

## MEDICINE AND SOCIETY

### How Should We Enhance the Process and Purpose of Prognostic Communication in Oncology?

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#### Abstract

We propose that effective prognostic communication requires attention to the process and purpose of communication, where purpose represents the will and process the ability to communicate. Prognostic communication has historically challenged clinicians and patients. Few interventions have been developed to improve prognostic communication, and those that have been developed largely target the process of communication. We argue that more work is needed to address the purpose of prognostic communication, because the first step in all effective communication is desiring to communicate well. In developing communication interventions, investigators should be thoughtful about the audience they are targeting, the goals of the intervention, and the feasibility of disseminating and implementing the intervention in busy health care systems with limited resources.

#### The Challenge of Prognostic Communication in Oncology

Effective prognostic communication in oncology is essential for informed decision making, and the majority of adult patients and parents of children with cancer prefer honest disclosure.<sup>1,2</sup> High-quality prognostic communication has been shown to support hope,<sup>3</sup> trust,<sup>4</sup> satisfaction with medical care,<sup>5</sup> and peace of mind.<sup>6</sup> Honest communication also allows patients to focus hopes on attainable goals.<sup>7,8</sup> However, patients who receive explicit prognostic communication tend to interpret this communication as less compassionate.<sup>9</sup>

Given the challenges of maintaining this delicate balance of hope and honesty, it is not surprising that many clinicians have historically avoided discussions of prognosis.<sup>10,11</sup> Starting in the 1970s, clinicians developed an appreciation for the value of honest communication with patients about a cancer diagnosis.<sup>12</sup> Prior to that time, cancer diagnosis and prognosis were largely synonymous due to limited treatment options. Over time, advancing technology has divided diagnosis from prognosis, but prognostic discussions remain challenging, and many deficiencies in this process persist. For example, many physicians avoid discussions of life expectancy unless initiated by patients.<sup>13</sup> When prognosis is discussed, few physicians use quantitative terms or check

the patient's understanding.<sup>14</sup> As a result, many physicians and patients with cancer hold discordant views of prognosis.<sup>15-17</sup>

In considering how to improve prognostic communication, we propose to define communication as the interplay of *purpose* and *process*. Purpose is the reason for which something is done or created, expressed in a person's will or desire to communicate. Process is the specific series of actions taken to reach a desired end, manifest in a person's ability to communicate effectively. When miscommunication occurs, it is related to a deficiency in one or both of these components. In this article, we will first explore impediments to the process and purpose of prognostic communication, and then we will make recommendations to guide the future development of communication interventions. Although communication is a bidirectional interaction, we will largely focus on clinicians' role in communication because clinicians possess prognostic information and thus have the onus to initiate prognostic discussions.

### **Barriers to the Process of Prognostic Communication**

The process of prognostic communication in oncology can be impeded in many ways, some related to knowledge deficits. In some instances, clinicians might fail to understand what their patients want or need to know.<sup>18,19</sup> Additionally, some patients might not want to hear poor prognostic information, or they might want to receive the information in specific ways that are not clear to the clinician. Other patients might not know how they prefer to hear this information since they have never had similar experiences before. In addition, prognostic disclosure can be overwhelming, making it challenging for some patients to absorb information while emotionally distressed.<sup>20</sup> Compounding this emotional distress, most patients have a limited understanding of complex medical information and statistics, necessitating effort and skill on the part of the clinician to satisfactorily explain pertinent information.<sup>20</sup>

Another impediment is the misconception that diagnostic and prognostic communication is mostly about talking, explaining, and sharing information. In reality, providing information is only one of several functions of communication in cancer care.<sup>21</sup> Active listening, for example, is equally essential for effective communication. Similarly, [responding to emotions](#) is another function of communication that is often overlooked. Scrimin et al. found that many physicians avoid discussions of emotion, even when patients use emotional statements, indicating either a lack of physician awareness or discomfort with addressing emotion.<sup>22</sup>

Cultural differences can also make it difficult for even experienced communicators to appropriately understand and interpret the meaning behind the patient's words. Language differences alone can be a significant barrier to physicians' information sharing, contributing to suboptimal communication along with feelings of frustration, anger, and sadness for patients and parents.<sup>23</sup> True cultural competence starts with

cultural curiosity, which relies on asking questions, actively listening, and acknowledging when additional resources (such as translators) are necessary. This cultural curiosity should be manifest from the onset of the physician-patient relationship, thus serving as a foundation for all communication, not just difficult conversations.

Given these challenges to the process of prognostic communication, clinicians require a robust skill set to satisfactorily fulfill their role. However, there is evidence that trainees might have limited exposure to difficult communications during their training,<sup>24</sup> resulting in some clinicians' lack of confidence in their communication skills<sup>25</sup> or, conversely, a lack of awareness of their own deficiencies in communication skills.<sup>26</sup> Despite the development of educational curricula to promote communication skills during medical training, much of a trainee's communication education relies on role modeling, which is often insufficient for honing communication skills.<sup>27</sup> These challenges to the process of communication are largely related to lack of knowledge or lack of skill, making them amenable to improvement with [skill building](#) sessions of various sorts. As we discuss next, challenges to the purpose of prognostic communication involve lack of motivation, and might not be so easily addressed.

### **Barriers to the Purpose of Prognostic Communication**

The first step in communicating well is actively intending to communicate well. Effective prognostic communication with patients is an intensive process that requires humility, taking risks, absorbing the emotional trauma of others, attentive listening, and investment of time. Even with a well-honed skill set, the most determined efforts at communication can be hampered by the clinician's time constraints and workload. This fast-paced clinical environment necessitates active, dedicated effort by clinicians to spend time developing relationships that support patient communication. Given the power dynamics in the clinical relationship, many patients might feel discouraged from pursuing prognostic discussions if not initiated by their clinician.<sup>20</sup> Therefore, most impediments to the purpose of prognostic communication originate with the clinician.

Many clinicians avoid discussion of life expectancy unless the patient initiates the discussion.<sup>28,29</sup> Such avoidance might be related to the clinician's perceived challenge in balancing hope and reality or to the clinician's fear of diminishing hope.<sup>20</sup> Fostering hope is viewed by many physicians as an essential part of their professional role.<sup>30,31</sup> In conveying poor prognoses to patients, some clinicians might feel like they are "hitting" patients "over the head" with [bad news](#).<sup>32</sup> We acknowledge that some patients truly do not desire prognostic information, and in these situations avoiding prognostic disclosure when such conversations are not clinically urgent may be the appropriate approach. (At times, urgent clinical situations such as acute decompensation requiring resuscitation decisions might require clinicians to address prognosis whether or not the patient and family desire these conversations.) More often, however, such avoidance of prognostic communication represents a misguided attempt by the clinician to protect the patient or

a manifestation of the clinician's personal discomfort with sharing bad news. This discomfort can lead physicians to frame discussions more optimistically,<sup>33</sup> or it can dissuade them from discussing prognosis at all. In one study of patients with terminal cancer, 28.3% of physicians reported that they would communicate an overly optimistic survival estimate to their patients, and another 22.7% of physicians stated that they would not communicate any survival estimate at all.<sup>34</sup>

This avoidance of prognostic communication might also result from clinician discomfort with responding to the patient's emotions. Patients often drop hints about their emotional state, waiting for clinicians to signal their openness to further discussion. Physicians, however, often miss these emotional cues, whether intentionally or not.<sup>22</sup> Taylor et al. studied the interactions between cancer patients and oncologists, finding that 50% of clinicians reported that they had "often" or "almost always" discussed emotional issues, whereas only 18% of patients felt the same way.<sup>35</sup> Given these discrepant perceptions, hesitance to engage with patients' challenging emotions creates a barrier to effective prognostic communication.

Lastly, **uncertainty** can deter clinicians from discussing prognosis. Clinicians generally desire certainty before discussing death or life expectancy,<sup>36</sup> but such certainty is largely elusive until late in the course of disease. Such lack of certainty can lead clinicians to withhold prognoses or frame discussions with overly optimistic phrases and euphemisms.<sup>37</sup> Although discussions of uncertainty can be challenging for clinicians and frustrating for patients, most patients want physicians to discuss uncertainty because uncertainty is unavoidable, and they believe physicians are the best source of accurate prognostic information.<sup>38</sup> The clinician's desire for certainty is understandable, but it could lead to worse communication and therefore worse support of ill and dying patients.

Targeting the purpose of prognostic conversations, however, is not just about motivating clinicians. By conveying the importance of considering prognosis, these conversations can also implicitly reinforce the purpose of prognostic communication for patients and their families. These conversations can also remind patients that their lives are valued and their wishes are fundamentally important. Finally, clinicians who are willing to talk about a difficult future also model this behavior for patients, who might themselves be contemplating how to address these issues with loved ones. Engaging with the purpose of communication, we would argue, is therefore an important act of communication in itself.

### **Interventions—Past, Present, and Future**

Given these impediments to the purpose and process of prognostic communication, several investigators have developed interventions in recent years that aim to support and improve difficult communications.<sup>27</sup> However, these interventions have focused

mainly on skill building and educational sessions that seek to bolster the process rather than the purpose of communication.<sup>39-41</sup> While we value this important work, we maintain that purpose is a critical element for effective communication. If a clinician has insufficient motivation to engage in prognostic communication, then educational sessions are unlikely to change the outcome. To maximize the effect of communication interventions in the future, investigators should seek out ways to motivate clinicians to engage in these conversations with patients and families. Future interventions to support prognostic communication could also benefit from attempts to leverage the roles of other clinicians or patients. Currently, because physicians largely serve as gatekeepers of prognostic information in the medical hierarchy, other clinicians might feel limited in their ability to address prognosis without the support of the primary physician. Some investigators have begun to address this issue by encouraging nurses and patients to use question prompt lists to initiate conversations.<sup>42-44</sup>

Targeting motivation, however, is a difficult venture. First, not all clinicians are willing to communicate about prognosis. We conceptualize 3 groups of clinicians: those highly motivated to communicate about prognosis, those conditionally motivated, and those unmotivated. Each group is likely to respond differently to interventions, and no single intervention is likely to effectively support all 3 groups. Second, health care budgets are limited and capital will likely be scarce to support longitudinal communication interventions. Therefore, investigators will need to make difficult decisions about the aims and scope of proposed interventions. For example, should interventions aim to maximize the quality of prognostic communication for highly motivated communicators, or should they aim to increase motivation for prognostic communication among unmotivated clinicians? Lastly, any intervention that requires clinicians' time or effort will likely be viewed as burdensome and onerous, even for those motivated to improve communication. Every moment spent engaged in an intervention has an opportunity cost. To maximize chances of success, future communication interventions should be integrated into clinicians' workflow as best as possible.

Effective prognostic communication requires that clinicians (and patients) have the will and ability to communicate about prognosis. As we have highlighted in this article, there are many impediments to prognostic communication. However, each impediment provides an opportunity in the form of a potential target for future communication interventions. By taking honest measure of the current challenges to communication and the limitations of clinicians, investigators can develop interventions that will meet the needs of clinicians and patients, paving the way to better communication and better care.

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