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“I wish someone had asked me earlier” – Perspectives on Advance Care Planning in Surgery

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Mini Abstract

Recent controversy has called into question the meaning and clinical utility of Advance Care Planning (ACP), however data have consistently shown potential benefit to patients and their surrogate decision makers. We present the concept of surgery-specific advance care planning and a structured, scalable approach to integrating it into clinical practice.

We cared for a 92-year-old woman who presented with perforated diverticulitis requiring emergency surgery. When asked about her goals of care and surrogate decision maker, she said, “I didn’t realize this would happen so quickly, I wish someone had asked me earlier.” Efforts to encourage, coordinate, and record wishes prior to crisis are important components of patient-centered, evidence-based surgical care.

Advance Care Planning (ACP) has consistently been associated with decreased anxiety/depression, post-traumatic stress disorder, complicated grief, and caregiver burnout,¹ yet it remains an underutilized and under-explored area of surgical practice and has recently been the subject of vigorous debate^{2,3} that has enlivened the conversation about how patients and surrogates are prepared for communication about medical decision-making. Some have argued that the benefits of ACP have not been realized because increases in ACP rates in primary care have not led to decreases in utilization or costs.³ We propose that a major shortcoming of this argument is that ACP is much more than just legal documentation and instead is “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding current or future medical care and prepares them for communication and decision making.”⁴

The emphasis on ACP as an iterative process, which prepares patients and their family and friends ‘today’ for decision making in the future, is especially well-suited to the surgical encounter because of the inherent risks of major surgery. An operation represents a unique, often acute, and time-limited change in a patient’s health trajectory and therefore warrants a unique process to understand and share personal values, life goals, and preferences.⁴ Furthermore, the surgical team has a critical perspective on surgical risk and, more importantly, post-operative recovery and implications for functional status. Surgeons nearly

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universally discuss risks, benefits, alternatives, and the potential for unanticipated outcomes with patients through the process of informed consent. However, too rarely are these conversations accompanied by a simultaneous process in which patients are supported to integrate their own goals and preferences with treatment recommendations.² The exploration, articulation, and documentation of these goals and preferences perioperatively forms the basis of a surgery-specific ACP. Although ACP has recently been portrayed as separate from “in the moment decision making,”³ decisions made at the time of crisis are nearly universally predicated on preexisting preferences and goals. Surgeons have an imperative to provide guidance on how a proposed treatment plan aligns with patient’s goals and preferences, a process facilitated by ACP.

Prior efforts to develop ACP for surgical patients have been hampered by a lack of sustainability and scalability, with roadblocks in engaging both surgeons and patients. These shortcomings are largely due to the unique challenges inherent to surgical practice, such as lack of time and difficulty with prognostication, the time-sensitive nature of surgical plans and changing preferences.⁵ There may be a disconnect between preferences that patients detail in their ACP documentation and clinical reality, highlighting that real life situations can have significantly more variables than can be accounted for in documentation.⁵ Finally, training for difficult conversations is lacking and leads to reticence in having these discussions, with up to 44% of surgeons avoiding ACP because of a lack of know-how.⁶

Factors embedded in the culture of surgery, such the inherent optimism in the patient-surgeon relationship, and manifestations of trust, influence perioperative ACP. Another of these factors is the concept of ‘surgical buy in’, wherein a surgeon’s normative response of “doing everything possible to save the patient” engenders a perceived need to create an unspoken contract between patient and surgeon in which the patient “buys in” to post-operative treatments, yet surgeons remain reluctant to discuss limiting life-sustaining therapy.⁷ According to a secondary analysis of a randomized clinical trial that looked at the frequency of ACP in older adults undergoing surgery, surgeons rarely discuss ACP with patients,² but in another study, 81% of 912 surgeons surveyed said they routinely discuss preferences to limit life-sustaining therapy with patients preoperatively.⁸ This disconnect between perception and reality highlights that ACP conversations can be difficult, and that training efforts are needed that not only provide practical tools for conversation, but also to address self-awareness.

Though some data⁹ show modest improvements in surgical ACP rates with programs to engage patients, these efforts have been personnel-, resource-, and time-intensive and therefore usually not scalable beyond the research context. For example, our institution attempted to increase ACP discussions with vulnerable older adults through biweekly phone contact from trained health coaches with scripted conversations regarding ACP, but this resulted in only modest changes in rates of documentation.⁹

Given past and current challenges with widespread adoption of ACP into surgical practice and culture, we propose the following solutions and roadmap:

- **Centralize and standardize documentation** – Efforts to streamline and centralize documentation of ACP conversations with readymade note templates

in the electronic health record (EHR) can make documentation simple, standardized, and readily accessible to everyone caring for a patient (Figure 1). To this end, based on the American College of Surgeons Geriatric Surgery Verification program and the literature, we have developed a templated surgical ACP note, which documents patient's preferences, goals, and surrogates related to the surgical disease and/or procedure. This ACP note is viewable from both the "Notes" section and an ACP Navigator within the EHR, which houses all ACP-related information (e.g., surrogate decision maker if available, ACP notes, and code status). Recognizing that everyone has a different level of comfort conducting ACP conversations, we encourage members of the care team to complete as much as they can of the templated note – starting with the identity of, and contact information for, the surrogate decision maker.

- **Engage the entire care team** – We promote using an integrated, iterative approach to ACP that harnesses the expertise of modern transdisciplinary health care teams, including patients, physicians of all disciplines, advance practice professionals (APP), chaplains, and social workers. In qualitative interviews we have found that sometimes, patients feel more comfortable discussing ACP with members of the care team other than the surgeon. We have used these preliminary observations to integrate routine APP-led discussion of ACP with patients during a pre-operative telephone visit in which patients are instructed on how to prepare for surgery (e.g., bowel prep if needed for colorectal procedures). Recognizing the importance of the care team, Medicare has introduced Current Procedural Terminology (CPT) codes to reimburse clinicians, including with collaboration from APPs and social workers, for time spent providing ACP services.¹⁰ To integrate ACP across the care continuum, it is increasingly imperative that we find ways to discuss and document patient goals and preferences. Programs such as accreditation in Geriatric Care for Emergency Departments have emphasized the unique needs of caring for older adults, including emphasis on improving information transfer with primary care providers or long-term care or community services. This information transfer should include receipt and review of any pre-existing ACP documentation when available, as well as communication about this documentation to specialists involved in the patient's care.
- **Enable patients to engage in ACP** – In order to engage patients and their family and friends in ACP in a sustainable and scalable way, we are piloting the use of an evidenced-based website called PREPARE, which is based in behavior change theory and the new paradigm of ACP that focuses on preparing patients and surrogates for complex medical decision making.⁴ The PREPARE website, which is easy to use, patient-facing, and requires no clinician- and/or system-level intervention, has been demonstrated to increase ACP documentation.⁴ Patients are prompted through EHR messaging to navigate through the PREPARE website before starting their surgical care. The surgical team is best equipped to conduct a focused ACP discussion within the context of the surgical diagnosis and procedure, which we term surgical ACP. However,

collaboration with primary care providers remains imperative to facilitate ACP in surgery.

- **Connect with historically marginalized populations** – Rates of ACP documentation have been consistently lower among patients with limited English proficiency, including in our own institution. Concerted efforts to involve these vulnerable groups in perioperative ACP are needed, lest we continue to exacerbate existing disparities. Future research in surgical ACP needs to address not just efficacy and scalability but also identify strategies to engage patients from historically marginalized groups. There are likely myriad factors, including communication-barriers in patients with limited English proficiency, varying views on autonomy and decision making, and cultural norms that may be different among certain groups of patients.

Surgeons and transdisciplinary surgical care teams must work together towards identifying creative and scalable ways to integrate ACP into perioperative care. In so doing, we can help patients and their families begin to prepare for urgent, unanticipated, difficult decisions so that care is better aligned with their unique goals and preferences.

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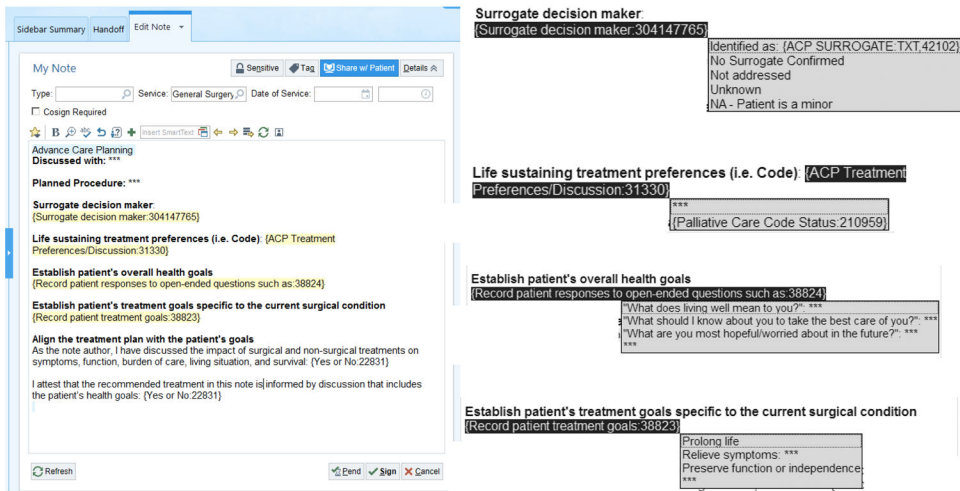


Figure 1. Surgical Advance Care Planning note template for the Electronic Health Record.

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