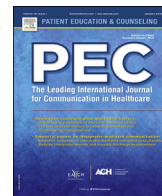




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# “I just need to know they are going to do what they say they’re going to do with my mom.” Understanding hospice expectations from the patient, caregiver and admission nurse perspective

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### ABSTRACT

**Objective:** The objective of this paper is to understand patient, caregiver and hospice admission nurses needs during the hospice admission conversation so patients and their caregivers can make informed decisions about hospice.

**Methods:** Resulting data set from this qualitative study included 60 h of observation and a total of 30 interviews with caregivers, patients and hospice admission nurses. Participants were from a large non-profit hospice; observation settings included: home, hospital and skilled nursing facility.

**Results:** Four themes were identified: (1) Wide variation in patient knowledge of hospice care prior to the admission conversation, (2) competing expectations and objectives for the admission conversation between patients, caregivers and hospice admission team members, (3) organizational influences around the goals of the admission conversation, (4) importance of integrating the patient and caregiver perspective to improve the quality of admission conversations.

**Conclusion:** Hospice services provided may be inconsistently explained by hospice personnel and therefore, can be misunderstood by patients and families. With the ubiquitous challenges surrounding hospice admission consults, there is a critical need for complete and accurate information during the admission process.

**Practice Implications:** Providing accurate and pertinent information at the time of the admission consult can help mitigate misinformed expectations of services provided.

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## 1. Introduction

Hospice care is associated with less distress, fewer hospitalizations, and improved caregiver outcomes [1–3]. The decision to enroll in hospice, however, is influenced by many factors: understanding of hospice care, emotions and fear, cultural and religious beliefs, and acceptance of terminal diagnosis [4,5]. Although 40% of all decedents in the U.S. are under the care of hospice [6,7], an estimated 10–15% of individuals who enroll with hospice subsequently disenroll prior to death [8] often due to not understanding hospice [9].

A critical interaction that often influences hospice enrollment is the hospice admission consult. This consult – which occurs when a patient has been referred to hospice but has not yet decided to enroll – is essential for communicating the values and expectations of hospice care. But this consult is typically unpredictable and highly variable. So inconsistent are practices across hospices in consenting patients that a 2016 report from the Office of Inspector General (OIG) highlights the critical need for complete and accurate information around hospice admissions [10]. A critical component of the decision to enroll in hospice is providing clear and concise information about the hospice eligibility criteria and the services hospice provides; yet no guidelines to help nurses conduct these consults exist. The lack of guidelines can lead to suboptimal outcomes (i.e. misinformed decisions and misinformed expectations) for patients and families considering hospice care [9].

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The objectives of this paper are to enhance clinician understandings of patient and caregiver expectations and needs during the hospice admission consult so patients and their caregivers can make informed decisions around transitioning to hospice. Before describing methods, it's important to provide context around the actual referral process to better understand the tensions surrounding hospice transitions.

To begin the process of electing hospice services, patients may self-refer, or a referral may be sent to a hospice agency from a hospital, a skilled nursing facility or a community physician. In all potential referral configurations, a hospice agency has to obtain an order for hospice admission from a physician who believes a patient's prognosis to be 6 months or less.

Ideally, hospice referrals are made after referring physician has engaged a patient and caregiver in a conversation about why a hospice transition is appropriate. These conversations may involve explanation of a patient's limited prognosis, disease progression, or the limited benefits of continuing medical interventions for the treatment of the terminal illness. However, these conversations do not consistently take place, and many factors influence this. For example, physicians may feel unprepared to speak with patients and caregivers about a patient's limited prognosis. Patient may be resistant to conversations about ending curative treatment. [4,5] In other instances, physicians may rely on hospice agencies to hold these challenging conversations with patients.

There is sometimes evidence, either as written in the medical record or communicated to hospice staff verbally, over the nature of the conversation held by a physician or other medical team member with patient and caregiver about the hospice consult. However, sometimes a clear conversation does not occur, and so hospice admissions staff can never assume that the patient and caregiver were told of a hospice referral, or that hospice services were adequately or correctly described to them by the referring group. The onus is thus on the admission nurse to ascertain during the admission consult what was explained to the patient by their physician, and what they understand about the progression of their illness.

The time frame from referral to admission visit is ultimately dependent upon the patient's schedule and when they want to meet. Hospices in competitive markets are often motivated to move quickly on referrals, and patients in crisis often need care to begin immediately. For this reason, many hospices aim to respond to referrals within the same day, and then set up an admission consult as soon as possible.

## 2. Methods

This was a qualitative study using critical discourse analysis [11]. The project methodology included nonparticipant observations of hospice admission visits between admission nurses, patients and their caregiver(s) from November 2016 to February 2017. Nonparticipant observation is a data collection method used extensively in qualitative research in which the researcher enters a social system to observe events, activities, and interactions with the aim of gaining a direct understanding of a phenomenon (e.g. hospice admissions) in its natural setting [12]. The resulting data set included 60 h of direct observation and in-depth interviews with 15 caregivers, 6 patients and 9 hospice admission nurses (n = 30). The observed admission visit lasted between 30 min and 1.5 h. Participants included: African Americans, LGBT, straight, married, widowed, Latino/a, Russian, Caucasian, tribal, homeless, and undocumented. Interviews were voluntary and occurred after the admission visit. At the beginning and again at the end of the admission conversation, the hospice nurse invited the patient and caregiver to participate in a short interview depending on the health of participants and any perceived stress. There were 3

incidents where patients and caregivers were not asked given the circumstances and desire to spend as much time with their caregivers that they had left. Similarly, in some cases, just the caregiver participated in the interviewer, or just the patient, or they chose to conduct the interview together. Participants were unique to a single visit. Said differently, each observation was comprised of different participants, including the hospice admission nurse.

Participants agreeing to being interviewed provided informed written consented by reading the consent sheet, or the first author reading it to them. The first author asked if there were any questions before participants signed the consent forms. Hospice nurses also completed written consent after being willing to be interviewed. Interviews with the hospice nurses occurred after the interview with patients and caregivers (while the first author was interviewing in the house of facility, nurses were charting so the timing did not interrupt their work flow). In some cases, when nurses needed to leave promptly for additional visits, interviews were conducted at a later time, but on the same day, at the hospice's care center. All interviews were audio-recorded and transcribed verbatim. Because of the ethical considerations guiding every stage of this project, interviews lasted no longer than 15 min to respect the comfort of participants and the time with their caregivers, if present. Prior to the consult starting, the nurse asked the patient and caregiver for verbal permission to be observing the interaction. The nurse introduced the first author as a researcher studying communication during the hospice admission consult. There were no instances that the patient or caregiver declined the presence of the first author. During the consult, the first author sat next to the nurse with a small notebook to capture words or phrases. Notes were taken after asking the patient and caregiver, and since the nurse was also taking notes, it was done in an unobtrusive way. There were 5 instances where the first author did not ask the participants to be interviewed given the perceived distress and circumstances that would have impinged participation. Of the observed admission visits, 20 enrolled in hospice, 3 were undecided, and 2 declined. Ethnographic field notes were written after each visit for a total of 250 pages (8–12 pages per visit). The first author attended hospice admission monthly staff meetings where "defining best practices" were a standing agenda item (n = 3). The Colorado Multiple Institutional Review Board approved this study.

### 2.1. Site and setting

The hospice where the data were collected is a large, urban, non-profit organization in the Rocky Mountain Region that has served more than 70,000 patients and their families since 1978. It is the fifth longest-established hospice in the country and remains a well-respected leader at local and national levels. In 2017, they served over 5000 patients, 80% of those in their homes.

### 2.2. Data analysis

Interviews were transcribed verbatim and analyzed alongside ethnographic field notes using critical discourse analysis (CDA) in an inductive, data-driven approach. CDA was used to capture the way larger discourses surrounding care, health and illness influence the way individuals think, act and reach decisions around end of life. The resulting framework for understanding the complexity of these conversations was developed to capture the organizational, social, interpersonal and cultural context in which these interactions are taking place. Each observed admission conversation was broken down and coded, allowing an established pattern to develop by relating codes/categories together [13].

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