Editorial

Living with uncertainty in surgery: integrating palliative care principles into conversations as a solution to patient and family, provider, and health system disquietude

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Introduction

Among the most challenging aspects of medical and surgical practice is in managing the omnipresent aspects of uncertainty. Although uncertainty itself poses no novelty, in recent years there has been increasing awareness of how clinicians manage uncertainty alongside evolving illnesses and developing therapeutics. Kopecky *et al.* examine the current state of palliative care interventions among surgical patients (1). The authors present an updated review of the literature and elegantly summarize recent contributions to surgical palliative care using three foundational domains for future study highlighted in the seminal work by Lilley *et al.* in 2018: (I) measuring outcomes that matter to patients, (II) communication and decision-making, and (III) delivery of palliative care to surgical patients (2). As the authors indicate, while progress has been made in measuring mechanisms of palliative care delivery to surgical patients, there remains important knowledge deficiencies about timing of palliative care interventions as well as a lack of empirical data aligning surgical treatments with patient-centered outcomes. From this, we posit that managing uncertainty may be at the crux of these research gaps and high-quality conversations may be a remedy for these critical issues.

While advances in medicine have improved cure rates and prolongation of life across multiple disease types, clinicians are arguably no better at confronting uncertainty when guiding patients and families (3-6). Managing uncertainty involves, in large part, effectively guiding patients through a wide range of encounters using serious illness conversations to understand their disease and prognosis, and to support patients in elucidating goals, values, and preferences (3,7-9). Clinician-led serious illness conversations (i.e., primary palliative care skills) have been shown to improve the quality of conversations for both patient and clinician, while simultaneously achieving uniformity in conversational elements between different providers to ensure the critical issues are addressed (5,10). The convergence of these skills with uncertainty are exemplified by palliative care specialists who have long harnessed advanced communications skills to deliver high-quality serious illness conversations. However, in the context of limited health care resources, these conversations can no longer rest exclusively with such experts. Interdisciplinary management requires that both generalists and specialists who care for patients with chronic and/or serious illnesses are also well versed and confident in conducting these discussions. For patients being considered for surgery or having undergone surgery, surgical specialists carry unique responsibilities owing to the nature of high-stakes surgical procedures and the challenge of appropriate patient selection. Surgeons are therefore in

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an advantageous, and arguably the best, position to have these conversations in surgical contexts given their expertise in surgical diseases and expected outcomes.

Many surgeons, however, still maintain the assumption that such conversations are limited to end-of-life circumstances given its roots in palliative medicine. The association between the terms, "palliative" and "end-of-life" are all too frequently interchanged, reflecting a dated misconception. This also speaks to a substantial missed opportunity in caring for surgical patients who would benefit from serious illness conversations beyond the contexts of terminal illness. Surgeons should consider themselves just as critical as palliative medicine specialists in contributing to the workforce of providers who conduct high-quality serious illness conversations. In addition to the widely reported benefits of having discussions about functional, diagnostic, and therapeutic uncertainties, the work in normalizing serious illness conversations in surgery must also factor the importance of initiating these conversations earlier in the course of disease to derive the greatest benefit (11-13). This contribution calls on surgeons of every discipline to ask themselves how prepared they feel to address uncertainty in routine discussions with patients and their family members.

Show me the data: addressing uncertainty head on

Early studies demonstrate that surgical patients receive fewer and delayed palliative care services when compared to their medical counterparts (14). Uncertainty in surgical outcomes and delays in introducing palliative care services have been shown to be closely linked (15). Surgeons encounter uncertainty routinely, yet it is unclear whether increasing experiences with uncertainty generates greater willingness, aptitude, or comfort in managing cases. Rather, the inability to offer tangible solutions or cure may deter surgeons to further engage with patients, to ensure candor about unclear prognoses, and to discuss alternative treatment options (5,16). The reasons for this encompass various interconnected factors such as clinician discomfort, lack of training in high-quality serious illness conversations among nonpalliative care specialists, and the non-standardized fashion in which serious illness conversations have been conducted among others (14,15,17).

Uncertainty introduces an undeniable stress. Data show that conversations centered on patient values and goals can minimize distress and permit goal-concordant care in serious illness (18). What we have failed to recognize is the communication strategies offered in shared decision making may also address the heightened angst associated with uncertainty (5,19). The added value of a palliative approach to surgical decision making allows patients to simultaneously hope and to prepare for the worst, whether treatments are directed towards cure or symptom relief, in as much as whether surgery is entertained or not.

Previous work has shown that surgeons commonly use the "fix-it" model to facilitate patient understanding of disease and to explain how surgery could solve a medical problem. This, however logical, highlights an important phenomenon—that surgeons routinely exclude the deliberation of the true value of an operation and its potential outcomes due to questions that cannot be answered or solved definitively (16). In other words, uncertainty about an outcome plays a central role in surgeons' reluctance to engage in true shared decision making. Perioperative discussions rarely involve the consideration of alternative treatment options, exploring information preferences, or views on tradeoffs and prognoses. More commonly practiced than not, the traditional dialogue of informed consent includes an explanation of the problem, a solution (often a procedure or operation) offered and described along with its risks and benefits, and then a decision is asked of the patient with little to no consideration of a patient's values and goals (13). For complex or seriously ill patients, descriptors of disease likely rarely quiet patients' anxieties and the need for solutions. An approach that includes these elements alongside a discussion of surgical and quality of life uncertainties provides context and normalizes fears associated with the unknown by eliciting patient goals and anticipating unmet needs alongside surgical care.

Building blocks: the dialogue of uncertainty in serious illness conversations

Although a strong fund of knowledge and critical thinking ability are important, these skills alone are insufficient for managing all challenging patients. Strong communication strategies that incorporate uncertainty are instrumental to shifting the quality of the patient-physician relationships to aid serious illness conversations. Fortunately, there are widely available communication tools and conversation guides to aid in such difficult encounters.

The benefits of "advanced communication skills" allow clinicians to integrate the practical elements of disease and treatment (e.g., mechanism, physiology, adverse reactions)

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and the obscure elements of uncertainty into a learned format to build trust in high stakes situations. The Serious Illness Conversation Guide developed by Ariadne Labs (20) is an evidence based, structured communication tool that factors best practices into conducting person-centered communication. This simple, stepwise approach is language-tested and guides physicians in various settings dealing with chronically ill, debilitating, or life limiting illness through key steps in the conversation (7,20). Evidence exists demonstrating that interactive case-based sessions with communication skills practice result in significant improvement in responses to patients' emotional cues, and providers demonstrate sustained improvement and comfort in their patient-centered skills (7). Similarly, the Best Case/Worst Case Communication Framework developed for discussion about treatment options in the context of serious illness combines the clinician's knowledge of the presenting illness and the patient's overall health to give patients and families the best estimate of what may happen (21). This allows patients and families to prepare for the uncertain. The key elements in utilizing Best Case/Worst Case Communication Framework are to utilize a graphic aid to illustrate a conversion of statistical probabilities into stories of what the patient's life may look like if these probabilities occur (21).

Additional works support the early integration of palliative care principles alongside active disease management, as well as the use of communication tools to address uncertainty in delineating goals of care (22,23). Gosh and colleagues emphasize the use of honesty to inform patients of developments in diagnosis and treatment, acknowledgement of emotional distress, and helping patients and caregivers to be mindful of the realities of their lives during conversations that supported patients to live in the present (22). Similarly, Sadler *et al.* detailed four critical parts to shared decision making in conversations with oncology patients to include the recognition and management of symptoms and suffering, building both personal and patient resilience, initiating early discussion on goals of care, and training in advanced communication skills (23). The duality of an approach that prepares a patient for the worst and encourages opportunities for the best are daily occurrences. To explore the utility of The Serious Illness Conversation Guide for example, one can envision the case of a 35-year-old man, Nick, diagnosed with metastatic melanoma to the lungs and brain. Early discussions with his medical oncologist, surgical oncologist, and palliative medicine specialist elicited concise goals to pursue the best available treatments that would allow maximal preservation of physical stamina to protect his wish to be as active for as long as possible for his young 6-year-old son. Whilst acknowledging the uncertainties of treatment efficacy and impact on prolongation of life, Nick was able to identify and address key concerns along his journey. By setting up the conversation through his providers, accepting the uncertainty of his prognosis, and exploring the key goals and tradeoffs of each treatment option, Nick made comfortable and decisive choices. In 3 years, Nick underwent surgery to relieve shortness of breath from bilateral malignant pleural effusions and radiotherapy targeted to the brain lesions. Due to disease stability, he has remained on dual agent targeted therapy with a tolerable adverse effect profile. Nick finds comfort despite the uncertainty of when his disease will progress due to the early recognition and respect for his goals in treatment from the time of diagnosis. The early conversations guided by the structure of recognizing Nick's sense of purpose and control serves an ongoing role in his treatment trajectory as he ultimately transitions to end-of life in the future.

Conclusions

Although palliative care at the end of life for surgical patients is readily accepted and supported by surgeons, each surgeon interprets the meaning of the term "palliative" differently than the next. However, the lack of awareness of the benefits of high-quality serious illness conversations in surgery is a significant barrier to widespread adoption of these approaches. As a result, the notion of synergistic palliative and surgical care early in disease trajectory is frequently fraught with reticence and perceived as unnecessary. Without modeling cultural change, this confusion perpetuates the delays of involving palliative approaches to care for surgical patients. Surgeons have the unique opportunity to advance normalizing discussions that factor uncertainty just as strongly as disease and treatment options into routine perioperative conversations through practice modeling and educational training avenues. While uncertainty and unclear health trajectories will undoubtedly remain a constant, the unified way in which we communicate with our seriously ill patients may be the first demonstration of certainty in successful health care systems reform. To this end, while we have asserted that communicating prognostic uncertainties are inherently difficult and potentially emotionally laborious (24), serious illness conversations between patients and clinical experts may be an ideal targeted approach in the larger complement

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of whole person care.

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