care referral and utilization between medical and surgical patients. Alternatively, if surgeons have preferences similar to those of other physician subgroups, this informs future interventions to increase earlier referral of palliative care services for surgical patients.

In this context, we sought to capture surgeon perspectives related to death and end-of-life care. We explored the values and goals of surgeons to draw comparisons with those of nonsurgeons and patients as previously described.<sup>16</sup>

## Methods

This study was part of a larger effort to identify factors contributing to the pervasive palliative care gap among surgical patients, and to better understand surgeon experiences caring for patients nearing the end of life.

### Study sample

Eligible participants included all current nonretired members of the American Society of Colon and Rectal Surgeons (ASCRS) who were  $\leq 70$  years of age. Surgeon members were invited to participate through e-mail in an online questionnaire created on SurveyMonkey (Palo Alto, CA). The recruitment e-mail was sent in April 2016 and reminder e-mails in April and May 2016. No identifiable respondent information was collected; therefore, all responses were anonymous. This study was endorsed and distributed by the ASCRS Survey Task Force and deemed exempt by the University of Michigan Institutional Review Board.

### Questionnaire format

The questionnaire was developed and modified from a previously validated instrument by the Critical Care Peer Workgroup of the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care Project to characterize barriers to optimal end-of-life care in the intensive care unit (ICU).<sup>17</sup> We augmented the questionnaire to include five open-ended questions designed to capture surgeon perspectives and experiences with seriously ill and dying patients and family members (Table 1). The goal of these questions was to gain much-needed insight into surgeon values and preferences as well as decision making at the end of life. Details of question development as well as analysis of the quantitative findings and perceived barriers to use of palliative care services have been previously described.<sup>18</sup>

### Analytic plan

Response rate was determined by the proportion of respondents who completed the survey after opening the e-mail

TABLE 1. COMPONENT OF THE SURVEY INSTRUMENT WITH OPEN-ENDED QUESTIONS DESIGNED TO ELICIT SURGEON PERSPECTIVES REGARDING DEATH AND DYING AS WELL AS EXPERIENCES WITH SERIOUSLY ILL AND DYING PATIENTS

Survey questions	
1.	Have you received any formal training in end-of-life and palliative care? Please describe.
2.	Please describe your most memorable experience caring for a dying patient. What went well? What could have gone better?
3.	Do you have a personal experience with a family member or friend dying? How has that affected the way you care for your patients?
4.	How would you want to die? What do you consider a good death?
5.	Additional thoughts.

invitation.<sup>18–20</sup> Qualitative responses were analyzed using deductive or directed content analysis.<sup>21,22</sup> B.R.D., M.J.S., and P.A.S. developed operational definitions of six major components of a “good death” identified by Steinhäuser et al.<sup>16</sup>: *pain and symptom management*, *clear decision making*, *preparation for death*, *completion*, *contributing to others*, and *affirmation of the whole person*.

B.R.D. and P.A.S. independently reviewed all of the responses from the qualitative portion of the survey and highlighted all text that pertained to death and dying. All highlighted text was coded using the predetermined categories, and text that could not be coded into one of the predetermined categories was coded *in vivo*, for example, assigning a label to a section of data using a word or short phrase. The coding team then met to discuss and resolve any coding discrepancies and to identify emergent themes. The themes were validated by triangulation among researchers and by reanalyzing the qualitative responses with the final coding structure to search for disconfirming evidence.

## Results

### Participants

Of the 2256 surgeons who received the e-mail, 796 opened the e-mail, and 131 surgeons responded yielding a response rate of 16.5%. Owing to agreements with the ASCRS Survey Taskforce, no participant characteristics were obtained. Among the 131 respondents to the survey, 117 surgeons (89.3%) completed all or part of the qualitative portion.

### Summary of findings

Surgeons' descriptions of a “good death” revealed the following components: (1) *pain and symptom management*, (2) *clear decision making*, (3) *avoidance of medical care*, and (4) *completion*. *Pain and symptom management* was defined as relief from the physical manifestations of death and disease. *Clear decision making* represented preservation of cognitive abilities allowing for continued participation in medical decision making. *Avoidance of medical care* referred to a desire for death to occur outside a health care facility while forgoing aggressive life-sustaining treatment. *Completion* was

TABLE 2. SURGEON DESCRIPTIONS OF A “GOOD DEATH”: PAIN AND SYMPTOM MANAGEMENT, CLEAR DECISION MAKING, AVOIDANCE OF MEDICAL CARE, AND COMPLETION

<i>Component</i>	<i>Surgeon reflections</i>
Pain and symptom management	“Death with no suffering” “No suffering or disfigurement” “Dying in my sleep with no pain or suffering” “Pain controlled” “Sudden cardiac event” “Sudden death in your sleep”
Clear decision making	“Would prefer to die without loss of cognitive function or profound changes in body appearance & function (i.e., would prefer not to be incontinent or grossly malnourished or after CVA but well aware that this is not controllable)” “Not with loss of mental facilities” “No mind altering or personality altering substances” “Would like to be conscious to make decisions” “In control” “Choose the time/method of death if feasible”
Avoidance of medical care	“Hospice at home” “Not in the hospital” “A pleasant environment (outside the hospital)” “Pain free death at home which is not traumatic to my loved ones” “Death in a manner not distressing to family and friends” “At home unless it bothered my kids” “Comfortably, no extraordinary measures” “Without prolonged futile high-cost care” “No heroic procedures” “No life support”
Completion	“Surrounded by family and peaceful. Able to say my good bye and thank them for all that they have given me” “Surrounded by family after I have been given the chance to thank them for their love and support” “I would like to die knowing that... I have made amends to people I’ve wronged.” “Some opportunity to tidy up affairs & say goodbye to loved ones i.e., sense of closure” “Fast enough not to suffer, but slowly enough to have time to get affairs in order and say my goodbyes” “All I ask is that I get to a point where the people who rely on me will not suffer when I am no longer with them.” “I would like to die knowing that my family is provided for emotionally and financially” “Peacefully. Respectfully. Truthfully.” “Satisfaction with my life” “Calmness and short time to say goodbye” “Being respected, keeping some of my dignity” “I’d like to die among my family, without pain, with dignity.”

defined as a sense of satisfaction and meaningfulness at the end of life. Surgeon reflections are presented in Table 2. Finally, respondents shared their experiences with death and end-of-life care, and how such experiences have impacted their attitudes and behaviors.

### **Components of a “good death”**

**Pain and symptom management.** Surgeons described the manner in which they would prefer to die and the features of the dying experience most important to them. A desire for minimal or no suffering was reported. When asked what they considered a “good death,” respondents reported, “as pain free as possible” and “without much suffering.” Similarly, many expressed a desire for rapid death, such as a “sudden cardiac event” or “sudden death in... sleep.”

**Clear decision making.** It was important for most surgeons to remain cognitively and functionally intact without “loss of mental facilities,” “profound changes in body appearance and function,” or use of “mind altering or personality altering substances.” There was also a frequent desire to die without loss of autonomy. It was important to “be conscious to make decisions” as well as a preference to “not be incapacitated or require full-time care for a prolonged period of time.”

**Avoidance of medical care.** Surgeons described the role they hoped medical interventions would play in their death, and many expressed a desire to avoid aggressive measures. One respondent preferred death “without prolonged futile high-cost care.” There was a preference for dying comfortably without the use of “extraordinary measures,” “heroic procedures,” or “life support.”

Furthermore, surgeons demonstrated a tendency for favoring death at home. Some surgeons described how they envisioned the physical environment and degree of care, with one respondent stating, “hospice at home,” and another wishing to be in “a pleasant environment” defined as one “outside the hospital.” Some were willing to rescind their wishes if it would negatively impact their loved ones. One respondent expressed a desire to die “at home unless it bothered my kids.” Only one respondent expressed ambivalence regarding the location and wrote, “with family and with the least amount of discomfort—the location (hospital vs. home) does not matter.”

**Completion.** It was important for many surgeons that death occurs in a setting with loved ones. There was a preference to be “surrounded by family,” as to “say my good bye and thank them for all they have given me” and “for their love and support.” Some surgeons desired conflict resolution at the end of life. One respondent said, “I would like to die knowing that... I have made amends to people I’ve wronged.” There was a hope to have affairs in order, and to die with minimal burden on loved ones. One respondent reported, “I would like to die knowing that my family is provided for emotionally and financially.” Another wished to “get to a point where the people who rely on me will not suffer when I am no longer with them.” Finally, surgeons often expressed hope for peace, respect, and dignity during the dying process with many wanting “satisfaction” and “calmness” at the end of life.

#### **Surgeon experiences with and desires for patients at the end of life**

Of the respondents, 76.1% reported no formal training in palliative care with a notable percentage reporting insufficient training in symptom management for seriously ill patients (40.3%) and in communication about end-of-life issues (42.7%). Surgeons commented on their perceptions of good and bad experiences with death and dying. Overall, there was an emphasis on the importance of communication and agreement (both between care teams and between care teams and families), and preparation for death. Surgeons highlighted the importance of “spending extra time with the patient and family” and having “frank discussions about prognosis and palliative options.”

Good patient deaths were described as when “everyone is on board,” and when “the patient and family have time to process and prepare.” Such experiences were facilitated by clear communication and “helping the patient/family pull away from uncomfortable, life-sustaining treatment in the setting of incurable disease.”

In contrast, surgeons described poor experiences that were characterized by inadequate communication, disagreement, and lack of preparation for death. One respondent noted a situation in which a “patient with a rare tumor never had proper counseling from [an] oncologist about prognosis,” whereas another expressed,

[I] just wish[ed] his goals of care and the reality of his prognosis had been discussed/realized sooner. [It] would have potentially saved cost and suffering.

Surgeons described examples of disagreements between care teams and within families, which led to delays in palliative care and hospice referrals. One respondent described an

experience caring for a patient with metastatic pancreatic cancer who continued to desire aggressive treatment with curative intent despite the surgeon’s efforts to communicate prognosis and encourage hospice. The respondent noted that this experience culminated in the patient, “spending a month in the hospital dealing with this and died as expected a few months later.”

Finally, surgeons reflected on their personal experiences with death and the impact on patient care. Many expressed how their experiences helped them better understand the perspective of patients and their loved ones. One respondent indicated, “I now understand the appropriateness of family involvement in every conversation about care,” whereas another respondent shared, “My father’s death made me realize that it is a process the entire family should share.” In some cases, personal experiences with death changed the way respondents communicated with patients and families. One respondent commented, “I began to speak more frankly with patients about treatment options, rather than requirements.”

Although surgeons expressed a preference for death outside a medical facility, one respondent described how the demise of a parent “in an inpatient hospital setting was a huge improvement over home/hospice” in the context of complex medical needs the family could not meet at home. The respondent commented,

There is a presumption/prejudice that the best death is at home with hospice care. We should not be imposing our own prejudices of ‘best death’ scenarios... it should be taken on a case-by-case basis.

Likewise, another respondent cautioned against a single “one-size-fits-all” approach to life and death within the medical field.

#### **Discussion**

To our knowledge, this is the first study aimed at examining surgeon preferences regarding death and end-of-life care. Overall, surgeons favored (1) *pain and symptom management*, (2) *clear decision making*, (3) *avoidance of medical care*, and (4) *completion*. Furthermore, surgeons reported their perceptions of good and bad dying experiences, and how such experiences influence the care they provide.

The surgeons surveyed in this study expressed preferences for end-of-life care similar to studies of physicians in medical specialties and nonphysicians.<sup>15,16,23–27</sup> Specifically, surgeons expressed a desire for a painless and peaceful death surrounded by loved ones. In contrast to prior studies, we found that surgeons were more explicit about avoiding aggressive and prolonged medical care at the end of life.

The surgeons surveyed in this study may have been more candid than prior reports of nonsurgeons due to their routine exposure to the suffering of seriously ill patients. Furthermore, surgeons may be more acutely aware of the poor quality of life and futility often associated with aggressive interventions at the end of life, and may have a greater understanding of the risk-balance trade-offs of specific treatments or operations given their experiences and expertise.<sup>15,28</sup> Finally, although surgeons indicated similar preferences overall, the responses that did not conform demonstrate the importance of always individualizing care based on the preferences of each patient rather than operating on presumptions.

Our results are consistent with other studies examining physician preferences for fewer interventions at the end of life; however, there is still uncertainty regarding whether actual care received is congruent with these preferences for both physicians and nonphysicians.<sup>15,23–25</sup>

For example, a survey of physician graduates from John Hopkins University Medical School indicated that they would forgo life-sustaining medical treatments in the event of a brain injury resulting in the inability to recognize others or to speak.<sup>23</sup> Multiple surveys of physician preferences at the end of life are consistent with these findings, yet a recent study comparing health care utilization at the end of life between physicians and nonphysicians demonstrated that despite similar hospitalization rates, physicians spend more days in the ICU in the last six months of life (3.1 vs. 2.8,  $p < 0.001$ ).<sup>28</sup> Although there were no differences between proportions of physicians and nonphysicians who died in the hospital, physicians were more likely to use hospice (odds ratio 1.21, 95% confidence interval 1.16–1.27).

Additional investigation is needed to resolve these conflicting findings and to better understand the discordance between patient and physician preferences for end-of-life care and actual care received. This is particularly relevant given physicians' intimate familiarity with health systems and expert knowledge of the limitations of medical care. The etiology for this discrepancy is likely multifactorial encompassing both physician and systemic factors. Physician factors include a tendency toward overly optimistic prognostication as well as their limited knowledge, comfort, and experience in providing palliative and end-of-life care. Systemic factors include a default to full intervention for all patients, financial incentives to provide high-intensity care, and lack of reimbursement for end-of-life care conversations.<sup>15,29,30</sup>

Future studies examining the use of invasive interventions at the end of life between surgeons, physicians, and nonphysicians may provide insight into the high rate of surgery at the end of life and the delay or lack of palliative care services in surgical patients.<sup>2–6,31</sup> In addition, efforts should identify whether surgeon perspectives around death and dying vary based on the nature of illness, such as medical or surgical.

Despite shared values between surgeons and nonsurgeons, surgical patients do not receive timely palliative care referrals.<sup>2,5,6</sup> The lack of or delay in receipt of palliative care services among surgical patients may be a consequence of challenges unique to surgical practice. The concept of “surgical buy-in” has been described, in which a surgeon's agreement to perform a high-risk surgical procedure is contingent on the underlying assumption that the patient commits to all postoperative care.<sup>32</sup> As a result, surgeons may tend to delay the decision to refer to palliative care or withdraw life-sustaining interventions.

Surgeons struggle with providing definitive recommendations on whether to continue or terminate life-sustaining therapies despite futility with ongoing treatment.<sup>33</sup> Our study further supports this phenomenon by demonstrating that surgeons shared preferences similar to those of their patients, yet they expressed difficulty in conveying their professional opinions. Although we did not directly inquire how surgeon preferences affect how they practice, the discrepancy between surgeon preferences and the care patients receive represents a potential avenue for expanding the use of palliative care services in surgical patients.

Specifically, this discordance may evoke an internal conflict for surgeons and serve as a prompt to reevaluate the goals and values of their patients through palliative care consultations. An important next step will be to better understand the influential factors in the decision to initiate end-of-life care conversations as well as the factors surgeons believe to most influence the outcomes of these conversations.

Our study had several limitations. First, the response rate was low, suggesting selection bias and response bias must be considered when evaluating the generalizability of our findings. Of note, the original work validating the survey instrument had a higher physician response rate of 31.7% but used a self-administered mail survey versus an online format. E-mail surveys, in general, have an ~20% lower response rate than mail surveys.<sup>34</sup> Also, our response rate corresponded to that of other web-based surveys of surgeons, and response rate thresholds are no longer considered the only measure of survey quality.<sup>20,35–38</sup> It is also possible that the differences between respondents and nonrespondents were related to a lack of interest or time in completing surveys in general, rather than their experiences or preferences surrounding death and end-of-life care.

Second, we were unable to collect demographic information and, therefore, could not fully characterize the study population. We note, however, that generalization is not a goal of qualitative research; rather, the goal is to provide contextualized experiences and perceptions of study participants.<sup>39,40</sup> Despite these limitations, these perspectives represent an important first step to characterize the viewpoints of surgeons with experience caring for seriously ill and dying patients.

In conclusion, we have identified and characterized surgeon preferences for death and end-of-life care. Surgeons had preferences similar to those of their nonsurgeon counterparts but were more explicit in their desire for limiting aggressive measures at the end of life, and valued palliative care approaches and specialist teams when available. With the knowledge that health systems incentivize procedures despite little or no benefit at the end of life, this intimate view of surgeons' personal preferences indicates a critical need for future studies to better align professional opinions, patient preferences, and care provided.

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