

Capstone for Impact Submission | GY2020

Project Title: Exploring Surgeons' Values and Perspectives Regarding Death and Dying: A Call to Better Honor the Preferences of Surgical Patients at the End of Life

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Summary:

Many surgical patients do not receive palliative care, and when they do, it is commonly within 24 to 48 hours of death. Late referral to palliative care has important consequences, as it is associated with greater use of aggressive and/or futile interventions at the end of life and poorer quality of dying with fewer hospice days and worse symptom control. Although palliative care encompasses end-of-life care, it is ideally provided to all seriously ill patients at any stage of disease.

The etiology behind delayed palliative care referral in surgical patients is unclear and likely multifactorial. Several studies of non-surgeons demonstrate that physician attitudes and beliefs about death and dying may be related to their willingness to refer to palliative care services and may partly explain late referral.

It is unclear whether surgeons share similar views when compared to other physician subgroups. On one hand, surgeons may have different opinions on advance directives, for example, given the frequent need for life-sustaining therapies in the perioperative and postoperative periods. If this is the case, this may partly explain the observed discrepancy in palliative care referral and utilization in surgical and medical patients. On the other hand, if surgeons and other physician subgroups share similar opinions, this would encourage future interventions to facilitate earlier and increased palliative care referral and utilization in surgical patients.

To this end, our objective was to describe surgeons' values and perspectives related to death and end-of-life care, in order to compare them with those of non-surgeons previously described and better understand their relationship to delayed palliative care referrals in surgical patients.

Methodology:

This study was part of a larger effort to identify barriers contributing to the widespread gap in palliative care utilization in surgical patients and to better understand the experiences of surgeons caring for these patients. In order to achieve this, a convergent mixed methods design was employed using a previously validated survey instrument augmented with five additional qualitative questions.

The survey questions included:

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.*

Surgeon members were invited to participate through e-mail in an online questionnaire. Eligible participants included all current nonretired members of the American Society of Colon and Rectal Surgeons (ASCRS) who were 70 years of age or younger. Our response rate was 16.5%. Close to 90% completed all or part of the qualitative portion. This study was endorsed and distributed by the ASCRS Survey Task Force. Per agreements with the taskforce, no participant characteristics were obtained. This study was deemed exempt by the University of Michigan Institutional Review Board.

Qualitative responses to the five questions were analyzed using deductive or directed content analysis.

Results:

In surgeons' descriptions of a "good death," four unifying components emerged: (1) *pain and symptom management*, (2) *clear decision making*, (3) *avoidance of medical care*, and (4) *completion*.

First, pain and symptom management was defined as relief from the physical manifestations of death and disease. There was a tendency to report a desire for minimal or no suffering. Similarly, many expressed a desire for a rapid death, such as a "sudden cardiac event" or "sudden death in...sleep."

A second component that emerged was clear decision making, defined as the preservation of cognitive abilities allowing for continued participation in medical decision making. It was important for many surgeons to remain cognitively and functionally intact without "profound changes in body appearance and function," "loss of mental facilities," or use of "mind altering or personality altering substances." Surgeons also expressed a preference for autonomy, as it was important to "be conscious to make decisions" and "not be incapacitated or require full-time care for a prolonged period of time."

Third, avoidance of medical care referred to a desire for death to occur outside a health care facility while forgoing aggressive life-sustaining treatment. There was a common tendency for surgeons to favor death at home. One respondent stated, "hospice at home," and another wished to be in "a pleasant environment" defining it further as one "outside the hospital." Some were willing to rescind their wishes if it would negatively impact their loved ones, with one surgeon expressing a desire to die "at home unless it bothered my kids," and another stating, "death in a manner not distressing to family and friends." 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." Surgeons frequently specified the role they hoped medical interventions would play at the end of life. There was a preference for dying "without prolonged futile high-cost care," "heroic procedures," and "life support."

Finally, surgeons described valuing completion, which was defined as a sense of satisfaction and meaningfulness at the end of life. It was important for many surgeons that death occurs in a setting with loved ones. One surgeon remarked, "surrounded by family, after I have been given the chance to thank them for their love and support." There was a preference 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." Many wished for satisfaction, calmness, and dignity at the end of life.

With regards to education and training, a majority of respondents reported no formal training in palliative care with nearly half reporting insufficient training in both symptom management for seriously ill patients and in communication about end-of-life issues.

Surgeons commented on their perceptions of both positive and negative experiences caring for patients at the end of life. Features of optimal experiences with such patients included clear communication and agreement (both between care teams as well as between care teams and patients/families) and adequate preparation for death. One respondent described how the presence of these elements facilitated in “helping the patient/family pull away uncomfortable, life-sustaining treatment in the setting of incurable disease.” Conversely, surgeons commented how the lack of these elements often resulted in challenging experiences caring for patients at the end of life. One surgeon reflected on one such experience and how, “[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.”

And while there was a tendency for surgeons to express a preference for death outside a medical facility, some did warn against a single “one-size-fits-all” approach. 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. They further expressed, “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.”

Conclusion:

Surgeons described their preferences for death and end-of-life care, favoring pain and symptom management, clear decision making, avoidance of medical care, and completion.

Surgeons had preferences similar to those of physicians in medical specialties and non-physicians previously described, but were more explicit about limiting aggressive measures at the end of life. A possible explanation may be that given their frequent exposure to the suffering of seriously ill patients, surgeons are acutely aware of the poor quality of life and futility often associated with aggressive interventions at the end of life and may have a better understanding of the risks/benefits of invasive treatments and operations.

Future investigation is needed to determine whether actual care received corresponds to the preferences of both physicians and non-physicians. There is conflicting evidence to date with one finding that physicians have higher palliative care utilization in the last 6 months of life compared to non-physicians and another that they have higher ICU utilization in the last 6 months as well. Nonetheless, the potential discrepancy between preferences and care received speak to the importance of identifying and addressing the likely multifactorial etiology, which includes both individual factors, such as overly optimistic prognostication on the part of physicians and limited knowledge and experience in providing palliative care, as well as systemic factors, such as our system’s tendency to default to full intervention and provide incentives for high-intensity care with lack of reimbursement for end-of-life care discussions.

With regards to communication, the surgeons in this study described it challenging to convey their professional opinions regarding futility of ongoing interventions, despite holding preferences similar to patients previously described. This represents a potential strategy for increasing the utilization of palliative care services in surgical patients. For example, the discordance between the preferences of the surgeon and the care their patient is receiving may prompt a reevaluation of the patient’s goals and values, such as through palliative care consultation. Additional investigation is needed to identify which factors prompt surgeons to initiate end-of-life care discussions and which they believe have the greatest impact on the outcomes of these discussions.

Reflection/Impact Statement:

Many surgical patients do not receive timely palliative care. Physician attitudes and perspectives may represent both a contributing factor and target for addressing this delay. To our knowledge, this is the first study to describe surgeon values and preferences regarding death and end-of-life care. Overall, surgeons expressed values and preferences similar to those of patients previously identified, yet described difficulty in communicating their professional opinions to patients and families. Implementation of communication tools and strategies for improving physician prognostication and comfort in providing/consulting palliative care may lead to increased palliative care utilization among surgical patients and improved quality of dying.

This project provided me with valuable experience in carrying out a study from the initial stages of background research and hypothesis generation to the later stages of data analysis and dissemination of our findings through an oral presentation and publication in a peer-reviewed journal. I have a new understanding of this process, which I will apply to future research pursuits. I also gained an appreciation for the value of both qualitative and quantitative data as well as the synergy that can be achieved when both are collected and analyzed.

Although I am not going into a surgical specialty, I plan to use what I learned from this project in my future training and career as an internal medicine physician, specifically in my direct interactions with patients, families, and colleagues as well as in my advocacy for more systemic changes to improve palliative care utilization for all patients.

Reference:

Dillon, B.R., Healy, M.A., Lee, C.W. et al, Surgeon perspectives regarding death and dying. *J Palliat Med.* 2019;22:132–13