

Surgery and the D-Word: Approaching the Topic of Death and Dying with Surgical Patients

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Abstract

The topic of death and dying arises frequently in surgical practice, yet represents one of the more challenging areas for many surgeons. Surgeons must feel comfortable addressing the issue of death whether it is a theoretical concern in the context of routine informed consent or an inevitable reality in the setting of end-of-life care. In the palliative setting, four essential elements must be present in order to properly address death and dying: compassion, communication, clarity, and closure. The skills set for optimally dealing with this topic in a surgical practice must not be assumed, but fortunately can and should be learned and nurtured during education and training and beyond. This will help ensure that Surgery as a profession maintains its commitment to leading the public discourse regarding death, surgery, and patient-centered policies that inform and protect.

Keywords: Palliative surgery; Risk; End-of-life; Consent; Mortality; Compassion; Communication; Complications; Discourse; Closure

Introduction

There was a time that those who are old enough may remember when it was socially awkward or even unacceptable to utter the word, "cancer". It was often whispered and frequently abbreviated as "C-A" for fear that saying it too loudly might engender stares of disapproval. Those times have long since passed, and for the most part, we can now speak openly and publicly with one another about cancer. Fund-raising events, foundations, public service announcements, outreach efforts, and research initiatives have all raised public awareness, and have as a result, made us more comfortable discussing cancer with our patients. The words we now have trouble uttering are "death", "die", and all the derivatives.

Why most of us do not feel comfortable discussing death is not entirely clear, but one of the most readily apparent reasons may be the inherent fear of death itself. In her landmark *On Death and Dying* more than four decades ago, the visionary Elizabeth Kubler-Ross brought death into the public discourse and reminded us that, "Death is a fearful, frightening happening, and the fear of death is a universal fear even if we think we have mastered it on many levels." [1]. The less comfortable we are with the topic, the less likely we are to talk about it with our patients. We may consciously or subconsciously assume that patients do not want to discuss their own death, or we lack confidence in our ability to carry out such a discourse in a compassionate and effective manner. Nonetheless, the failure to discuss this topic begins with ourselves. Surgeons may feel that mentions of death in relation to surgery project a lack of confidence in their technical skills, or worse, suggest an expectation of poor outcomes. Worries arise that these open discussions may prompt our patients to seek another surgeon or forego surgery altogether.

Socio-political factors can create barriers to open and honest dialogues about death, which at times seems like a politically incorrect word. Terms such as "death panel", sometimes frivolously thrown about by uninformed politicians and others, accent, and even exploit, the negative connotations of the word. These inflammatory terms become incorporated into public discourse regarding policies that impact end-of-life healthcare, potentially extinguishing nascent health policy development and squelching important discourse within healthcare communities and our professional discipline. However, many of the key issues relating to quality, value, and access to healthcare today

cannot be discussed in any meaningful way without explicitly talking about death.

Despite this, surgeons can and do discuss death on a regular basis. We discuss it at clinical and scientific meetings, at quality assurance and morbidity/mortality case conferences, and with families in the aftermath of a poor outcome. We discuss death in many forums, for many different reasons, and with many different people. But as a surgical community we do not adequately or consistently address the issue of death with the people we are here to serve -our patients.

There are a variety of settings in which it is vital for a surgeon to have the ability to discuss death and the events that might lead up to death openly, honestly, and compassionately, allowing patients to feel comfortable and empowered, rather than shell-shocked or overwhelmed. Whenever possible, the discussion should take place over more than one meeting with the patient, and it is helpful and sometimes crucial to have one or more family members, friends, and/or significant others present. Three situations in which surgeons may benefit from a strong skill set in discussing death include: (i) the informed consent process, (ii) surgical procedures in the end-of-life setting, and (iii) high-risk surgical procedures.

Discussion of Death as Part of Routine Informed Consent

The importance of transparency with regard to the risk of mortality associated with surgery cannot be overstated. This assertion may be supported with an analogy from financial investment. If approached by someone offering an attractive investment opportunity, most of us would demand that major risks be revealed. If there were a significant chance of losing the *entire* investment, we would insist on

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being notified of that possibility and the relative likelihood that this would occur. Since most would agree that one's life is more valuable than financial investments, similar information regarding the risk of catastrophic outcomes should be provided before a decision is made regarding whether to undergo surgery.

The "informed consent process" for surgery comprises a series of steps in which a patient, or appropriate surrogate, of legal age and competence is educated regarding the nature of a procedure, as well as the anticipated benefits and risks, is afforded the opportunity to have questions about the procedure answered to his/her satisfaction, and is able to make a willful decision regarding whether to undergo the proposed procedure. The actual piece of paper referred to as a "consent form" is simply one form of documentation - ideally not the *only* record - that the informed consent process took place. Despite the requirement to document death as a concern in the consent form, discussion regarding the risk of death is often under-emphasized or altogether omitted during this process.

In fact, there is no dictum that death must be included among the risks of every surgical procedure; when the risk of death is so low as to be unexpected and highly improbable, including it may actually be misleading. A surgeon may consciously or subconsciously invoke the "therapeutic privilege" in which the use of deception is rationalized in the name of preserving the patient's hope and protecting the patient from stress, anxiety, and/or mental anguish [2]. However, if the surgeon knows the risk of death to be "high enough" to disclose, then this adverse outcome should be discussed among the risks, and the patient must be informed (in a manner he or she can comprehend) of the relative risk of mortality. How high is high enough? There is no universal answer to this question, but it may range from *any* chance of death to about 0.1% risk as a reasonable threshold for inclusion.

Advancing the consent process to be more open, honest, comprehensible, and interactive, especially regarding the life-threatening risks of surgery and death itself, requires a multi-pronged effort. First is education, beginning in medical school and continuing throughout the surgeon's career, which should include (i) comprehensive education regarding the consent process itself from a legal, ethical, and medical perspective; (ii) cultivation of effective communication skills, especially with respect to sensitive topics such as death; and (iii) continuous updating of knowledge regarding the relative risks of various surgical procedures and best practice approaches in doctor-patient communication. Second, from a health system standpoint, there should be processes and procedures in place to ensure that appropriate patient education, informed consent, and documentation is easy to conduct in a consistent manner. Electronic means, such as online videos and electronic health records, may also help by providing an efficient method for role-modeling and updating practice as new techniques are identified. Third, from a health policy and public health standpoint, informed consent, inclusive of the disclosure of death and other catastrophic risks, must be incorporated into the forum of public education and public dialogue. As with many aspects of medicine and surgery, culture changes over time, as it has with the culture of safety, now a norm of behavior. Promoting a culture of transparency with regard to the risks of surgical procedures, including death and other catastrophic outcomes, will ultimately establish a comfortable environment of two-way communication for both the patient and surgeon.

Discussion of End-of-life Surgery in the Context of Palliative Care

Surgeons are frequently asked to perform procedures that provide

comfort and improve quality of life in the setting of advanced life-limiting illness and in those with terminal disease. In a review conducted by Krouse and colleagues, 12.5% of surgical procedures at one major medical center were palliative [3]. These data reflect cases performed from 1998 to 1999; with increasing use of procedures such as video-assisted thoracoscopic surgery, intraperitoneal chemotherapy, gastrointestinal and tracheobronchial stent placement, and other palliative interventions, one might hypothesize that the proportion and absolute numbers of palliative surgeries have increased substantially. Clearly, given the regularity of surgical consultation regarding the potential role of palliative surgery, it is imperative that surgeons exercise good judgment, participate in multi-disciplinary care, and communicate effectively with patients, families, and other members of the healthcare team. The surgeon must be more than just a "technician".

The clinical problem of malignant bowel obstruction illustrates the importance of active involvement of the surgeon as a member of the healthcare team. The surgeon is the one who is best equipped to convey that while major surgery may be the only option that could allow the patient to eventually eat again, and conceivably prolong life by weeks to months, there is no guarantee of this, and the risk of complications may be high. Complications in this setting have the potential to erode the theoretical improvement in quality of life the procedure may have otherwise afforded. While the potential risks may not necessarily outweigh the potential benefit of palliative surgery, careful consideration and effective communication are essential to determining whether such a procedure is appropriate for the individual patient.

A discussion of the potential benefits and risks of palliative surgery cannot be considered complete without discussion of other common options for treatment. If a patient hears only about surgical options of treatment from the surgeon, this could bias the patient toward or against surgery, particularly reflecting the bias of the surgeon. While impossible for a surgeon to completely eliminate his/her bias from discussions with patients, failing to discuss and equally emphasize alternatives may contribute to this bias and decreases the chance that the best decision for the individual patient will be reached.

This problem may be mitigated by a willingness of the surgeon to speak openly about death and the practical issues that a person with life-limiting illness faces. The clinical problem at hand is one relating to the process of dying. The solution, therefore, should also revolve around the process of maintaining the highest quality of life for the period of life left and it should be framed in that manner. The surgeon must build upon the core skills used routinely in conducting the informed consent process, and incorporate new skills for palliative care and communication in the setting of advanced life-limiting illness. The palliative triangle [4-6], a concept involving shared decision-making among the patient, family and surgeon, has been advocated as a useful paradigm in this context [6]. There is no easy way to discuss end-of-life clinical management, but four key principles to bear in mind include *compassion, communication, clarity, and closure*.

Compassion

There is no substitute for compassion, and it is imperative for discussions of end-of-life surgery. Yet beyond *having* a sense of compassion, which surgeons presumably already possess, is the ability to *express* compassion, made possible through emotional intelligence and good communication skills. The ability to show compassion in difficult clinical situations also necessitates *commitment* to showing compassion. Particularly for surgeons who are less experienced with end-of-life care and conversations, a conscious checklist is warranted before walking into the patient's room:

- Do I myself understand the clinical scenario and the management options?
- Am I committed to educating the patient/family regarding these options?
- Am I in a state of mind such that I can carry out such a discussion?
- Do I have the time to commit to such a discussion?

If the answer to any of these questions is “no,” then the surgeon needs to determine what must happen to shift the answer to “yes,” or the discussion should take place at a different time or should be conducted by another surgeon. Afterwards a simple mental self-assessment or debriefing is indicated; the most fundamental question is: “When I walked out of the room, was the patient convinced that my number one priority was his/her well-being?”

Communication

Much of what physicians - including surgeons - do in their day-to-day profession involves communication. A successful surgical practice is, in part, dependent on the quality of communication with patients, family members, health care professionals, administrators, and a host of other stakeholders. It is tempting for a busy surgeon to assume, therefore, that he or she is a good communicator. This, of course, may not be the case, and deficiencies in communication skills may be particularly evident in the context of end-of-life discussions.

Thomas Miner has emphasized the critical nature of communication skills in the discussion of surgical palliation and end-of-life matters and has reviewed a framework for enhancing communication in this setting [7]. In this review he offers the CLASS protocol of Buckman as a potential resource to guide medical communication [8]. In this paradigm, CLASS represents an acronym for five elements of effective communication: *context* (establishing the proper setting and demeanor), *listening*, *acknowledgment* (of emotions), (management) *strategy*, and *summary*. Buckman has also described a variant of this approach that is particularly useful at times of high stress, such as during a discussion of upsetting news. The SPIKES protocol refers to the appropriate *setting*, patient's *perception* of the situation, *invitation* from the patient to the physician to provide information, *knowledge* transfer, and acknowledgment of *emotions* [8]. Importantly, teaching communication regarding palliative surgery and end-of-life issues as part of the core curriculum during residency can have a dramatic impact on the ability and comfort level of trainees in discussing these matters [9].

Clarity

While compassion and communication are vital to the conduct of difficult conversations about end-of-life surgeries, upon concluding a discussion with a patient and/or family, clarity is of utmost importance. Hence, this element of communication deserves special mention. The surgeon must be able to discuss death not as a theoretical or improbable possibility, but rather as a distinct near-term possibility or inevitability. When discussing palliative surgeries, it is important to emphasize that cure is not expected and that the focus must be on symptom management and improving quality of life regardless of the length of life. Physicians may be averse to or even avoid giving patients precise prognostic estimates. This may occur in part because of the need to deliver “bad news” and/or because of a concern about being incorrect, and, in fact, there is a tendency for physicians to convey overly optimistic estimates [10,11]. Nonetheless, when patients wish to know, it is appropriate to provide this information. Surgeons must

distinguish clarity from extinguishing hope; outcomes can be framed in a positive way, as a focus on comfort and quality of life. Nonetheless, a patient and his/her family should have as much time as possible to carefully consider options and prepare for death, and the surgeon should contribute to this in an effective, positive manner whether surgery plays a role in the management or not.

In the discussion of surgery, clarity also mandates that the *goals* of surgery be clearly stated and understood. This is particularly important in the context of palliative surgery because it may necessitate complex or unconventional procedures that may be difficult for the patient to understand. For example, some patients with malignant bowel obstruction have carcinomatosis and/or a pattern of obstructing lesions such that resumption of an oral diet may not be a realistic goal. This often directs the conversation more specifically to symptom control and whether surgical procedures should play a role in management.

Closure

Despite the gravity of the situation, overwhelming realities, and potentially confusing treatment options offered, patients and/or family members must still make an informed decision regarding surgery. While some type of time frame for decision-making is implicit, it is common for there to be difficulty in reaching a decision. While it is important to provide enough time and guidance for patients and their loved ones to reach the best decision for them, it is imperative to reassure them once the decision has been made that this is an acceptable and appropriate option under the circumstances. It is important to emphasize that dying is an inevitability that every human being will face and that what we can control - comfort, dignity, and the presence of loved ones - should be accomplished according to the wishes of the individual person. Putting this into perspective for the patient and family, and ensuring that they have control over the aspects of their life that they can, will help to provide much-needed calm and closure in an otherwise confusing and overwhelming time.

Death and High-risk Surgery

The previous two sections focused on two ends of a spectrum of mortality risk: the typical surgical consent for routine procedures and discussion of end-of-life surgery. Not uncommonly, very high-risk surgical procedures are performed in a setting in which death does not represent inevitability, but rather a very real possibility, and yet there is a significant chance for cure or long-term survival. Surgeries with mortality risks ranging from 5% to >50% fall into this category, such as emergency surgeries, high-risk cardiovascular procedures, and surgical procedures performed for advanced malignancy (emergent procedures that must be performed so quickly that informed consent is considered implicit for the patient's well-being are beyond the scope of this discussion). For example, major surgical procedures performed within 30 days following a myocardial infarction have a post-operative risk of death that exceeds 15% at 30 days and 50% at one year [12]. In the realm of oncology, complex sometimes multi-visceral resections performed for advanced malignancies are associated with major complication rates exceeding 50% and risk of death exceeding 5% [13].

Like discussions of death in the context of routine procedures and end-of-life procedures, it is of utmost importance to establish clear goals of surgery and to ensure that the patient understands them. Essentially, the surgeon builds a communication toolbox incorporating the skills of discussions about death as a potential complication for routine procedures and the realities of end-of-life within the context of palliative surgeries. He or she is thus able to blend discussions in the midst of the anxieties of life and death decision-making within these

key skills sets, creating a patient-centered communication portfolio appropriate for application even to the tough scenario of high risk surgery.

In general, there are two potential goals of virtually all surgeries: (i) to alleviate a symptom or symptom complex and (ii) to treat the underlying disease process. A particular surgery may achieve one or both of these goals; in some circumstances -sometimes because of a failure to clearly delineate intent -it may achieve neither. In order for a patient to understand and consent to a high risk surgical procedure, particularly when associated with a substantial risk of perioperative death, it is essential for them to understand the potential value of surgery along these two dimensions. When it is unclear that one or both of these goals may not be successfully met, as is often the case with heroic procedures, the patient must be able to accurately weigh the benefits and risks, each adjusted for the estimated probability of each. It is entirely appropriate for the surgeon to emphasize that the most worrisome risk is death and to give a best-estimate of its probability, and to explicitly point out that this is the primary concern regarding the decision to proceed with surgery.

Conclusion

Death is a word and concept that we often wish were not a part of medicine. It reflects a failure to save patients from dreadful diseases, and it represents the imperfect nature of modern medicine and those who practice it. But it also represents an intrinsic and inevitable part of life, and thus an important facet of the job of a surgeon. It is natural to fear death itself, but that must not deter surgeons from discussing the topic with patients.

The ability of surgeons to discuss death with patients in an honest, comprehensible, and compassionate manner is a fundamental aspect of our profession. It is indeed possible to improve patient-centered communication about palliative care and end-of-life issues within general surgery residency training [6,9]; this should become part of our continuing professional development, as well. It is imperative that

we, as a professional surgical community, maintain our commitment to leading the public discourse regarding death, surgery, and patient-centered policies that inform and protect.

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