

Chapter 4

Patient and Family Engagement in THE Conversation: Pathways from Communication to Care Outcomes

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ABSTRACT

This chapter uses a patient-centered communication framework to examine observational studies of patient and family engagement in communication about end-of-life care. It analyzes how the literature has connected communication with health outcomes in end-of-life care. Within this analysis, it brings together three main ideas. First, family plays an important and overlooked role in communication about end-of-life care. Second, the literature describes communication that serves multiple functions, and it describes the special challenges presented by end-of-life care communication. Finally, it links these communicative functions with health outcomes and outlines directions for future research.

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INTRODUCTION

In this chapter, we focus on patient and family engagement what is often called the conversation: when physicians, patients, and families discuss healthcare at the end of life. Indeed, movements in advance care planning such as The Conversation Project and Angelo Volandes' popular work *The Conversation: A Revolutionary Plan for End-of-Life Care* (2015) underscore the idea that conversations about this kind of care are perhaps the most important of our lives. Those who have experienced and studied the conversation know that the word "conversation," which paints a simple picture of two people talking, perhaps looking one another in the eye and nodding knowingly, does not describe the complexity of the circumstances in end-of-life care (See, e.g., Barnes et al., 2012). In reality, communication about end-of-life care involves many important people in addition to the patient and her physician, such as nurses, social workers, and other caregivers. Additionally, it involves members of the patient's family who will ultimately become surrogate decision-makers, using communicative behaviors that are difficult to unravel because they are informed by a tangle of individual experiences, beliefs, and goals (See, e.g., Gance-Cleveland, 2005). Thus the conversation is ongoing talk involving a clutter of people who sometimes cannot connect. Thus, to improve the effect of these conversations on patient care, our focus must shift from merely advocating for these conversations to critically studying how they work, what they accomplish, how they affect health outcomes, and how to engage all stakeholders.

Current literature describes the importance of patient, physician, and family engagement in a patient-centered approach to end-of-life care communication (See, e.g., Tang et al., 2014; Weeks et al., 2012). A patient-centered approach emphasizes the importance of considering patients' needs and experiences; encouraging patients to actively engage in their healthcare; and enhancing the patient-physician relationship (Epstein & Street, 2007; Stewart, 2003). The overall goal of this approach is to improve healthcare quality for individual patients. Patient-centeredness, then, changes the image of the conversation to one in which all participants are situated around the patient (who is both subject and participant), attending to one another for the purpose of improving the patient's well-being and quality of life.

In other clinical settings, the patient-centered approach has positively impacted patient satisfaction with their care, the quality of healthcare patients' received, and can contribute to improved health outcomes (Stewart, 2003; Epstein & Street, 2007; Hibbard & Greene, 2013). Some studies involving end-of-life care communication indicate similar results (See, e.g., White, Braddock, Bereckney, & Curtis, 2007a). Unfortunately, results from large-scale studies show an ongoing disconnect between patients' wishes for end-of-life care and their experiences, which means we need to further examine how patient-centered communication could work in this context

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