Chapter 9

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.

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, Bereknyei, & 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 (Hall, Levant, & DeFrances, 2013). What we lack is a broad picture of exactly how patient-centered communication about end-of-life care functions and what health outcomes it produces. To that end, our goal in this chapter is to reexamine existing literature involving observational studies of patient-physician communication about end-of-life care so that we more clearly see how patient-centered communication functions in this context, how it affects health outcomes, and how future research might target gaps in this area. We frame the literature reviewed in a patient-centered communication framework so that we can more clearly see how different types of communication have been linked to health outcomes.

To accomplish this goal, we bring together three main ideas. First, we examine the important role of family engagement in patient-centered communication generally and in end-of-life care communication specifically. Previous studies have reported mixed results on the effects of family presence in healthcare encounters on health outcomes (Wolff & Roter, 2011), but models of patient-centered communication acknowledge that family plays a critical role in achieving the goals of patient-centered care (Epstein & Street, 2007; White et al., 2007a). We argue that family engagement is uniquely important in end-of-life care communication because families often transition from stakeholders in the patient's care to surrogate decision makers.

Second, we use a patient-centered communication framework to describe the challenges of end-of-life care communication. Using Epstein and Street's (2007) model of patient-centered communication, we analyze existing studies in terms of the communicative functions they target. These functions include engaging in information exchange, responding to emotion, managing uncertainty, fostering relationships, making decisions, and enabling self-management. For example, some studies focus on informational

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