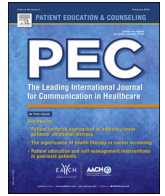




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Research paper

Communication among cancer patients, caregivers, and hospice nurses: Content, process and change over time

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ABSTRACT

Objective: First, to describe communication of home hospice nurse visits to cancer patient-caregiver dyads. Second, to assess change in communication related to domains of care over the course of visits.

Methods: Multi-site prospective observational longitudinal study of audio-recorded home hospice visits (N = 537 visits; 101 patient-caregiver dyads; 58 nurses). Communication was coded using the Roter Interaction Analysis System to describe content and process. Conversation representing three care domains (physical, psychosocial/daily life, and emotional) was calculated from RIAS categories across speakers and analyzed to assess change in communication over time.

Results: On average, nurses spoke 54% of total utterances, caregivers 29%, and patients 17%. For all participants, the predominant conversational focus was on physical care. Linear mixed effects models indicated that combined participant emotional talk showed a small systematic decrease over time; however, the results for all domains indicated variability unexplained by time or speaker effects.

Conclusions: Home hospice conversations are predominantly focused on physical care. Systematic change in communication versus responsiveness to the dynamic effects of patient death and family response over time are discussed.

Practice implications: Communication strategies already in use by hospice nurses could be leveraged and expanded upon to better facilitate family competence and confidence.

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1. Introduction

Current trends in healthcare include the increased use of home-based services and a growing focus on family-centered care. Many advanced cancer patients and their families are turning to home hospice services, in which the family is considered the unit of care [1]. While hospice enrollment has been associated with “good death”, end of life is inherently stressful [2]. Advanced cancer hospice patients often face a more rapid decline than other hospice patients [3], and caregivers face increased care demands as well as physical and emotional stress as the patient death approaches [4]. Effective communication is critical to meeting patient and caregiver needs [5], and has been linked to improved caregiver physical and emotional wellbeing [6], and reduced caregiver burden [7]. Communication is said to be at the core of the hospice “family cancer experience” [8], yet it is often noted as a significant challenge by both hospice clinicians and families [9].

Cancer communication beyond the patient-oncologist dyad has been infrequently studied despite the impact of advanced cancer on multiple stakeholders, including caregivers and the involvement of other health care professionals [10,11]. The study of end-of-life communication in the home for cancer patients and their families has been relatively unexplored. Hospice cancer communication provides a critical lens for study because of the identified need to: (1) focus on multiple stakeholders; (2) examine care in the home; and (3) to address nurse-caregiver-patient interactions that are often intimate, and can rapidly shift from discussions of physical care to emotional concerns that occur along-side with family and daily life events.

To examine the unique nature of communication in home hospice cancer care and potentially identify areas for improved communication, we conducted a multi-site observational longitudinal study. Multiple stakeholders participated: the patient, who gradually relinquishes autonomy as death approaches [12]; the family caregiver, who provides increasingly complex care while managing their own stress and impending loss [12]; and the hospice nurse, who oversees and coordinates patient and caregiver interdisciplinary care [13]. As necessitated by the relatively short periods of hospice care in the U.S. for cancer patients (i.e. average

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days spent in hospice care within the last six months of life; 23.3 days, range 12.3–36 representing all 50 states) [14], relationships among patient-caregiver dyads and their hospice nurses develop quickly and intensely [15]. As patients decline, caregivers assume more tasks for which they are often unprepared while simultaneously managing feelings of loss and grief [16] [6]. The hospice nurse has the opportunity to both support as well as educate patients and caregivers as death approaches, requiring strong communication skills across domains of care [12].

With patient decline at end of life, we were curious if nurse-family communication would show a predictable pattern of relative focus of conversation related to specific care domains. Derived and adapted from the National Consensus Project for Quality Palliative Care [17], and situated within the concepts of patient centered communication [5], we focused on three key domains of hospice care that could be captured by a comprehensive quantitative coding scheme: physical, psychosocial/daily life and emotional. First, because end of life requires complex symptom management, particularly pain for cancer patients, we focused on communication related to physical care [18–20]. As opposed to a clinic appointment where the setting is institutional, designed to serve multiple patients in the care process at once, the family home is highly personal, not set up to address complex physical and end-of-life care needs. Typically, family members and others in the social network congregate in the home during the patient's final days all of which are typically coordinated by the primary caregiver. These unique factors necessitated by home hospice, led us to focus on communication related to the second care domain of psychosocial and daily life. Finally, end of life is inherently an emotional time when patients and family members experience and express a range of emotions from grief, uncertainty, loss and fear to emotions that are more positive such as peace, deep connection and a sense of meaning [21–23].

We speculated that the early nurse visits would represent a relatively strong focus on physical care ensuring that the patient and family caregiver felt secure in managing patient symptoms. At this initial stage of the care relationship, it is important for nurses to establish their credibility and competency in keeping the patient comfortable and minimizing cancer related pain. After initial stabilization of symptoms and increased interpersonal comfort among nurses and family members, we speculated that there would be a relative increase in discussion of psychosocial (e.g., “A lot of his family want to visit.”) and daily life topics (e.g., “He sits in the yard while I garden.”) in visits. In the final days of a patient's life, we expected the discussion on psychosocial and daily life to dissipate replaced by a relative focus on family caregivers' emotions and an intense discussion of physical care while the nurse is responding to patient symptoms and helping the family face the imminent death.

Our approach of including several stakeholders allowed us to systematically capture and explore home hospice interactions and how conversations vary over time. There were two primary objectives for this new area of research, one descriptive and one predictive. The first objective was to describe communication content and processes of hospice nurse home visits at a detailed level using Roter Interactional Analysis System (RIAS) [24]. For the second objective, we predicted that, on average, the relative level of talk by both nurses and patient-caregiver dyads devoted to the three care domains (physical, psychosocial/daily life and emotional) would change over the course of home visits.

2. Methods

We used a multi-site prospective observational longitudinal design as part of larger parent project. All procedures were

approved by the University of Utah Institutional Review Board and home hospice agencies.

2.1. Participants

Nurse participants were recruited from nurses employed in participating hospice agencies. Study staff met with nurses during regularly scheduled staff meetings without administration present. Caregiver-patient dyads were recruited through participating nurse caseloads. From the larger parent project sample, we selected all spouse/partner caregivers of individuals with a cancer diagnosis admitted to home hospice. Spouse/partner caregiver inclusion criteria were 45 or more years of age, English-speaking, and cognitively able to participate. Enrollment began August 2011 and was completed December 2014, and data collection was completed in March of 2016. Participants were enrolled from 10 hospices in two geographically diverse areas in the U.S.: eight hospices in the Intermountain West, and two in the Northeast.

2.2. Procedures and data sources

Upon study enrollment, consented dyads and nurses completed self-report measures. Nurses were asked to audio-record all home hospice visits with participating dyads, provided digital recorders, trained in their use. Recordings for each visit began with nurses identifying themselves, the patient, and stating the date before entering the home. Nurses reminded those present that the visit was being recorded and that the recorder could be turned off at any time. Recordings were collected by study staff at interdisciplinary team meetings and then data were uploaded to a secure server. Nurses received reminder calls or texts when they had scheduled visits with consented families to ensure they remembered to record. Rates of individual nurse recordings of visits were monitored monthly. Study staff spoke individually with nurse participants with low recording rates to strategize solutions.

2.3. Variables

Self-report demographic data was collected from nurses and caregivers. After study completion, nurses and caregivers rated their comfort with recording and the degree it affected the interaction (caregiver) or their work (nurse). Caregiver-patient dyad case characteristics (date of death) were abstracted from hospice records by trained staff.

We selected up to 10 audio recordings of visits per caregiver-patient dyad to code for communication (range: 1–91). We analyzed complete data for those with 10 or fewer recordings. For those with more than 10 recorded visits (24 dyads), we randomly chose recordings within quartiles of hospice enrollment to ensure representation of the full hospice trajectory.

Home visit conversations were coded using RIAS [24] to capture both the content and process of hospice nurse-caregiver/patient conversation. Trained coders identified each individual utterance for physical care information and questions (predominantly related to patient symptom management), lifestyle and/or psychosocial information and questions, positive emotion, emotional responses, caregiver and patient distress, and a nurse category we labeled as teach, activate and partner. This last nurse category consisted of the following RIAS codes: shows approval; shows agreement or understanding; partnership; gives orientation, instruction; paraphrases/checks for understanding; asks opinion; and asks permission. This combined category of teach, activate and partner was created because a key goal of home hospice is for nurses to assess, teach, activate and support family caregivers in managing care on their own. Other statements, such as criticisms/disagreements were coded but excluded from

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