Hospice Nurse Communication with Patients with Cancer and their Family Caregivers

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Abstract

Background: Effective communication by hospice nurses enhances symptom management for the patient, reduces family caregiver burden and distress, and potentially improves bereavement adjustment. However, research has not kept pace with the rising use of hospice by patients with cancer and thus we know little about how hospice nurses communicate.

Methods: The overriding objective of this pilot study was to provide insight into these in-home visits. Hospice nurses audiorecorded their interactions over time with family caregivers and patients with cancer. The communication within these tapes was coded using Roter Interaction Analysis System (RIAS) and analyzed.

Results: We found that tape recording home hospice nurse visits was feasible. RIAS was suited to capture the general content and process of the home hospice encounter and the coded interactions show the range of topics and emotions that are evident in the dialogue. Implications and future directions for research are discussed.

Introduction

HOSPICE REGISTERED NURSES must have extensive skills including, but not limited to, patient assessment, symptom management, and communication proficiency to assess the holistic needs of both family and patients. There is a widely held assumption that nurses are innately skilled communicators given their reputation for empathy and their need to interface with other healthcare providers, patients and families.¹ However, nursing curricula, including that in hospice and palliative nursing, are largely geared toward direct physical care and may not adequately provide nurses with the unique communication skills required.

Effective hospice registered nurse communication has the potential to enhance patient symptom management, reduce family caregiver burden and distress, and improve bereavement adjustment.² Although effective communication at end-of life is critical, little systematic research has been conducted on home hospice registered nurse interactions with families.^{3–7} The overriding objective of this pilot study was to provide insight into in-home visits. Specifically, the pilot project aims were to: (1) test the feasibility of in-home audiorecording of interactions among hospice nurses, patients, and families, (2) study the nature and content of communication during in-home hospice nurse visits, and (3) assess the fit of a widely used communication coding system, Roter Interaction Analysis System (RIAS),⁸ to hospice encounters. This project was

conducted as a pilot for a larger, since-funded study on home hospice family caregivers and nurses.⁹

In this study, we used RIAS codes to broadly operationalize content and process communication behaviors in the home visit consistent with a patient-centered care model. Patient-centered communication can be generally defined as an effort to address patient concerns. The hospice nurse elicits (largely through question asking and listening), and then responds to, concerns which involve patient care issues (e.g., clinical symptoms, performing physical care tasks). Additionally, the nurse is attentive and responsive to the family members' emotions. According to this conceptual framework, each participant in the encounter possesses unique goals, values, and knowledge that can influence the interactions.^{10–12} A component of this approach that is particularly salient for home-based hospice care is that both the hospice nurse and caregiver mutually define the problems and goals for care and achieve them through a working partnership. Additionally, patient-centered communication has been linked to patient outcomes, such as improved emotional states,^{13–15} and RIAS has been widely used to capture this type of communication.^{16–18}

Methods

Participant recruitment

Hospice nurse recruitment. We collaborated with two hospice organizations for this project. Nurses shared concerns

and ideas on how to efficiently implement the project to minimize impact on work flow and respect the family's needs.

Caregiver-patient recruitment. Patients 50 years or older, admitted to the hospice program with a cancer diagnosis and a spouse/partner designated as the primary caregiver were considered eligible for participation. Eligibility criteria for spouse/partner caregivers included English-speaking and writing, living in the home, cognitive ability to participate (verified by hospice team), and assignment to a nurse participant. Nurses briefly introduced the study to eligible caregivers and patients during the admission visit and asked for permission for study staff to contact them. If permission was granted, study personnel telephoned potential participants, explained the study, and made an appointment for a home visit where written consent was obtained. Initial home visits occurred within 72 hours of hospice admission to increase the likelihood that all subsequent nurse visits were recorded.

Study protocol

The current investigation was approved and performed in accordance with the ethical standards of the University of Utah Institutional Review Board and all participants signed informed consent to participate and be tape-recorded. Hospice visits were audiotaped by nurses wearing small, unobtrusive digital recorders. Each recorder held approximately 8 hours of data, allowing nurses to record multiple visits with minimal disruption to their work flow. At the beginning of each visit, nurses reminded family members that the visit was being recorded, saying, "Remember that I'm recording" as they entered the home and any time new people arrived. This procedure allowed others who might be present to provide or refuse verbal consent to be recorded.

Study staff came to hospice offices on a regular basis to download digital recorder data to a laptop and were available to answer nurse questions, promoting adherence to study protocols. Data were uploaded to a password-protected, dedicated drive on a secure university server.

Coding system: RIAS

Digital audio files were coded using RIAS.⁸ RIAS codes are applied to the smallest unit of expression to which a meaningful code can be assigned, generally a complete thought. Coders work directly from recordings using specialized direct-entry software. This approach has multiple advantages in that it: (1) allows coding for both content and process; (2) considers dialogue context; (3) allows dialogue to be marked for future qualitative analysis; and (4) reduces the cost and time associated with transcription. RIAS is a widely used coding system with demonstrated levels of reliability and concurrent validity.¹⁹ Because this project represents a preliminary examination of hospice nurse-caregiver communication, the flexibility and strength of RIAS makes it a valuable tool to systematically study these encounters (Aim 2). To demonstrate the degree of focus of each participant's dialogue, communication behaviors are presented as ratios. For example, the registered nurses, on average, devoted 21.8% of all their utterances to the topic of physical care. Although the length of the entire visit is noted, a specific participant's talk is not timed.

Results

Demographics

Patients/caregivers. Thirteen caregiver/patient dyads were asked by hospice staff for permission to be contacted by the study team. Five declined contact, one consented but later decided not to participate, and seven enrolled. Demographics are presented in Table 1. Average caregiver age was 72 (standard deviation [SD]=16.5), while average patient age was 81.5 (SD=3.5). These couples had been together from 2–63 years. All caregivers except one had at least a high school education. Four caregivers reported their health as very good while three described their health as average.

Hospice registered nurse. All 15 registered nurses at the two hospices consented to participate. Five nurses had patients and family caregivers who both met eligibility criteria and consented to participate. Nurses were all female, Caucasian, non-Hispanic, had a mean age of 41.75 (range, 33–49), had been practicing as a registered nurse for an average of 12 years (range, 6–18), and were employed as a hospice nurse for an average of 7 years (range, 2–15). Demographics for one nurse are missing.

Case Characteristics

In total, 32 nurse home visits for 7 cases were audio-recorded by 5 hospice nurses (2–10 visits per case). Thirty-three visits were recorded; however, one was actually a physician visit accompanied by the nurse. In this tape, the nurse spoke very little and was not integrally involved in assessment or care, so we have omitted this visit from analyses. Visits lasted an average of 55.38 minutes (SD=23.26). In 66% ($n=21$) of visits across 5 cases, the patient was active to some extent in conversation. In 56% of the visits ($n=18$) across 6 cases, family members (other than the primary caregiver) were present and mainly included adult children.

TABLE 1. PATIENT AND DESIGNATED FAMILY CAREGIVER DEMOGRAPHICS

Variable	Patient	Designated family caregiver
Age	M=81.5 (SD=3.5)	M=72.0 (SD=16.5)
Gender		
Male	71.4	28.6
Female	28.6	71.4
Ethnicity		
Caucasian	83.3	83.3
Other	16.7	16.7
Education		
<High school		14.3
High school graduate		28.6
Some college		28.6
Graduate/professional degree		28.6

SD, standard deviation.

Application of RIAS

Due to the exploratory nature of the study, 15 audio-recordings were consensus-coded and the remaining cases were double-coded (inter-rater reliability >0.65) by two trained coders. Our previous work has resulted in somewhat higher reliability ($rs > 0.70$)^{20,21}; however, given this pilot study is the first application of RIAS to hospice care, we believe this is acceptable.

RIAS description. To describe hospice interactions (Aim 3), we created seven composite categories of RIAS codes to reflect visit tasks and processes. Table 2 demonstrates the task/process (left-hand column) associated with each composite category (middle column) and provides example statements (right-hand column). The tasks associated with the

hospice nurse visits include data gathering (typically question asking) and information provision. As can be seen in Table 2, these communication behaviors cover three broad domains of care: Physical, Psychosocial, and Lifestyle. All open and closed questions are in the Questions composite. Physical Care talk includes symptom assessment, management and treatment. Psychosocial talk includes statements related to stress, values and beliefs. Lifestyle talk represents non-healthcare related home activity and personal/family history talk. The Counseling composite represents the nurses' attempts to directly persuade, suggest, or change behavior.

The lower half of Table 2 depicts the relational processes that occur during visits. Emotional talk consists of affective statements typically related to grief and anxiety. For hospice nurses, this category typically represents responses to caregiver/patient expressions of emotions (reassure, empathy,

TABLE 2. RIAS CODES AND EXAMPLES

Visit task	Communication behavior (coded elements)	Examples
Data Gathering	Questions: Open and closed-ended questions across all topic domains (Physical Care, Psychosocial, & Lifestyle)	<i>Nurse:</i> (1) What are the symptoms she is experiencing? (2) Did you sleep OK last night? (3) Would you like to meet with our social worker? (4) How important is your religion to you and your husband? <i>CG:</i> (1) Why does his breathing sound like that? (2) Do you think God is here with us now? <i>PT:</i> (1) How should I explain this to my grandchildren? (2) When will the pain stop?
Information Provision	Information-giving: (1) Physical Care (2) Psychosocial (3) Lifestyle	<i>Nurse:</i> (1) The itching should clear up in a day or two. (2) We can help the anxiety if it becomes troublesome. (3) I can see that you were a very active gardener. <i>CG:</i> (1) My diabetes seems under control. (2) I believe she will be in heaven soon. (3) We have lived in this house for over 40 years. <i>PT:</i> (1) I have trouble getting out of bed. (2) I worry about leaving my wife alone. (3). I like to look out the window at the birds.
Counseling by Nurse	Counseling (Nurse only): Statements which attempt to directly persuade, suggest, or change behavior across all topic domains (Physical Care, Psychosocial, & Lifestyle)	<i>Nurse:</i> (1) I want you to pick up the medication tonight from the pharmacy. (2) You need to make the effort to take a break every day. (3) It may help to talk about your fears with your minister.
Relational/Emotional	Emotional Concerns Emotional talk (Nurse only): (1) Reassurance (2) Empathy (3) Concern (4) Self-disclosure Humor	<i>CG:</i> (1) I am worried that he is not comfortable. (2) I don't want him to be taken away from me—I hope I will be with him soon. (3) It is so scary when he can't recognize the grandkids. <i>PT:</i> (1) I'm afraid of how the kids will take my death. (2) Will there be someone to help my wife? (3) Is there an afterlife? <i>Nurse:</i> (1) It will get easier. (2) You sound very frustrated with your family. (3) I am really worried that you aren't getting enough sleep. (4) I was very close with my mother too. <i>CG:</i> She will be telling jokes in heaven <i>PT:</i> I can't wait to tell the kids what you just did (said with humor) <i>Nurse:</i> That's the funniest story I ever heard.
Activating and Partnering	Partnering (Nurse only): (1) Asking for opinion (2) Asking for understanding (3) Check for understanding (4) Orient	<i>Nurse:</i> (1) What do you think would help? (and) How do you think you could tell your kids about this? (2) Could you review with me what you should do when you think her pain has increased? (3) Okay? (4) First, we will review his medications and then next, let's talk about his ...

TABLE 3. RIAS CODE DESCRIPTIVES FOR NURSE, CAREGIVER, AND PATIENT

<i>Nurse RIAS Code</i>	<i>Min</i>	<i>Max</i>	<i>Mean F</i>	<i>Percent of talk</i>	<i>Percent SD</i>
Physical Care	3	446	143.53	21.81	8.00
Lifestyle	7	191	59.63	9.23	4.78
Emotional	6	170	58.72	8.70	4.96
Partnering	15	405	105.03	17.33	6.84
Psychosocial	2	201	54.63	8.09	7.34
Questions	10	105	42.06	8.38	4.83
Laugh	0	75	23.41	4.29	2.77
Counseling	0	68	20.88	3.39	2.38
Total	109	1534	616.63		356.20
Caregiver RIAS code					
Physical care	0	284	50.63	15.42	12.15
Lifestyle	0	334	82.72	22.57	16.89
Emotional	0	72	8.50	2.26	2.94
Psychosocial	0	133	32.43	7.80	6.71
Questions	0	63	10.46	2.76	2.32
Laugh	0	77	19.97	5.31	5.30
Total	0	1398	358.09		282.34
Patient RIAS code					
Physical care	0	208	44.13	31.16	24.48
Lifestyle	0	326	47.13	18.69	13.12
Emotional	0	29	5.3	3.08	3.36
Psychosocial	0	96	12.13	5.84	5.67
Questions	0	14	2.97	1.91	1.99
Laugh	0	75	8.56	3.32	4.11
Total	0	716	178.75		205.35

Percent of Talk is the ratio of each participant's utterances in a specific category to the respective participant's total utterances as an indication of the degree of the conversation focus. RIAS codes not included in the composites described above are those that were not deemed relevant to the current aims and those with average frequencies of two statements or less per visit.

RIAS, Roter Interaction Analysis System; SD, standard deviation.

and concern). There was evidence of Humor in the visits, which captures actual laughter or when individuals use humor, joke, tease, or respond to another's humor. Hospice nurse-specific composites also included Partnering, i.e., nurse attempts to activate and partner with the patient/caregiver.

Initial analysis showed that partner/spouse caregiver talk was not significantly different from the talk of other family caregivers. For the purposes of this paper and to better represent the family as the unit of care, we grouped all caregiver talk. Overall proportions of talk reflect that hospice registered nurses spoke slightly more than family caregivers or patients ($M=54\%$ versus 29% of total talk; patients' $M=17\%$; average total utterances=1153). The Composite categories for each party are presented in Table 3 as percentages of each participant's total talk (e.g., frequency of composite for nurse/ total nurse talk).

Nurse communication. A key task of health care providers is gathering information, typically by asking questions. Hospice registered nurses devoted approximately 8% of their talk to questions, representing an average of 42 questions/visit. Another significant portion of the nurse's task is information provision, largely relating to Physical Care. As can be seen in Table 3, 22% of nurse talk was in this category. The hospice nurses also provide Psychosocial information (8% of talk) on topics ranging from relationships to affective states. In addition to information provision, nurses devoted about 4% of talk to counseling or instructing caregivers and, to a lesser extent, patients what to do. Finally, the nurse provides Lifestyle comments 9% of talk.

In terms of the relationship aspects of the visit, we examined hospice registered nurse talk devoted to Partnering with family caregivers/patients and responding to Emotional concerns. Over 17% of hospice nurses' talk, on average, is partnership building. On average, the nurse devoted 8% of talk to emotional responses, approximately 59 statements per visit. Finally, 4% of nurse statements reflected Humor.

Caregiver communication. Family caregivers are also somewhat active in question asking and information provision. On average, 3% of their talk was devoted to asking the nurse Questions. Approximately 15% of their talk was devoted to providing Physical Care information to the nurse. Caregivers also discuss Psychosocial issues (8%). Interestingly, the largest portion of talk is devoted to Lifestyle statements (23%); much of this is reminiscing. Caregivers devoted, on average, 2% of statements to emotional concerns. Even though the percent of Emotional talk was low, the range is quite large, from none to 72 utterances per visit. More talk reflected Humor ($M=5\%$) than distress.

Patient communication. In 11 of the 32 visits, the patients were silent. In the other 21 visits, when the patients spoke, most of their talk represented Physical care information ($M=31\%$). Another significant portion of their talk was Lifestyle statements; on average, approximately 19%. Patients spent some time sharing Psychosocial information ($M=6\%$) and asked few Questions (2%). As with family caregivers, talk devoted to Emotional concerns and expression of emotion

was relatively infrequent, on average ($M=3\%$), but the range was none to 29 emotional utterances per visit. Patient Humor showed a similar average number of statements (3%) to patient Emotion, but exhibited a wider range (0–75).

Variability in communication. As can be seen from Table 3, the standard deviations of RIAS composites tend to be quite large, especially for patient and caregiver communication. Because of our small sample size, more complex statistics could not be conducted, but the wide variability deserves note.

Discussion

This study demonstrates the feasibility of audiorecording and coding nurse hospice visits. Our findings provide an initial picture of home hospice communication lacking in the existing literature.

Description of home hospice visit dialogue

Hospice registered nurses devote more talk to providing information on physical care than any other topic. Their other talk is fairly equally distributed across other domains, indicating a balanced care approach. From this analysis, we cannot determine when the nurse is talking to caregivers about patient care or about caregiver self-care. This is important for future research, as caregivers often neglect their own physical and emotional health while devoting their attention to the dying patient.^{22,23}

Hospice nurses engage in substantial talk directed toward building partnerships with family caregivers and patients (17%) rather than telling them what to do (4%). Building a collaborative relationship is associated with improved patient satisfaction,^{24–26} adherence,^{27–30} and health.³¹ Encouraging shared involvement may be particularly important in home health to promote agency in family members responsible for the majority of the day-to-day care.

Caregivers and patients devote nearly a third to half of talk to physical care and lifestyle, with both domains being fairly equally represented. Somewhat unique to end-of-life care, health is recognized in a broader biopsychosocial context where the palliative care provider and family address a range of concerns from past, present, and future. Both family caregivers and patients express humor and distress, consistent with the literature indicating the dying process can be a time of both joy and sadness.^{32–34}

It is difficult to compare how hospice nurse communication compares to other end-of-life encounters, because little research has been conducted in this area. Timmerman and colleagues^{35,36} applied RIAS to initial palliative care consultation sessions with radiation oncologists. Although there is less verbal exchange in the consultations³⁶ (median=811 versus median=1159 total utterances for visits), there are some similarities. In both hospice nurse communication and physician consultations, the clinicians talk more than the patients and caregivers and they tend to lead with the provision of physical care information, followed by partnership-type statements. In both types of encounters, the families expressed relatively few emotional concerns and the caregivers tended to ask more questions than the patients. A significant portion of caregiver and patient talk in the hospice visits centered around activities of daily living and reminiscing (Lifestyle).

However, the Lifestyle code was not reported in Timmerman and colleagues' studies^{35,36}; it is likely that these topics were infrequent in the radiotherapy appointments, as families may be more comfortable discussing lifestyle issues in the comfort of their homes with nurses and in the context of an ongoing relationship with a clinician, compared to an initial consult visit with a physician. There was variability in communication patterns across visits.

Communication behaviors are likely to vary within a single case across multiple visits as physical and emotional needs of the family change. Additionally, communication behaviors may vary between cases as each patient's condition and family caregiver's response will be unique. Another contribution to variability in communication behaviors may include differences between nurses' styles of communication. Literature suggests that health care providers tend to manifest a consistent communication style across encounters.^{19,37} Each hospice nurse is likely to have a personal style in response to family demands. For instance, when a patient is stable and less symptomatic, one nurse may spend more time addressing the family caregivers' psychosocial needs, whereas another nurse may shorten the visit and devote time to another case later in the day.

RIAS application to hospice encounters

Previously, RIAS has been successfully applied to patient-physician dialogue related to end-of-life^{38–40} and nurse communication.^{41–45} We found that RIAS was suited to capture the general content and process of hospice encounters. However, these encounters provide some unique challenges compared to traditional applications of RIAS (e.g., primary care, hospital, and clinic settings). First, the home setting invites personal and broad conversations compared to clinic/hospital settings. For example, the Lifestyle composite was substantial, ranging from activities of daily living to reminiscing. In future research, it may be important to disentangle this grouping.

Second, some key domains of end-of-life care, such as spirituality,⁴⁶ are addressed in complex, yet nuanced ways which can be difficult to capture using quantitative coding. However, because of the *a priori* decision to capture spirituality, coders digitally marked specific spiritual dialogue. This marking allows for expedient access for secondary qualitative analysis (unpublished data).

Third, even though RIAS has the capacity to distinguish between multiple speakers,^{37,47,48} this presented a challenge when coding the hospice home visits. The patient is often surrounded by multiple family members talking to him/her, each other, and the nurse. At a practical level, it can be difficult for coders to discern who is talking. One alternative is to use video, but due to the mobility of the nurses within the home, we did not believe this was feasible. Despite the challenges and given the exploratory nature of this study, the application of RIAS provided important insights into home hospice visits.

Fourth, consistent with the results of most quantitative communication coding studies, our results provide insight into describing what is said during home visits. However, our findings are limited in explaining the nurse-family relationship over time and reciprocity within encounters. There is increasing interest in sequential analysis and capturing reciprocity within large health communication coded data sets.^{49–53}

Given the sequential, digitally-captured nature of the RIAS coded data and with the use of more complex statistical tools (e.g., augmented latent growth curve analysis), future work will be able to illuminate the trajectory of interactional processes across the course of home hospice visits.

Limitations

The small sample size of this study meant we were unable to examine change over time in communication and how change relates to antecedent factors and outcomes. A potential drawback of using an interactional analysis system such as RIAS is that it may miss some of the depth and complexity derived from qualitative methodology. Given that this project was a pilot study for a larger project, qualitative analysis was not our goal. However, as stated above, the RIAS software allows the dialogue to be marked for more detailed secondary data analysis.

In summary, this study is among the first to demonstrate the feasibility of collecting interaction data from hospice visits. Despite limitations, our findings provide preliminary evidence of the breadth and complexity of both content and process during these critically important, but understudied, health care encounters. Future research can begin to identify specific communication patterns and examine their linkage to patient physical care and family caregiver outcomes. Previous work has shown that intensive communication skills training can change the communication behaviors and increase the confidence of clinic-based cancer palliative care nurses.⁵⁴ Given this evidence on communication improvement, the present study provides clinical examples on which to base future communication skills training to advance hospice clinicians' interactions with patients and families.

Acknowledgment

This project was supported by Huntsman Cancer Institute pilot funds P30CA042014 from the National Cancer Institute.

Author Disclosure Statement

No competing financial interests exist.

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