Published in final edited form as:
Patient Educ Couns. 2018 March ; 101(3): 414–421. doi:10.1016/j.pec.2017.09.013.

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

Lee Ellington, PhD[1], **Margaret F Clayton, PhD APRN**[1], **Maija Reblin, PhD**[2], **Gary Donaldson, PhD**[1], and **Seth Latimer, MStat**[1]

[1]College of Nursing, University of Utah, Salt Lake City, USA

[2]Department of Health Outcomes and Behavior, Moffitt Cancer Center, Tampa, USA

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.

Keywords

Caregiver; hospice care; cancer; communication; longitudinal studies

---

Corresponding Author at: Maija Reblin, PhD, Department of Health Outcomes & Behavior, Moffitt Cancer Center, 12902 Magnolia Drive, Tampa, FL 33612, USA, Tel: 813-745-8705, Fax: 813-745-6525, maija.reblin@moffitt.org.

Conflict of Interest: There is no conflict of interest.

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 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] [19, 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. Recorders 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 analyses due to low frequency. Weekly coder meetings were held to resolve discrepancies and ensure adherence to coding categories. Example statements can be found in Table 1. A random sample of 10% of audio-recordings were double coded for inter-rater reliability and drift throughout the coding process and Cohen’s Kappa scores were good at 0.68 [25].

2.4 Analysis

Demographic data, the impact of audio-recordings, and RIAS variables were assessed using descriptive statistics. For the analyses related to change over time, we combined RIAS categories into three broad care domains: physical, psychosocial/daily life, and emotional. Conversation representing the three care domains was calculated from RIAS categories across speakers: physical care (physical information and questions and nurse teach, activate and partner), psychosocial and daily life (psychosocial and lifestyle information provision and questions), and emotional talk (positive emotion, emotional response, caregiver and patient distress). We used linear mixed effects regression models to capture and statistically control for the unique effects that caregiver-patient dyad and nurse (random effects) have on communication, as well as the overall time trend across hospice visits (fixed effect). The random effects of dyad and nurse were “cross-classified” rather than hierarchical because they may vary autonomously (i.e. a dyad may have more than one nurse). As the outcome, we used a ratio of RIAS utterances by speaker in a specific care domain in one visit in relation to all talk in a particular visit. Change over time was operationalized as the beta weight of the fixed effect of time (amount of change in communication from visit to visit).

3. Results

3.1 Demographics

Our final sample consisted of 101 caregiver-patient spouse dyads and 58 nurse participants. Demographic participant data are presented in Table 2. Caregivers were predominantly female (60%) and patients were predominantly male (60%) and had been in a relationship with each other for 34.9 years on average. On average, patients were 67.4 and caregivers were 65.7 years old. Approximately 56% of caregivers were not working and 63.4% self-reported very good to excellent health. Nurses were mostly female (87.9%) with a mean age of 42.1 years. Most nurses had an Associate Degree (65.5%) and had been practicing in hospice for 4.5 years on average.

3.2 Visit and Recording Data

Families were enrolled in hospice an average of 82.6 days (54 median, SD=75.9). Our reported length of stay is longer than the U.S. national average [26] [14], as patients who died before they were able to have a recorded visit were excluded. Recording most frequently began at the median (6th) visit after enrollment. Analysis of systematic missingness of recordings (recordings not obtained by the nurse during a scheduled hospice visit) showed a steady rate of recording at approximately 60% until the last week of life; during this last week of life the number of recordings stayed constant, while the number of visits increased (recording rate 45%). Based on study staff notes, missed recordings occurred for a variety of reasons, including the nurse forgetting or not having a recorder, or because visits were made by non-participating on-call nurses.

Our sample consisted of 537-recorded visits. The average number of recorded visits for each caregiver-patient dyad was 5.32 (SD=3.53). Recorded visit length averaged 40.2 minutes (Median=38, SD=20.69, R = 4.75 – 113.83). There were no changes in the average length of visits over time. Caregivers reported that they were comfortable being recorded (median=5;

5 point scale with higher numbers indicating greater comfort) and recording did not affect their interactions with the nurse (median =1; 5 point scale with lower numbers indicating no impact on interaction). Similarly, nurses indicated that they were comfortable recording the visit (median=6; 7 point scale with higher numbers indicating greater comfort) and that it did not influence their workflow (median=2; 7 point scale with lower numbers indicating lesser impact).

3.3 Communication Data Descriptive Analysis

The last row of Table 1 shows that, on average, nurses spoke 54% of the total utterances per visit (M = 311; SD = 161). Caregivers spoke 29% of utterances (M = 165; SD=139), and patients spoke 17% (M = 99; SD = 96). As shown in Table 1, detailed coding results indicated that providing physical care information was the most frequent communication behavior for nurses (37% of total utterances; M = 116.39; SD = 82.01), caregivers (45%; M = 74.58; SD = 67.52), and patients (48%; M = 47.71; SD = 49.70). For nurses, frequently coded communication types were physical care questions (13%; M = 39.01; SD = 23.49), lifestyle/psychosocial information (8%; M = 25.50; SD = 26.05), and positive emotion (7%; M = 22.13; SD = 15.10). Nurse teach, activate and partner statements (6%; M = 18.30; SD = 15.64) were largely related to engaging caregivers in physical care issues. For caregivers, the next most common types of communication were lifestyle/psychosocial information (23%; M = 37.65; SD = 55.58), physical care questions (6%; M = 10.36; SD = 12.0), and positive emotion (5%; M = 8.82; SD = 9.71). Patients' communication types were lifestyle/psychosocial information (15%; M = 14.86; SD = 24.12), followed by positive emotion (6%; M = 5.87; SD = 8.12), physical care questions (5%; M = 5.38; SD = 6.82), and distress (4%; M = 4.44; SD = 9.14).

To assess whether domains of conversational focus changed over the course of hospice, we conducted linear mixed effects regression (Table 3). Results indicate that emotional talk significantly decreased over time (B= −.57, SE=.23, t = −2.84), whereas there was no significant linear change over time in physical care or psychosocial/daily life talk. However, the results for all domains indicated variability unexplained by time, nurse or dyad effects. Residual variance accounted for 74.7% of total random effect variances for lifestyle/psychosocial talk, 75.6% of emotional, and 63% of physical talk.

4. Discussion and Conclusion

4.1 Discussion

The present study examined conversations during home hospice cancer care among patients, caregivers, and nurses, identifying potential areas for future communication skills training. With a growing number of terminal cancer patients wanting to spend their final days at home, and the critical nature of communication for patient and caregiver outcomes, it is essential to better understand current practice. In addition, nursing support and relationships during critical events across care domains are likely to be remembered by the caregiver and family for years, and woven into the story as part of how caregivers relay the death of the patient to others in the future[12].

Home hospice family caregivers manage care on a 24/7 basis supported by the hospice team, primarily by their nurse. Our data indicate that visits, on average, last only 40 minutes; thus, it is important to engage caregivers in the care process so that they can be empowered to make decisions in the nurse's absence. As expected, our findings show that nurses speak the most in home hospice conversations and that patient symptom management was the primary conversational focus for nurses, patients, and caregivers. Patient and caregiver concerns about the patient's physical comfort and nurse prioritization of symptom management is consistent with other research [27].

We found that about 6% of nurse talk was focused on teaching, activating and partnering. Although the nature of this category between nurses and families varied, our qualitative work on a smaller subset of this same data suggests nurse efforts toward teaching, activating and working together tend toward guiding caregivers through experiences as if they were a spectator ("Let me reposition her.") rather than including caregivers as active members of the health care team teaching tasks and skills as others have reported [28] [29]. Other evidence suggests that hospice caregivers ask for increased involvement and teaching, suggesting that more can be done to help hospice nurses feel comfortable when teaching caregivers [30].

Nurses also build relationships with patients and caregivers on a personal level, balancing their professional relationship with being a guest in the home [31]. The rich conversations collected in our study consist of more every-day talk and discussions of lifestyle and psychosocial issues than other outpatient or inpatient oncology consultations [32]. This includes what is sometimes labeled as social chit-chat, which in a clinical setting is considered moderately important for relationship building, but is typically kept at a minimum to save time; whereas, in the home setting this talk pertained to activities of daily living. We found nurses, caregivers and –patients frequently discussed topics such as gardening, special foods or recipes, family memories, and holidays, weaving this conversation within physical assessment. The home provides a unique canvas in which the nurse has many cues to evaluate physical and psychosocial needs. Furthermore, the seemingly small events of daily life can become topics of shared conversation, and when shared have been linked to wellbeing and meaning making which may take on increased importance at end of life [33].

A fair amount of nurse, patient, and caregiver visit talk pertained to emotion—around 10% of all talk. This is in contrast to findings of a systematic review of office based video/audiotaped physician-patient discussions across 10 years that reported emotional issues are addressed rarely or not at all and emphasized the need for improved communication skills to address emotion and sensitive topics [34]. Although expressions of anxiety and sadness were expected, we also found comparable levels of positive emotional talk, including expressions of gratitude, love, humor, and joy. Emphasis in communication interventions has largely focused on teaching clinicians to identify distress and respond with empathy [35], with little to no research on clinician enhancement of patient and caregiver expressions of positive affect. This is somewhat surprising given that a growing body of research demonstrates the association of positive emotional expression with health, enhanced coping and meaning making [36]. Some research suggests that clinician-caregiver positive communication may be particularly beneficial to caregivers as they enter bereavement [37]. The facilitation of meaningful and beneficial communication of positive emotions is virtually an untapped domain in existing patient-provider communication research, providing a fruitful area for future interventions.

There has been an increasing call for palliative care researchers to examine the effects of the disease trajectory on communication and caregiver wellbeing [38]. In our study, communication related to emotional care showed a small systematic decrease over time. It is unclear if this decrease is clinically significant. Perhaps a more compelling finding is the high variability in the communication domains across visits. Rather than a systematic pattern of communication, the high variability in discussion may suggests the relative focus of hospice visit conversations represents an event-based pattern. The communication “demand” at a specific visit may be related to the complexity and dynamic nature of the cancer patient status at end of life which varies and is dramatically impacted by multiple factors (e.g., type of cancer, symptom experience, caregiver responsiveness, timing of nurse visit) [39] [40]. This variability seems to override any predictable formation of nurse-family communication patterns. It is well documented that in the U.S., cancer patients are in hospice for a short period of time[14], perhaps not allowing nurses and families sufficient time to develop a rhythm or pattern in their interactions. For example, when symptoms are well controlled and the patient is comfortable, the nurse and caregiver may make room for other conversation foci [29], or the nurse may simply shorten the visit time to balance the demands of her/his caseload. Another potential explanation for the high variability in communication across visits is that we were unable to get into the home during the nurses’ early visits; thus, it is possible that we missed visits where the patient was more stable and a time when more systematic communication patterns may be evident. Further research and a better understanding of the patterns of communication relative to patient decline and caregiver needs is warrented.

4.1.1 Limitations and Directions for Future Research—Although the present study provides comprehensive insight into what occurs during home hospice visits for cancer patients and their caregivers, there are limitations that provide opportunities for future research. First, our focus on the hospice nurse-caregiver–patient communication excludes other members of the hospice team (e.g., social workers, chaplains). Although other team members visit less frequently than nurses, their conversations may reflect a different emphasis (e.g., emotional expression; discussion of psychosocial issues). While there has been some research on hospice interdisciplinary team meetings [41], virtually no research has examined hospice team care within the home. Given that in other care contexts, effective communication by health care teams has been found to reduce health care costs, increase satisfaction and improve health outcomes [42] [43]; hospice team research is ripe for investigation. Second, there is unavoidable selection bias in our sample with nurses occasionally acting as gatekeepers in terms of whom or when they recorded, and participating dyads may are biased towards those who were willing to share their intimate moments during hospice care. Forty percent of eligible visits were not recorded despite reminders. Our research approach to recording is unique compared to clinic visits where a research staff person places and collects a recorder from a clinic room. Hospice nurses were responsible for their own recording in the home. Nurses typically drive to multiple homes in a single day, only return to the agency once or twice a week thus, they reported difficulty remembering to record given their busy caseloads. Additionally, some likely chose to not record for other reasons. Nonetheless, we were able to capture a large range of dialogue content and processes. Finally, application of a quantitative coding system limited some contextual richness that could be captured from a qualitative approach. Because of the relative lack of specific home hospice communication research, we chose to start with a large-scale descriptive examination of communication content and processes. Our unique data are archived for further exploration through qualitative methods.

4.2 Conclusion

This research addresses the call from leaders in the field for more ambitious studies to capture the contextual, dynamic, longitudinal and complex nature of cancer communication [5] [44]. We found hospice visit conversations to be generally biopsychosocial in nature, maintaining a relatively stable focus for the domains of physical and psychosocial/daily life care and a significant but small decrease in emotional expression over time, although there was a great deal of unsystematic variability by dyads and nurses. Further work is needed to assess communication precision in terms of eliciting, identifying, and responding to patient and caregiver needs especially as these may vary over time and in response to end-of-life events. Although our data does not address the effectiveness of communication in meeting patient and caregiver needs, significant evidence suggests that patients and caregivers report multiple unmet needs [45], and experience distress due to poor communication [46]. Furthermore, clinicians often fail to recognize the critical role of caregivers, and do not fully address their concerns about how to provide patient care, nor do they encourage caregiver self-care [47] [48] [49].

Practice Implications—Our findings establish a foundation for future research on caregiver-patient engagement and partnerships as well as provider education on effective communication in home hospice care, and possibly other palliative care venues. While there are a growing number of communication skills training programs for physicians, including oncologists and palliative care physicians who provide in-patient or clinic based ambulatory care (e.g., Oncotalk®) [50], there has been substantially less effort directed towards developing programs for nurses and other clinicians who practice in the home setting. This is a vital need due to the known difficulty clinicians face in facilitating caregiver competence and confidence in the management of complex symptom management, a 24/7 job without previous education or preparation. Our study identifies communication strategies already in use, such as teach, activate, and partner and expression of positive statements that could be leveraged and expanded by hospice nurses and other team members to facilitate optimal communication processes and outcomes in home hospice cancer care delivery.

Acknowledgments

We would like to thank the families and nurses that participated in this study.

Funding: The National Cancer Institute (Grant Number P01CA138317 PI: Mooney; Project leader Ellington) supported this work. The American Cancer Society (MRSG 13-234-01-PCSM PI: Reblin)

References

1. Family Caregiver Alliance. Fact sheet: Selected Caregiver Statistics. 2015
2. Cagle JG, et al. Correlates of a good death and the impact of hospice involvement: findings from the national survey of households affected by cancer. Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer. 2015; 23(3):809–818. [PubMed: 25194877]
3. Teno JM, et al. Dying Trajectory in the Last Year of Life: Does Cancer Trajectory Fit Other Diseases? Journal of Palliative Medicine. 2001; 4(4):457–464. [PubMed: 11798477]
4. Williams AL, McCorkle R. Cancer family caregivers during the palliative, hospice, and bereavement phases: a review of the descriptive psychosocial literature. Palliative & Supportive Care. 2011; 9(3): 315–325. [PubMed: 21838952]
5. Epstein, RM., Street, RL, Jr. Patient-centered communication in cancer care: Promoting healing and reducing suffering. National Cancer Institute; Bethesda, MD: 2007.
6. Hebert RS, et al. Preparing family caregivers for death and bereavement: Insights from caregivers of terminally ill patients. Journal of Pain and Symptom Management. 2009; 37(1):3–12. [PubMed: 18538977]
7. Wright AA, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA: Journal of the American Medical Association. 2008; 300(14):1665–1673 9. [PubMed: 18840840]
8. Siminoff LA, et al. The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF): a new measure. Psychooncology. 2008; 17(12):1216–24. [PubMed: 18504807]
9. Wittenberg-Lyles E, et al. Targeting communication interventions to decrease caregiver burden. Seminars In Oncology Nursing. 2012; 28(4):262–270. [PubMed: 23107184]
10. Institute of Medicine (IOM). Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Live. Washington, D.C.: 2015.
11. Laidsaar-Powell R, et al. Exploring the communication of oncologists, patients and family members in cancer consultations: development and application of a coding system capturing family-relevant behaviours (KINcode). Psycho-Oncology. 2016; 25(7):787–794. [PubMed: 26514374]
12. Clayton MF, et al. Nursing Support of Home Hospice Caregivers on the Day of Patient Death. Oncology Nursing Forum. 2017; 44(4):457–464. [PubMed: 28632241]
13. Milone-Nuzzo, P., Ercolano, E., McCorkle, R. Home Care and Hospice Care. In: C, N.P, JA., Ferrell, BR., editors. Oxford Textbook of Palliative Nursing. Oxford University Press; NY, NY: 2015. p. 727-739.
14. The Dartmouth Institute for Health Policy & Clinical Practice. Dartmouth Atlas of Health Care. The Dartmouth Institute for Health Policy and Clinical Practice; Lebanon, NH: 2017. Hospice days per decedent during the last six months of life.
15. Meier DE, et al. A National Strategy For Palliative Care. Health Affairs (Project Hope). 2017; 36(7):1265–1273. [PubMed: 28679814]
16. DuBenske LL, et al. CHESS improves cancer caregivers’ burden and mood: Results of an eHealth RCT. Health Psychology. 2014; 33(10):1261–1272. [PubMed: 24245838]
17. Care, N.C.P.f.Q.P.. Clinical Practice Guidelines for Quality Palliative Care. Third. National Consensus Project for Quality Palliative Care; Pittsburgh, PA: 2013.
18. Tsai JS, et al. Symptom patterns of advanced cancer patients in a palliative care unit. Palliative Medicine. 2006; 20(6):617–622. [PubMed: 17060255]
19. McMillan SC, Small BJ. Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: A clinical trial. Oncology Nursing Forum. 2007; 34(2):313–321. [PubMed: 17573295]
20. McMillan SC, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. Cancer. 2006; 106(1):214–222. [PubMed: 16329131]
21. Jiang D, et al. Limited time perspective increases the value of calm. Emotion. 2016; 16(1):52–62. [PubMed: 26214569]

22. Melo CG, Billings J. Including personal development in palliative care education to address death anxiety. International Journal Of Palliative Nursing. 2017; 23(1):36–45. [PubMed: 28132602]
23. Planalp S, Trost MR. Communication issues at the end of life: Reports from hospice volunteers. Health Communication. 2008; 23(3):222–233. [PubMed: 18569051]
24. Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. Patient Education And Counseling. 2002; 46(4):243–251. [PubMed: 11932123]
25. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics. 1977; 33(1):159–174. [PubMed: 843571]
26. Sengupta M, et al. Trends in length of hospice care from 1996 to 2007 and the factors associated with length of hospice care in 2007: Findings from the National Home and Hospice Care Surveys. American Journal of Hospice & Palliative Medicine. 2014; 31(4):356–364. [PubMed: 23744976]
27. Steinhauser KE, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA: Journal of the American Medical Association. 2000; 284(19):2476. [PubMed: 11074777]
28. Tjia J, et al. Managing Medications During Home Hospice Cancer Care: The Needs of Family Caregivers. Journal Of Pain And Symptom Management. 2015
29. Cloyes KG, et al. A True Human Interaction. Journal of Hospice & Palliative Nursing. 2014; 16(5): 282–290.
30. MacKenzie MA, et al. Does Diagnosis Make a Difference? Comparing Hospice Care Satisfaction in Matched Cohorts of Heart Failure and Cancer Caregivers. Journal of Palliative Medicine. 2015; 18(12):1008–1014 7. [PubMed: 26275175]
31. White ZM, Gilstrap CM. Inside Patients’ Homes. Omega: Journal of Death & Dying. 2016; 72(4): 302–315 14.
32. Ford S, Fallowfield L, Lewis S. Doctor-patient interactions in oncology. Soc Sci Med. 1996; 42(11):1511–9. [PubMed: 8771634]
33. Reis HT, et al. Are you happy for me? How sharing positive events with others provides personal and interpersonal benefits. Journal of Personality and Social Psychology. 2010; 99(2):311–329. [PubMed: 20658846]
34. Fine E, et al. Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature. J Palliat Med. 2010; 13(5):595–603. [PubMed: 20491550]
35. Tulsky JA, et al. Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. Annals of Internal Medicine. 2011; 155(9):593–601. [PubMed: 22041948]
36. Tugade MM, Fredrickson BL, Barrett LF. Psychological resilience and positive emotional granularity: Examining the benefits of positive emotions on coping and health. Journal of Personality. 2004; 72(6):1161–1190. [PubMed: 15509280]
37. Eggly S, et al. Language analysis as a window to bereaved parents’ emotions during a parent–physician bereavement meeting. Journal of Language and Social Psychology. 2015; 34(2):181–199. [PubMed: 26726278]
38. Pottie CG, et al. Informal Caregiving of Hospice Patients. Journal of Palliative Medicine. 2014; 17(7):845–856 12. [PubMed: 24992371]
39. Bostwick D, et al. Comparing the Palliative Care Needs of Those With Cancer to Those With Common Non-Cancer Serious Illness. Journal Of Pain And Symptom Management. 2017; 53(6): 1079–1084.e1. [PubMed: 28457746]
40. Lasheen W, et al. Symptom variability during repeated measurement among hospice patients with advanced cancer. The American Journal Of Hospice & Palliative Care. 2009; 26(5):368–375. [PubMed: 19571321]
41. Washington KT, et al. A multimethod analysis of shared decision-making in hospice interdisciplinary team meetings including family caregivers. Palliative Medicine. 2016; 30(3):270–278. [PubMed: 26281854]
42. Grumbach K, Bodenheimer T. Can health care teams improve primary care practice? JAMA: The Journal Of The American Medical Association. 2004; 291(10):1246–1251. [PubMed: 15010447]

43. Wagner AK, et al. Physical medicine and rehabilitation consultation: relationships with acute functional outcome, length of stay, and discharge planning after traumatic brain injury. American Journal Of Physical Medicine & Rehabilitation / Association Of Academic Physiatrists. 2003; 82(7):526–536.
44. McGuire DB, Grant M, Park J. Palliative care and end of life: The caregiver. Nurs Outlook. 2012; 60(6):351–356 e20. [PubMed: 23141194]
45. Teno JM, et al. Timing of Referral to Hospice and Quality of Care: Length of Stay and Bereaved Family Members' Perceptions of the Timing of Hospice Referral. Journal of Pain and Symptom Management. 2007; 34(2):120–125. [PubMed: 17583469]
46. McCarthy B. Family members of patients with cancer: What they know, how they know and what they want to know. European Journal of Oncology Nursing. 2011; 15(5):428–441 14. [PubMed: 21094087]
47. Gillick MR. The critical role of caregivers in achieving patient-centered care. JAMA. 2013; 310(6): 575–576. [PubMed: 23867885]
48. Boehmer KR, et al. Missed opportunity? Caregiver participation in the clinical encounter. A videographic analysis. Patient Education & Counseling. 2014; 96(3):302–307. [PubMed: 24998721]
49. National Academies of Sciences, E., and Medicine. Family caring for an aging America. Washington, DC: 2016.
50. Back, A., Arnold, R., Baile, W., Tulsky, J., Fryer-Edwards, K. Oncotalk: Improving oncologists' communication skills. [cited 2016 july 30]; Available from: http://depts.washington.edu/oncotalk/

Highlights

- Advanced cancer patients and their families are increasing use of home hospice care
- Longitudinal audio-taping of home hospice visits is feasible
- Home hospice conversations predominantly address patient physical care and comfort
- Emotional communication decreases over time
- Hospice nurses could use positive emotion to improve communication effectiveness

Table 1

RIAS Codes, Conversation Examples, and Descriptive Statistics per Visit

		NURSE			CAREGIVER			PATIENT		
VARIABLE	**EXAMPLE**	**MEAN FREQ (SD)**	**R**[*]	**Percent**[**]	**MEAN FREQ (SD)**	**R**[*]	**Percent**[**]	**MEAN FREQ (SD)**	**R**[*]	**Percent** [**]
Physical Care Domain										
Physical Care Information	His blood pressure is 136/80. The red spot his on tailbone is getting bigger.	116.39 (82.01)	3–487	37.42	74.58 (67.52)	0–328	45.20	47.71 (49.70)	0–379	48.19
Physical Care Questions	Has he eaten today? Is it OK to still get him into his chair?	39.01 (23.49)	0–137	12.54	10.36 (12.00)	0–109	6.28	5.38 (6.82)	0–40	5.43
Teach, Activate, and Partner (Nurse)	Now I am going to take her blood pressure. Is it all right if we talk about your getting out of bed on your own? We can work as a team to make sure Jim’s pain is under control.	18.30 (15.64)	0–130	5.88	– –	–	– –	–	–	–
Lifestyle/Psychosocial Domain										
Lifestyle/Psychosocial Info	I’ve been working out in the yard most days. It always bothers him if he isn’t the first to see the newspaper.	25.50 (26.05)	0–202	8.20	37.65 (55.58)	0–756	22.82	14.86 (24.12)	0–184	15.01

		NURSE			CAREGIVER			PATIENT		
VARIABLE	**EXAMPLE**	**MEAN FREQ (SD)**	**R**[*]	**Percent**[**]	**MEAN FREQ (SD)**	**R**[*]	**Percent**[**]	**MEAN FREQ (SD)**	**R**[*]	**Percent**[**]
Lifestyle/Psychosocial Questions	Is your daughter still really upset? Has the new grandbaby come yet?	9.09 (8.91)	0–53	2.92	2.96 (3.80)	0–24	1.80	2.01 (3.18)	0–24	2.03
Emotional Domain										
Positive Emotion	We love you! My pants are getting kinda loose but that just means I’m going to look great in the Christmas pictures right?	22.13 (15.10)	0–106	7.12	8.82 (9.71)	0–66	5.35	5.87 (8.12)	0–60	5.93
Emotional Response	It’s okay to feel that way; I’m so sorry. Wow, that’s rough	12.25 (13.41)	0–89	3.94	2.05 (3.68)	0–24	1.24	.94 (2.03)	0–20	0.95
Distress (Patient and Caregiver)	I just can’t stand to see my wife in pain. I don’t know if I can do this much longer.	–	–	–	4.34 (3.09)	0–71	2.63	4.44 (9.14)	0–87	4.48
Total Utterances										
		MEAN FREQ (SD)	R[*]	Percent[***]	MEAN FREQ (SD)	R[*]	Percent[***]	MEAN FREQ (SD)	R[*]	Percent[***]
Total Utterances		311 (161)	42–968	54.19	165 (139)	0–1045	28.70	99 (96)	0–776	17.22

[*] R refers the range of particular category by speaker. In the bottom row, it refers to range for total talk by a speaker.

[**] These columns represent the percentage of talk in a particular category relative to all talk by the speaker.

[***] These columns represent the percentage of a speaker’s total talk relative to all speakers’ talk during a visit.

Table 2

Participant Characteristics

	Patient N=101	Caregiver N=101	Nurse N=58
	n (%)	**n (%)**	**n (%)**
Gender			
Male	60 (60.0)	40 (40.0)	5 (8.6)
Female	40 (40.0)	60 (60.0)	51(87.9)
Missing			2 (3.5)
Ethnicity			
Hispanic	1 (10)	7 (7.0)	2 (3.7)
Non-Hispanic	89 (91.8)	92 (92.0)	50 (92.9)
Race			
Asian	2 (2.0)	0 (0)	2 (3.5)
Black/African American	2 (2.0)	1 (10)	4 (7.0)
White	87(87.0)	98 (98.0)	52(91.2)
Other	10 (9.0)	2 (1.0)	4 (7.0)
Nursing Education			
Diploma	–	–	1 (1.7)
Associate	–	–	38 (65.5)
Bachelors	–	–	15 (25.9)
Masters	–	–	2 (3.4)
Missing	–	–	2 (3.4)
Education			
High school graduate	–	21 (21.0)	–
Some college	–	37(37.0)	–
Bachelor’s degree	–	19 (19.0)	–
Some graduate education	–	5 (5.0)	–
Graduate degree	–	18 (18.0)	–
Annual Household Income			
Less than $10,000	–	2 (2.0)	–
$10,000–24,999	–	12 (12.0)	–
$25,000–39,999	–	15 (15.0)	–
$40,000–59,999	–	14 (14.0)	–
$50,000–74,999	–	27 (27.0)	–
$75,000 or more	–	25 (25.0)	–
Declined to answer	–	5 (5.0)	–

	Patient N=101	**Caregiver N=101**	**Nurse N=58**
	n (%)	**n (%)**	**n (%)**
Employment			
Not working	–	57 (56.4)	–
Part-time	–	11 (10.9)	–
Full time	–	33 (32.7)	–
Self-reported Health			
Excellent	–	15 (14.9)	–
Very good	–	49 (48.5)	–
Average	–	30 (29.7)	–
Poor	–	6 (5.9)	–
Very Poor	–	1 (1.0)	–
Primary Insurance			
Private	–	32 (30.8)	–
Medicaid	–	5 (4.8)	–
Medicare	–	57 (54.8)	–
Self-Pay	–	1 (10)	–
Other (e.g., TriCare)	–	4 (3.8)	–
	M (SD) Range	M (SD) Range	M (SD)Range
Age	67.4 (10.8) 45–91	65.7(10.2) 45–89	42.1 (14.6) 23–69
Length of Relationship	34.9 (17.9) 2–68		
Days on Hospice	82.6 (75.9) Median = 54	8–413	
Years Hospice Experience			4.5 (4.9) Range: 1 month-21 years

Table 3

Linear Mixed Effects Regression on Care Domain Communication Variables

Care Domain	**Effect Size (Standard Error)**	**Variance (Standard Deviation)**	***ICC***	***t***
Physical				0.16
Time	0.14 (0.88)			
Patient-Caregiver Dyad		5978.0 (77.32)	0.178	
Nurse		6463.0 (80.93)	0.163	
Residual		21,195.0 (145.59)		
Psychosocial /Daily Life				−1.80
Time	−0.85 (0.47)			
Patient- Caregiver Dyad		789.3 (28.09)	0.086	
Nurse		1526.4 (39.07)	0.184	
Residual		6829.4 (82.64)		
Emotional				−2.84*
Time	− 0.57 (0.23)			
Patient- Caregiver Dyad		263.7 (16.24)	0.086	
Nurse		239.9 (15.49)	0.103	
Residual		1559.1 (39.49)		