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# Communicating terminal prognosis: The provider's role in reframing hope

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For patients with advanced cancer, the role of hope is often misunderstood. This essay will posit that understanding and reframing hope may help with conversations about prognosis. Telling patients that they have only months to live can be spiritually distressing for the healthcare provider, the patient, and the patient's family. Many healthcare providers may feel that divulging the full reality of a prognosis, especially when it is extremely poor, will destroy a patient's hope. However, we propose that, framed in the proper context, hope can thrive in conversations about a patient's terminal prognosis. We will explore the critical role of hope in difficult conversations about prognosis for patients diagnosed with advanced cancer.

## Hope in a time of uncertainty

When individuals with advanced illness encounter declines in their physical function, they experience worry about their future, what death entails, and what happens after death. Health insecurity frequently revolves around constantly declining physical abilities (Nissim, 2008) and thoughts of a shortened lifespan and the finitude of death (Banning & Tanzeem, 2013; Nissim, 2008). Physical changes commonly spur emotional, social, and spiritual distress in knowing how to prepare for the future. Additional uncertainties arise when medical providers fail to educate individuals about their illness and what may happen as their disease progresses (Benzein et al., 2001).

Medical providers hold significant power in fostering and depleting hope through the communication of disease information, prognosis, and anticipated disease progression. The medical team can foster hope by treating the person who has cancer like a human being and by answering questions (Karlsson et al., 2014). The team can also provide affirmation about patient's progress and reduce feelings of vulnerability (Karlsson et al., 2014). According to Nierop-van Baalen and colleagues (2016), hope holds a purpose in preventing people from sliding into depression. Even small amounts of hope, such as prolonged life, increased quality of life, and a peaceful death, can help to combat the inevitability of death, present momentary options for escaping the unbearable, and fend off hopelessness and depression (Breitbart et al., 2000; Eliott & Olver, 2007; Mystakidou et al., 2008; Nierop-van Baalen et al., 2016).

In contrast to hope, pessimism can remove a person's sense of agency (Eliott & Olver, 2007) and facilitate feelings of increased anxiety, hopelessness, and depression (Breitbart et al., 2000; Reb, 2007). As feelings of physical impairment worsen, social/spiritual wellbeing and hope may decrease (Brown, 2005; Lethborg et al., 2006) and demoralization and depression may increase (Lethborg et al., 2006). Feelings of physical pain and abandonment by the medical team act as triggers of despair (Nissim, 2008). Conversely, those who trust their providers and can share their intimate concerns with them feel relief and the potential for hope (Banning & Tanzeem, 2013; Olsson et al., 2010). Healthcare providers must frequently navigate the tenuous balance between imparting realistic prognostic information and fostering realistic hopefulness among those with advanced cancer.

## Challenge of prognostication

Many factors can influence accuracy in prognostication. This is especially true in the rapidly evolving field of oncology. Despite clinician access to various prognostic tools, significant variances in survival prediction remain (Fallowfield et al., 2002). Over the past decade, momentous advances in cancer treatments have emerged, making the aptness of prognostication even more complex. As the landscape of oncology optimistically transforms, so do options available for patients with advanced cancer. Precision medicine advances allow for options that often result in less toxicity and ultimately improved rates of survival for patients (Schwaederle et al., 2015). Hui (2015) best summarizes the complexities in survival predications in oncology by reporting that prognosis is a process, rather than an event. Therefore, patient-centric communication and clinical decision-making must be an ongoing and adaptable process in oncology.

## Essay/Personal Reflections

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## Desire for information

Health professionals' opinions have varied regarding the best practices in communicating diagnosis, prognosis, and expected disease progression for patients with advanced disease. The ongoing concern is that sharing difficult information may deplete patients' will to live and diminish their hope. Furthermore, the unpredictability of an individual's illness trajectory can make health professionals leery of sharing prognosis information (Fallowfield et al., 2002). However, extant literature consistently supports that most patients want to learn about their illness, prognosis, treatment course, and how their illness could affect their daily functioning (Clayton et al., 2008; El-Jawahri et al., 2014; Hagerty et al., 2005a; Innes & Payne, 2009; Umezawa et al., 2015). In particular, patients tend to want qualitative information more than percentages and statistics (Innes & Payne, 2009).

Most patients desire to be told complete or moderate amounts of information about their prognosis (Schofield et al., 2001). Patients expressed varied preferences in the timing and dose of information that they receive, with some preferring to have difficult conversations spread throughout their treatment (Deschepper et al., 2008) and others preferring details about life expectancy and treatment decisions close to the time of diagnosis (Schofield et al., 2001). In addition to the breadth, depth, and timing of communications about their illness and disease progression, studies have reported that patients want physicians to be realistic, patient, trustworthy, reliable, tactful, understanding of psychosocial needs, provide time to ask questions, and individualize their prognosis (Hagerty et al., 2005b; Sapir et al., 2000).

## Communication and patient outcomes

The ways in which healthcare providers communicate information to those with cancer affects both the alliance between the patient and provider and the overall well-being of the patient. Meeting patients' desires for detailed prognostic information results in enhanced levels of satisfaction (Heyland et al., 2009; Schofield et al., 2003) and communication between the patient, family members, and providers (Nakajima et al., 2015), including end-of-life care wishes (Heyland et al., 2009). The utilization of communication guides increases asking questions about prognosis, understanding illness trajectory, and recalling information (Brown et al., 2001).

Negative outcomes arise when patients have limited understanding of their prognosis, including unwanted or unnecessary medical care, including hospital admissions, increased expenses in the last week of life, and death at the hospital (Aabom et al., 2005; Zhang et al., 2009). Patients with limited insight into their prognosis have less time to plan for their futures, more anxiety about their imagined horrific fate, and are less likely to communicate end-of-life decisions (Fallowfield et al., 2002). Common negative psychological and spiritual impacts of not receiving information about disease trajectory included anxiety, depression, and situational and religious well-being (Fallowfield et al., 2002; Leung et al., 2006); however, El-Jawahri et al. (2014) suggested that increased awareness of advancing illness and symptomatology may result in patients' needs for enhanced psychosocial support for their coping process.

## Reframing hope within prognosis communication

Realistic understanding of their prognosis may help individuals with advanced cancer to reframe their goals to those that are more attainable when considering physical and emotional energy/abilities. Reframing hope within the context of a life-threatening illness involves an adaptive process of forming goals that are short-term, realistic, and attainable (Eustache et al., 2014) and require less physical strength (Benzein et al., 2001). Practitioners can engage patients and their families in identifying what they are hoping for now, in the present context of their illness. This exploration can only occur if they are fully aware of their prognosis. As previous goals for the future start to appear unrealistic, healthcare providers may assist those with advanced cancer in the process of reevaluating their goals and creating new ones that are more realistic in relation to time and physical ability (Knox et al., 2017). This transparent and supportive communication prompts patients and their loved ones to gather a sense of certainty about their illness, control, and hope as they prepare for the future. Hope is not antithetical to a poor prognosis but instead may be the tool with which practitioners can help patients face their shortened future.

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