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Understanding patient expectations around therapeutic benefits, risks, and the chance of cure☆

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ABSTRACT

Conversations around surgical goals of care should focus on relational (e.g., empathy, trust, understanding) instead of transactional processes (e.g., communication). Rather than reducing the patient-surgeon relationship to isolated variables such as "communication," a "relational lens" that considers all the aspects of the patient-surgeon relationship and its dynamic processes is needed.

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The National Cancer Institute (NCI) defines a cancer survivor as "one who remains alive and continues to function from the time of diagnosis until the end of life."[1] In 2018, an estimated 1,735,350 new cancer cases will be diagnosed and 609,640 cancer-related deaths will occur. While cancer is still among the leading causes of death worldwide, survivorship in the United States is on the rise and the number of cancer survivors is estimated to increase by 31% (~20.6 million) by 2026. Cancer survivors are also living longer than before; in 2016, 67% of survivors had survived five years or more after their diagnosis.[2] Despite these promising statistics, the experience of cancer patients is still uniquely and profoundly stressful due to multiple ambiguities that can accompany the disease, including the uncertainty of treatment-related decisions. For patients considering surgery as a part of their cancer treatment plan, an ill-informed decision to undergo a major procedure can result in unwanted immediate and downstream outcomes that decrease the quality and duration of their survivorship. Therefore, it is critical that surgeons take a patient-centered approach to support and develop goals of care that contextualized patient values and wishes. Unfortunately, research suggests that surgeons rarely employ shared decision-making (SDM) strategies, which may result in different goals of treatment, including patients believing that a surgical procedure has the potential to cure their cancer even when this goal may be highly unlikely.

Although SDM is defined as a "joint" or collaborative process, most research solely examines choice with an either/or lens framing incongruity in therapeutic goals as either patient misunderstanding *or* a failure of the surgeon to effectively communicate. Exploration of the cancer "cure" concept, possible misconceptions of both physicians and patients, and the benefits of using a "relational lens" to expand our current understanding of the complex, dynamic nature surgeon-patient relationship may, however, be equally or more important.

The search for "the cure"

While cancer care involves many forms of treatment that are intended for either cure or palliation, at least 60% of survivors will undergo a surgical procedure.[3] The conversation around curative intent surgery can be complex and often involves disease prognosis, quality of life, possible side-effects, as well as the chance for cure. These conversations can be particularly challenging given there is no standard practice around how physicians communicate the chances of cure. Traditionally, "cure" has been defined as survival beyond five years after diagnosis. Winner and colleagues reported, however, that cancer surgeons can have a wide variation regarding

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how they defined "cure."[4] In particular, some surgeons defined "cure" as "the patient will not experience recurrence of the cancer in his or her entire lifetime (36%)," while other surgeons defined "cure" as "patient is alive and well without evidence of the index cancer 5 years after treatment (32%)."[4] Additionally, many surgeons reported discussing "cure" in less than half of patient conversations or not at all, citing reasons for avoiding the topic such as "cure can't be estimated" or "patients have a hard time incorporating information about cure into their decision-making."

Despite the challenges in defining "cure," half of the surgeons identified "be cured" as a first or second priority of cancer patients.[4] Acknowledging cure as a patient priority but electing not to discuss cure in treatment-related conversations, may not be in line with SDM practices. In turn, avoidance of these conversations may contribute to increased patient misunderstanding of the intent of cancer-directed surgery. For example, when cure is unlikely, patients may be more likely to consider other non-surgical interventions for palliation of symptoms that interfere with function and quality of life (QOL).[4] Whether curative or palliative therapies are being considered, surgeons should use SDM strategies to align therapy with both patient and surgeon goals of care. Unfortunately, research suggests that cancer patients often misunderstand or feel uninformed regarding the intent of treatment.[2,3]

The employment of patient-centered care (PCC) and SDM should help address the aforementioned barriers between surgeons and patients, yet PCC and SDM are still rarely used. The challenges in implementing PCC, including SDM strategies, relate to the difficulty in changing the traditional patterns of patient-surgeon interactions. Traditionally, surgeons have often approached treatment conversations with a paternalistic stance and employ a "fix-it" model linking the patient's cancer with a surgical solution. In this model, "decision-making" is largely aimed at obtaining informed consent. Informed consent requires surgeons to convey risks that are typically described as objective estimates of isolated physiological harms; however, this approach does not describe outcomes in a way that allows patients and families to understand the realistic consequences of life after surgery. In addition, some surgeons present risks and benefits without eliciting patient preferences or discussing possible "trade-offs" that are often more representative of preferences and values. Many patients face difficulties personalizing the surgical procedure when surgeons emphasize in-hospital risks and technical aspects of the procedure rather than patient-centered outcomes.[5] Without contextualizing information relative to the patient's particular situation and goals, surgeons risk failing to help patients weigh the value of surgery given their diagnosis, prognosis, goals of treatment, and QOL preferences. In turn, patients who are not meaningfully involved in treatment-related decisions are often more vulnerable to decisional regret post-treatment, which can negatively impact their QOL.[4]

The movement towards PCC and SDM in surgical cancer care has been a paradigm shift from the surgeon as expert towards patients as experts in their own illness experience and goals of care. While the role of communication is undoubtedly important in PCC, research in SDM can sometimes be reductionist in nature and focus on unilateral (e.g., information-giving by the provider to the patient) instead of more dynamic and reciprocal (e.g., information given vs. information received vs. context of the patient, conversation, etc.) processes.[6,7] In fact, some surgeons believe that too much information and conversation about prognosis can be antithetical to hope. Specifically, focusing too much on the chance that the treatment may or may not provide a cure may cause the patient to lose hope resulting in adverse emotional consequences to both the patient and their family.[8] Evidence suggests, however, that honest, clear conversations about prognosis can be achieved without damaging the patient's well-being or harming the patient-surgeon relationship, even when the prognosis is poor. Rather than focusing on the desire for cure alone, a robust dialogue can empower patients and their families by framing hope in terms of attainable goals that may include preparation for a potentially non-curative outcome.[9]

SDM is often approached from only the patient or physician perspective, even though patient-physician relationships are interactive, interwoven, bilateral interactions.[10] When researchers only consider the isolated individual perspectives of the patient or physician, the combined influence of both perspectives may be lost. Rather, a "relational lens" should be employed to understand the reciprocal dynamic nature of the patient-physician relationship. To this end, the relational lens may facilitate the conceptualization and measurement of the dynamic and reciprocal processes that occur within the context of a patient-surgeon relationship (e.g. shared-decision-making) as opposed to more unilateral concepts (e.g. information exchange).[11] Relational techniques capture multiple perspectives of the individuals engaged in the cancer journey (e.g. physician, patient, nurse, spouse, family members, etc.). By considering decisions in light of a wide array of relations beyond just the patient and physician, a greater understanding of the dynamic between all decision-makers, as well as the mutual and reciprocal context of these relationships on treatment decision-making can be considered. In turn, gathering data from multiple perspectives allows for a more advanced understanding of concordant and discordant perceptions of treatment and goals of care, thereby more fully facilitating a PPC approach.

Surgeons and other care providers who treat cancer patients are in a unique position to develop a therapeutic relationship with patients from the initial cancer diagnosis through survivorship and end-of-life. Establishing a firm relationship foundation begins with the initial conversations around surgical goals of care. These conversations should focus on relational (e.g., empathy, trust, understanding) rather than solely transactional processes (e.g., communication). Rather than reducing the patient-surgeon relationship to isolated variables, such as "communication," a "relational lens" that considers all the aspects of the patient-surgeon relationship and its dynamic processes is needed.

Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.amjsurg.2018.08.012.

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