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Caregiver, patient, and nurse visit communication patterns in cancer home hospice

Maija Reblin¹, Margaret F. Clayton², Jiayun Xu², Jennifer M. Hulett², Seth Latimer², Gary W. Donaldson³, and Lee Ellington²

¹Department of Health Outcomes and Behavior, Moffitt Cancer Center, Tampa, FL, USA

²College of Nursing, University of Utah, Salt Lake City, UT, USA

³Pain Research Center, Department of Anesthesiology, University of Utah, Salt Lake City, UT, USA

Abstract

Objective—Few studies have examined the triadic communication between patients, spouse caregivers, and nurses in the home hospice setting. Thus, little is known about the types of communication patterns that unfold. The goals of the study were to, first, identify common patterns of communication in nurse-patient-caregiver home hospice visits and, second, to identify nurse, caregiver-patient dyad, and visit characteristics that predict visit communication patterns.

Method—Nurses (N = 58) and hospice cancer patient and spouse caregiver dyads (N = 101; 202 individuals) were recruited from 10 hospice agencies. Nurses audio recorded visits to patient/caregiver homes from study enrollment until patient death. All patient, caregiver, and nurse utterances from the audio recordings were coded using an adapted Roter interaction analysis system. Using identified codes, cluster analysis was conducted to identify communication patterns within hospice visits. Logistic regression was used with demographic variables to predict visit communication patterns.

Results—Six visit communication patterns were identified and were defined largely by 2 dimensions: (1) either the patient, the caregiver, or the patient and caregiver dyad interacting with the nurse and (2) the relatively high or low expression of distress during the visit. Time until death significantly predicted several clusters.

Conclusion—This study leads the way in outlining triadic communication patterns in cancer home hospice visits. Our findings have implications for nursing education, letting future nurses know what to expect, and lays the foundation for future research to determine effectiveness and interventions to improve health care communication.

Keywords

cancer; caregiver; health communication; home hospice; longitudinal research

1 | BACKGROUND

Home hospice is a growing area of health care in which informal family caregivers take on responsibility for the majority of patients' day-to-day symptom and emotional care tasks at the end of life. An interdisciplinary hospice team, usually coordinated by a nurse, is available to support patients and caregivers in these tasks.¹ Hospice provides a unique context to understand how health care occurs in a family-based context. As patients decline, caregivers take on a larger role and more responsibility; thus, the hospice ideal is for nurses and other health care providers to consider the family as the unit of care.¹

Effective communication with health care providers is an important factor in patient-centered care, and key to more successful health care interactions.² For example, in addition to addressing the purpose of a visit pertaining to physical care, a provider using effective communication addresses psychosocial aspects of care and facilitates mastery and meaning. This can be done through information exchange, eliciting and addressing questions, shaping skills and expectations, identifying goals of care, and allowing space for emotional expression and validation.³

There is extensive research on physician-patient communication in clinical settings,⁴ even at the end of life.⁵ While clinic-based interactions often represent important conversations such as breaking bad news or treatment decisions,^{6,7} they may neglect other key milestones in a care trajectory, such as managing active decline and day of death.⁸ Moreover, few studies have focused on the triadic communication processes of provider, patient, and caregiver in health care; those few studies have largely focused on a clinical consultation setting.^{9,10} Although caregiver input is often helpful and in some cases necessary, a caregiver can add complexity to interactions with health care providers, and may require management of the caregiver's expectations and needs, which may conflict with the expectation and needs of the patient.¹¹ The decline of the patient in home hospice can add additional communication complexity. Initial health care interactions between the provider, patient, and caregivers emphasize the roles of the provider and patient as primary decision makers and place the caregiver in a supportive role. Few caregivers have a dominant role in the triadic relationship.¹² However, patients at the end of life often lose the capability to take an active role in their care, requiring caregivers to step in as an advocate and decision maker. Little is understood about how this transition impacts communication.

The change of venue from clinic to home is another important difference that may change how communication unfolds in home hospice. The home setting may empower caregivers to take on a more active role for both patient and caregiver to engage in more emotional disclosure. Some qualitative work exists to show that patients and caregivers may feel more in control at home.^{13,14} Moreover, the home environment may equalize the balance of power in health care interactions.¹⁵ This may invite the open expression of emotions that may not be evident elsewhere¹⁶ and provide a facilitative space to build relationships.¹⁷

In addition to setting and other more traditional factors such as illness severity, patient and provider factors including gender and age will likely also dictate communication content and processes. For example, male patients, male health care providers, and older adults are

typically less likely to engage in relationship-building talk about personal or social issues.^{6,18} These findings suggest that participant characteristics may play an important role in understanding how an interaction will unfold.¹⁹ As families are increasingly supporting patients with the assistance of interdisciplinary care teams at home, understanding the factors that impact health communication and how it changes outside the clinic is critical.

1.1 | Objective

The goals of the current study were to, first, identify common patterns of communication in home hospice nurse-patient-caregiver home hospice visits and, second, to identify nurse, caregiver-patient dyad, and visit characteristics that predict visit communication patterns.

2 | METHODS

2.1 | Participants

Nurse participants were recruited from 10 hospice agencies in the Intermountain West (n = 8) and Northeastern (n = 2) regions of the United States as part of the Caregiver Cancer Study, a large, multisite, prospective, program project grant focused on advanced cancer home hospice caregivers (P01CA138317: PI Mooney, Project Leader Ellington). Caregiver-patient dyads were recruited from participant nurse caseloads. All eligible caregivers were contacted about participation in the study. Patients were involved in recruitment and consent when possible. Further details about enrollment can be found elsewhere.²⁰ Eligibility criteria for the current sample included caregivers who were spouses or partners to individuals with a cancer diagnosis newly enrolled in home hospice, over 45 years of age, spoke English, cognitively able to participate, and had at least 1 visit with their hospice nurse recorded. Up to 10 visit recordings for each caregiver-patient dyad were selected to represent points across the hospice trajectory for inclusion in our analysis. This study was approved by the Institutional Review Board and participating home hospice agencies.

2.2 | Procedures

Upon study enrollment, nurse and caregiver participants completed demographic questionnaires. Patient data was provided by caregivers. Nurse participants audio recorded their visits in dyad participant homes from study enrollment until patient death using a small, unobtrusive digital recorder. Visit recordings were coded using an adapted Roter interaction analysis system (RIAS).²¹ Using this system, trained research assistants coded each nurse, patient, and caregiver utterance within the visit. Weekly meetings were held to address issues of validity and reliability. A random 10% of recordings was double coded and reliabilities were good (Kappas >.65). As described in Table 1, codes included physical care information and questions, lifestyle or psychosocial information and questions, positive emotion, emotional response, caregiver and patient distress, and nurse partnering. To control for varying amounts of talk within visits, we conducted an analysis on communication code ratios, defined as percentage of type of talk compared to total talk by each individual speaker in each visit. Average communication code frequencies and ratios are presented in Table 1 and discussed in more detail elsewhere.^{20,22}

3 | ANALYSIS AND RESULTS

3.1 | Sample

We analyzed 537 home visits made by 58 nurses to 101 spouse/partner cancer caregiver-patient dyads across the span of enrollment in home hospice to patient death. Each family had an average of 5.32 recorded visits (standard deviation [SD] = 3.53) in this sample. The average length of visit was 40.2 minutes (SD = 20.69; Range 5114 minutes). Patients in this sample had a median of 54 days in hospice.

As shown in Table 2, caregiver average age was 65.7 years (SD = 10.2) and 60% of caregivers were female. Our sample is predominately white (87% of patients and 92% of caregivers); however, national hospice statistics report similar low diversity (over 75% of hospice patients are white¹). Average patient age was 67.4 (SD = 10.8). The majority of study couples were of high socioeconomic status, with high education and annual household income levels. Almost all participants were covered by some form of insurance. Nurses were 92% female, with an average age of 42.1 years (SD = 14.6). The average number of years practicing in hospice was 4.5 (SD = 4.9).

3.2 | Communication cluster identification

Finite normal mixture modeling is a commonly used cluster analytic approach for identifying self-similar groups of observations.²³ It allows for flexible parameterization of covariance structure and selects between competing models based on Bayesian information criteria (BIC). We conducted this analysis using the mclust package in R²⁴ to analyze nurse, patient, and caregiver RIAS communication code ratios within each visit and identify clusters of visit communication. Two RIAS categories were eliminated from analyses; criticism/disagreement was eliminated as it represented less than 1% of talk, while talk coded as other (eg, “uh huh”) was eliminated as less meaningful.

A 6 cluster solution provided an optimal fit under the BIC scoring rule, in which the model with the lowest BIC score in a finite set of models is preferred (BIC = 57 702.76). The study team reviewed means both across and within cluster and verified the conceptual fit. Figure 1 presents the standardized cluster means. As expected, nurse physical care talk was dominant and relatively consistent across visits. However, as shown in Table 3, distinct communication patterns emerged. Patterns of visit communication were largely defined by 2 dimensions: (1) who interacts most with the nurse (patient, caregiver, or dyad) and (2) the relative high or low expression of distress by patient and/or caregiver during the visit as defined by the standardized cluster means.

Visits dominated by patient-nurse interactions fell into 2 communication patterns: patient low distress and patient high distress. The first showed relatively low patient expression of distress (n = 109; 20%) and the second showed relatively high patient distress (n = 64, 12%); both had little caregiver talk. Both types of visits likely reflect nurse assessment—asking questions about physical status and the patient responding. The lack of caregiver talk in these 2 types of visits suggests that patients were actively participating in their own care, even in home hospice. In patient low-distress visits, both nurses and patients appear to be exchanging positive affect statements and patients are engaging in psychosocial/lifestyle

talk, which in this context typically includes sharing personal stories. In contrast, patient high-distress visits include expressions of patient distress and emotional responses. Nurses respond to expressions of patient distress by providing information, offering partnership, and being emotionally responsive (eg, reassurance). The difference between the 2 patterns may signify the difference between nurse communication used to generally check-in with a patient versus nurse communication addressing problems and concerns.

Visits dominated by caregiver-nurse interactions also fell into 2 communication patterns: caregiver low distress and caregiver high distress. These 2 types of visits were the 2 most frequent patterns (caregiver low distress $n = 124$, 23%; caregiver high distress $n = 149$, 28%), indicating the role that caregivers assume in patient care management; both had little patient talk. Caregiver low-distress visits featured nurses asking physical care questions and expressing positive affect. Caregivers responded with physical care information and positive emotion. On the other hand, in the caregiver high-distress visits, rather than the question and answer pattern, caregivers and nurses exchanged physical care information. Caregivers also expressed distress and positive emotion. This co-occurrence of emotion is worth noting; despite the sometimes distressing nature of the end of life, caregivers also appear to be engaging in talk including humor or gratitude. These patterns are similar to patient patterns previously described above. The caregiver low-distress visits feature nurses eliciting information and expressing positive affect, similar to a general check-in. Caregiver high distress may prompt nurses to address problems by providing information.

Visits dominated by the dyad-nurse interactions fell into 2 communication patterns: dyad low distress and dyad high distress. These visits were the least common overall (dyad low distress $n = 59$, 11%; dyad high distress $n = 32$, 6%). Dyad low distress featured all members of the triad exchanging lifestyle/psychosocial and positive emotion talk. Patients and caregivers also engaged in emotional response talk. In the dyad high-distress visits, both caregivers and nurses are responding to patient distress. These visits featured relatively high levels of multiple caregiver communication behaviors. Caregivers had especially high levels of physical care questions likely directed to the nurse, while emotional responses were directed to the patient. Nurses showed relatively high levels of partnering talk. The 2 dyad patterns are perhaps the most disparate types of visit. Dyad low-distress visits may be indicative of patients and caregivers building a relationship with the nurse through positive emotional expression and sharing of personal information or storytelling. In contrast, the dyad high-distress visits have a much more anxious tone, suggesting a patient and caregiver in distress and the nurse working to partner with and orient the couple to what is happening.

3.3 | Prediction

Multinomial logistic regression analysis was used to identify demographic and visit characteristics that predicted cluster membership. Since data included multiple visits for each patient-caregiver dyad and nurse, we controlled for the dyad and nurse in the analysis. Predictive variables by dyad included caregiver sex, age, and employment. Predictive variables that changed or could change by visit (with different nurses) included nurse years of hospice experience and time until patient death. Patient sex and age were omitted from

analyses because of high multicollinearity with caregiver data. Race/ethnicity and nurse sex were not included based on low variability in our sample.

The patient low-distress cluster was selected as the reference group in this analysis, as we felt it was the best representation of a routine health maintenance visit; the patient appears to be managing his/her own care with a relative lack of distress. There were no significant differences in nurse years of hospice experience or caregiver age by cluster.

Time until death significantly predicted several clusters, presenting different stages in the illness trajectory. There were no significant differences from the reference group (patient low distress) in time until death for the patient high-distress and caregiver low-distress visits, suggesting that on average these visits occurred in a similar timeframe. However, dyad low-distress visits were significantly more likely to occur further from death (ie, earlier in hospice care; odds ratio [OR] = 1.011, $P = .002$) than the reference group. Caregiver high-distress and dyad high-distress visits were significantly more likely to occur closer to death than the reference group (ie, later in hospice care; caregiver OR = .958, $P = .000$; dyad OR = .964, $P = .005$).

In comparison to the reference group, caregivers in the caregiver low-distress and dyad low-distress visits were significantly less likely to work full time (caregiver OR = .564 $P = .021$; dyad OR = .188, $P = .000$), and were more likely to be male (caregiver OR = 2.378, $P = .016$; Dyad OR = 18.968, $P = .000$).

4 | DISCUSSION

Because of the paucity of systematic, prospective health care communication research focused on nurse-patient-caregiver triads in home hospice, our first goal of this study was to identify communication patterns that occur in health care visits. We found 6 distinct patterns of visit communication defined by 2 dimensions: (1) who interacts most with the nurse (patient, caregiver, or dyad) and (2) the relative high or low expression of distress during the visit. Our second goal was to identify predictors of visit communication patterns, and we were able to establish a general timeline of the stages of the end of life.

As expected, we found that patients managed their own care in home hospice, even when things were distressing, for a good proportion of visits. Patients in other research report feeling involvement in their own care and care decisions is important and that they find nurses who actively involve them more trustworthy.¹⁹ Our predictive modeling shows that as patients approach death care transitions to the caregiver, who ultimately becomes the primary voice at the very end of life. Although some patients are lucid until day of death, many require a family member to act as a surrogate.²⁵

The earliest visits in the timeline, based on our predictive modeling, were the dyad low-distress visits. On the basis of the sharing of lifestyle/psychosocial information and positive emotional expression, these visit patterns appear to embody triadic relationship building among the patient, caregiver, and nurse. Relationship-building talk involves more than talking about disease and death. It is seen as essential for nurses working in a home setting and is an important foundation for problem identification and problem solving for the

family.²⁶ Often becoming a confidante involves sharing emotions through story telling,²⁷ represented here with lifestyle/psychosocial talk. Humor, reassurance, and empathy are also important factors in this relationship development.²⁸ Research has shown that relationships may develop quickly between nurses and families,²⁹ but caregivers report this process is facilitated by in-home providers who spend time with them, especially time focused on relating to each other and mutual self-disclosure.^{28,30}

One unexpected finding in our analysis included visit communication patterns in which caregiver and patient emotional response talk was present, but not a likely response to distress, such as in the dyad low-distress and patient high-distress visits. Both of these clusters occur early on in the trajectory and may reflect relationship building with the nurse. Although emotional response primarily includes reassurance and validation talk, patients or caregivers may be using common polite phrases (eg, don't worry; it's not a problem)—more superficial emotional responses—to make the nurses feel comfortable and welcome in the home.

The dyad high-distress visits typically occurred at the very end of life and were relatively uncommon overall, at only 6% of visits. These communication behaviors suggest that caregivers are likely reacting to patient distress with high distress of their own. This finding is supported by previous research showing couples' distress emotions are linked and reciprocal.³¹ Although caregivers are in distress, addressing the patient's distress may be more pressing and activates caregivers to offer reassurance to the patient and to ask nurses questions about patient care. At the very end of life, often, patients communicate less, but some patients may experience uncontrolled pain with verbalization of physical suffering. Visits with exclusive expressions of patient distress are likely qualitatively different than when patient distress is accompanied by other types of communication. The caregiver high-distress visits, where patients are no longer communicating, may represent a more typical or more frequent end-of-life hospice visit (28% of overall visits) than the dyad high-distress visits. Although caregivers express distress in both types of end-of-life visits, in the more common caregiver high-distress visits, distress is tempered with positive emotion expression, such as humor, savoring the moment, and gratitude.

Although our visit patterns are somewhat defined by the relative presence of distress, 5 of our 6 clusters featured relatively high levels of positive emotion talk from at least 1 speaker. Positive emotion is pervasive in the hospice experience.^{20,32} This may reflect attempts to bolster the patient or caregiver's mood or efforts at positive emotion coping.³³ Often, expressions of distress occur in conjunction with positive supportive talk. Although determining the sequence of talk is outside the scope of the current analysis, communication patterns that included patient and caregiver distress also frequently included nurse partnership (eg, orienting and asking opinion) and emotional response (eg, validation and reassurance). This response grouping has also been shown in previous work in home hospice research.³⁴ Nurse physical care information also commonly occurred in high-distress clusters. Nurses often report that they address distress by providing physical care information or advice, such as explaining why something is happening or what to expect next.³⁵

Our predictive modeling also showed that men and caregivers who did not work full time were more likely to be involved in the caregiver low-distress and dyad low-distress visits, which featured characteristics of caregiver relationship building. It is somewhat expected that caregivers who are not at work will be more present, and thus have more opportunity to establish a relationship with the nurse. Although communication patterns may be more situationally dependent than based on gender,³⁶ there is some evidence that male patients, especially interacting with female providers, are engaged in less relationship-building talk.³⁷ In our study, the fact that men were more likely to be engaged in relationship building may reflect the context of the home. The home environment likely facilitates relationship building talk through psychosocial cues or lifestyle information (eg, television programs and ability to cope). In addition, home hospice features a unique power dynamic based on new roles of guest/host.^{13,38} This study suggests that the home context may present an important opportunity for men in particular to develop better relationships with health care providers.

4.1 | Limitations

While this study is one of the first to describe patterns of communication in home hospice triads, it is not without limitations. Our coding approach, while providing some insight into overall content and processes, is limited in its scope of capturing interpersonal interactions. For example, while RIAS can capture communication behaviors and responses, it does not adequately represent the cocreation of meaning that can occur in communication interactions. Further, the quantitative emphasis may skew findings towards high-frequency communication behaviors rather than highly meaningful communication behaviors. A more in-depth qualitative analysis could identify richer themes and complexities within our data. Obtaining more information about participants could also help account for many of the contextual complexities that can impact communication, not captured within this analysis, such as cultural differences, family processes, or role transitions. Additionally, cluster analysis limits us to exploring what communication behaviors group together across an entire visit. Sequential analyses could model how conversations unfold within those visits.

4.2 | Clinical implications

This study has identified clusters of unique communication patterns that can help home hospice nurses and other care providers to plan and prepare for different types of interactions. For example, as patient death approaches, we found that distress becomes more prevalent in communication. Hospice nurses can anticipate this and use strategies to help patients and caregivers effectively manage their distress, such as by offering referrals to community or spiritual resources and/or providing emotional support. Our study also found a communication shift from interaction with the patient to more interaction with the caregiver that is likely to occur as death approaches. Caregivers may be unaware of future tasks and responsibilities as they become patient communication surrogates and may be unsure how to integrate their needs and expectations with the patients' needs and expectations. The need for a patient to relinquish health care decisions can be difficult. Nurses can help patients and caregivers prepare for this transition by providing education about what to expect as patient death approaches and by creating opportunities for discussions within the dyad or family regarding arrangements, goals, and plans.

Further, much of hospice care continues to revolve around patient needs despite the holistic family-centered model of hospice-care delivery. Educational programs should increase awareness of how to assess caregiver needs and mitigate potential distress to better enact a family-centered model of hospice care. This implies education for nurses and others about how to foster the exchange of information while maintaining hope, how to facilitate caregiver and patient emotional expression, how to elicit caregiver and patient questions, and how to help caregivers and patients to identify their personal goals for end-of-life care.

Home hospice nurses operate in a unique context, different from a hospital or clinic. The home setting allows a provider to witness family interactions in their private space, and combined with the frequent and intimate nature of hospice care delivery, an opportunity arises for nurses to create closer bonds with the patient and family than may be found in clinical settings. Helping less-experienced nurses to maintain and adapt to professional boundaries in the home setting is crucial to maintaining optimal relationships with caregivers and patients and is informed by recognition of cultural and social norms. For example, witnessing and participating in family humor, reminiscing with the family over photos or mementos, and occasionally sharing a snack with the family are activities unique to the home environment that home hospice nurses are privileged to share in. These activities foster relationship building and develop trust among the caregiver, patient, and nurse. Nurses and other hospice providers need to be aware of, and integrate communication approaches congruent with caregiver and patient preferences, context and culture, and the anticipated end-of-life trajectory.

5 | CONCLUSION

This study extends health communication research from patient-physician interactions in a clinic setting to patient-caregiver-nurse in home hospice. We identified hospice visit communication patterns; these patterns were largely defined by the patient and/or caregiver speaker involvement and the relative presence or absence of distress. We used predictive modeling to establish a general timeline of the types of visit communication that occurs across the hospice trajectory. Our findings suggest the trajectory begins with relationship building with patient, caregiver, and nurse, then transitions to patients managing their care. As patients decline, caregivers are establishing their individual relationship with nurses and begin to more fully take on the patient's care management, partnering with the nurse until the end of life. While distress was a defining characteristic in our analysis, it was often present in conjunction with positive emotion expression. Home hospice provides a context that allows us to investigate unique characteristics, such as the home, nonphysician providers, and family involvement, which are growing elements of today's health care landscape. Our descriptive analysis, identifying existing communication patterns across the cancer home hospice trajectory, is an important foundation to more prescriptive work. Further investigation is warranted to determine effectiveness of the communication patterns identified in our study in addressing family needs and improving hospice outcomes, including caregiver satisfaction and bereavement. Our findings have implications for improving communication in more traditional health care settings and for educating new hospice nurses to know what to expect during home hospice visits.

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References

1. NHPCO. Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization; 2015.
2. Constand MK, MacDermid JC, Dal Bello-Haas V, Law M. Scoping review of patient-centered care approaches in healthcare. *BMC Health Serv Res*. 2014; 14(1):271. [PubMed: 24947822]
3. Bernacki RE, Block SD, for the American College of Physicians High Value Care Task F. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014; 174(12):1994–2003. [PubMed: 25330167]
4. Ha JF, Longnecker N. Doctor-patient communication: a review. *The Ochsner J*. 2010; 10(1):38–43. [PubMed: 21603354]
5. Fine E, Reid MC, Shengelia R, Adelman RD. 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]
6. Bousquet G, Orri M, Winterman S, Brugiere C, Verneuil L, Revah-Levy A. Breaking bad news in oncology: a metasynthesis. *J Clin Oncol*. 2015; 33(22):2437–2443. [PubMed: 26124489]
7. Kane HL, et al. Implementing and Evaluating Shared Decision Making In Oncology Practice. CA: A cancer journal for clinicians. 2014; 64(6):377–388. [PubMed: 25200391]
8. Clayton MF, Hulett J, Kaur K, Reblin M, Wilson A, Ellington L. Nursing support of home hospice caregivers on the day of cancer patient death. *Oncology Nursing Forum*. 2016 In press. scheduled for print July 2017.
9. Eggly S, Penner LA, Hagiwara N, et al. Patient, companion, and oncologist agreement regarding information discussed during triadic oncology clinical interactions. *Psychooncology*. 2013; 22(3): 637–645. [PubMed: 22337320]
10. Laidsaar-Powell RC, Butow PN, Bu S, et al. Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns*. 2013; 91(1):3–13. [PubMed: 23332193]
11. van de Bovenkamp HM, Trappenburg MJ. Comparative review of family-professional communication: what mental health care can learn from oncology and nursing home care. *Int J Ment Health Nurs*. 2012; 21(4):366–385. [PubMed: 22510087]
12. Laidsaar-Powell R, Butow P, Bu S, 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). *Psychooncology*. 2016; 25(7):787–794. DOI: 10.1002/pon.4003 [PubMed: 26514374]
13. Cloyes KG, Carpenter JG, Berry PH, Reblin M, Clayton M, Ellington L. “A True Human Interaction”: Comparison of Family Caregiver and Hospice Nurse Perspectives on Needs of Family Hospice Caregivers. *Journal of Hospice & Palliative Nursing*. 2014; 16(5):282–290.
14. McGarry J. Defining roles, relationships, boundaries and participation between elderly people and nurses within the home: an ethnographic study. *Health Soc Care Community*. 2009; 17(1):83–91. [PubMed: 18700870]
15. Waisbrod N, Buchbinder E, Possick C. In-home intervention with families in distress: changing places to promote change. *Soc Work*. 2012; 57(2):121–132. [PubMed: 23038874]
16. Brown D, McWilliam C, Ward-Griffin C. Client-centred empowering partnering in nursing. *J Adv Nurs*. 2006; 53(2):160–168. [PubMed: 16422714]

17. Cloutier DS, Martin-Matthews A, Byrne K, Wolse F. The space between: using 'relational ethics' and 'relational space' to explore relationship-building between care providers and care recipients in the home space. *Soc Cult Geogr.* 2015; 16(7):764–782.
18. Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns.* 2006; 62(3):355–360. [PubMed: 16860520]
19. Tay LH, Hegney D, Ang E. Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: a systematic review. *Int J Evid Based Healthc.* 2011; 9(2):151–164. [PubMed: 21599844]
20. Ellington, L., Clayton, MF., Reblin, M., Latimer, S., Wong, B., John, KK. Paper presented at the 2015 AAHPM & HPNA Annual Assembly. Philadelphia, PA: Feb. 2015 Discussions of physical, spiritual, and emotional needs during home hospice care.
21. Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Educ Couns.* 2002; 46(4):243–251. [PubMed: 11932123]
22. Reblin M, Clayton MF, John KK, Ellington L. Addressing methodological challenges in large communication datasets: Collecting and coding longitudinal interactions in home hospice cancer care. *Health Communication.* 2016; 31(7):789–797. [PubMed: 26580414]
23. McLachlan, G., Peel, D. *Finite Mixture Models.* New York: Wiley; 2000.
24. R Core Team. *R: A language and environment for statistical computing [computer program].* Vienna, Austria: Foundation for Statistical Computing; 2013.
25. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med.* 2010; 362(13):1211–1218. [PubMed: 20357283]
26. Wiechula R, Conroy T, Kitson AL, Marshall RJ, Whitaker N, Rasmussen P. Umbrella review of the evidence: what factors influence the caring relationship between a nurse and patient? *J Adv Nurs.* 2016; 72(4):723–734. [PubMed: 26692520]
27. Stoltz P, Lindholm M, Uden G, Willman A. The meaning of being supportive for family caregivers as narrated by registered nurses working in palliative homecare. *Nurs Sci Q.* 2006; 19(2):163–173. [PubMed: 16624988]
28. Funk L, Stajduhar K. Analysis and proposed model of family caregivers' relationships With home health providers and perceptions of the quality of formal services. *J Appl Gerontol.* 2013; 32(2): 188–206. [PubMed: 25474216]
29. Hagerty BM, Patusky KL. Reconceptualizing the nurse-patient relationship. *J Nurs Scholarsh.* 2003; 35(2):145–150. [PubMed: 12854295]
30. Gantert TW, McWilliam CL, Ward-Griffin C, Allen N. Working it out together: family caregivers' perceptions of relationship-building with in-home service providers. *Can J Nurs Res.* 2009; 41(3): 44–63. [PubMed: 19831054]
31. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs.* 2012; 28(4): 236–245. [PubMed: 23107181]
32. Ellington, L., Terrill, AL., John, KK., Reblin, M., Clayton, MF. Expression of Positive Emotions among Family Caregivers of Hospice Cancer Patients. In: Ellington, L., editor. *Advanced Cancer Caregivers: Implications of Communication with Patients and Providers Symposium* conducted at the International Conference on Communication in Health Care; New Orleans, LA. Oct. 2015
33. Lambert NM, Fincham FD, Stillman TF. Gratitude and depressive symptoms: The role of positive reframing and positive emotion. *Cognit Emot.* 2012; 26(4):615–633. [PubMed: 21923564]
34. Clayton MF, Reblin M, Carlisle M, Ellington L. Communication behaviors and patient and caregiver emotional concerns: a description of home hospice communication. *Oncol Nurs Forum.* 2014; 41(3):311–321. [PubMed: 24769595]
35. Kehl KA. How hospice staff members prepare family caregivers for the patient's final days of life: An exploratory study. *Palliat Med.* 2015; 29(2):128–137. [PubMed: 25249240]
36. Street RL Jr. Gender differences in health care provider-patient communication: are they due to style, stereotypes, or accommodation? *Patient Educ Couns.* 2002; 48(3):201–206. [PubMed: 12477604]

37. Peck BM, Denney M. Disparities in the Conduct of the Medical Encounter. The Effects of Physician and Patient Race and Gender. 2012; 2(3):1–14.
38. Dillon EC. How home hospice care facilitates patient and family engagement. *Death Studies*. 2016:1–10.

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FIGURE 1.

Standardized cluster means. CG indicates caregiver. LS/PS indicates Lifestyle/Psychosocial

TABLE 1

Communication codes, examples, and descriptive statistics

Variable	Example	Nurse			Caregiver			Patient		
		Mean Freq (SD)	Min/Max Freq.	Mean % (SD)	Mean Freq (SD)	Min/Max Freq.	Mean % (SD)	Mean Freq (SD)	Min/Max Freq.	Mean % (SD)
Physical care information	His blood pressure is lower today.	116.39 (82.01)	3–487	36 (13)	74.58 (67.52)	0–328	40 (21)	47.71 (49.70)	0–379	47 (19)
Physical care questions	Has he eaten today?	39.01 (23.49)	0–137	13 (6)	10.36 (12.00)	0–109	6 (7)	5.38 (6.82)	0–40	6 (7)
Partnership (nurse only)	Would you hold his legs while I give him a boost?	18.30 (15.64)	0–130	6 (4)	–	–	–	–	–	–
Lifestyle/Psychosocial information	Gardening always makes me happy.	25.50 (26.05)	0–202	8 (7)	37.65 (55.58)	0–756	19 (16)	14.86 (24.12)	0–184	12 (12)
Lifestyle/Psychosocial questions	Is your daughter still really upset?	9.09 (8.91)	0–53	3 (3)	2.96 (3.80)	0–24	2 (3)	2.01 (3.18)	0–24	2 (3)
Positive emotion	This is like a day at the spa!	22.13 (15.10)	0–106	8 (4)	8.82 (9.71)	0–66	5 (5)	5.87 (8.12)	0–60	6 (6)
Emotional response	It's okay to feel that way. I'm so sorry.	12.25 (13.41)	0–89	4 (4)	2.05 (3.68)	0–24	1 (2)	.94 (2.03)	0–20	1 (2)
Distress (Patient/Caregiver only)	I just can't stand to see her in pain.	–	–	–	4.34 (3.09)	0–71	2 (4)	4.44 (9.14)	0–87	6 (15)
Total talk	NA	311 (161)	42–968	–	165 (139)	0–1045	–	99 (96)	0–776	–

TABLE 2

Nurse and dyad demographics

Demographics	Patient N = 101 n (%)	Caregiver n = 101 n (%)	Nurse N = 58 n (%)
Gender			
Male	60 (60.0)	40 (40.0)	5 (8.9)
Female	40 (40.0)	60 (60.0)	51 (91.9)
Ethnicity			
Hispanic	1 (1.0)	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 (1.0)	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 (1.8)
Associate	–	–	38 (67.9)
Bachelors	–	–	15 (26.8)
Masters	–	–	2 (3.6)
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)	–
Employment			
Not working	–	57 (56.4)	–
Part-time	–	11 (10.9)	–
Full time	–	33 (32.7)	–
Self-reported health			
Excellent	–	15 (14.9)	–

Demographics	Patient N = 101 n (%)	Caregiver n = 101 n (%)	Nurse N = 58 n (%)
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 (1.0)	–
Other (eg, TriCare)	–	4 (3.8)	–
	M (SD)	M (SD)	M (SD)
Age	67.4 (10.8)	65.7 (10.2)	42.1 (14.6)
Length of relationship	34.9 (17.9)		–
Days on Hospice	82.6 (75.9) Median = 54		–
Years hospice experience		–	4.5 (4.9)

TABLE 3

Visit communication patterns

Low distress	Patient N = 109; 20% (Cluster 5)	Caregiver N = 124; 23% (Cluster 1)	Dyad N = 59; 11% (Cluster 6)
	Patient	Patient	Patient
	Lifestyle/psychosocial information Lifestyle/psychosocial questions Physical care information Physical care questions Positive emotion	Low talk	Lifestyle/psychosocial information Lifestyle/psychosocial questions Positive emotion Emotional response
	Caregiver	Caregiver	Caregiver
	Low talk	Physical care information Positive emotion	Lifestyle/psychosocial information Lifestyle/psychosocial questions Positive emotion Emotional response
	Nurse	Nurse	Nurse
	Physical care questions Positive emotion	Physical care questions Positive emotion	Lifestyle/psychosocial information Lifestyle/psychosocial questions Positive emotion
High distress	Patient N = 64; 12% (cluster 4)	Caregiver N = 149; 28% (cluster 2)	Dyad N = 32; 6% (cluster 3)
	Patient	Patient	Patient
	DistressEmotional response Physical care information Physical care questions	Low talk	Distress
	Caregiver	Caregiver	Caregiver
	Low talk	Physical care information Distress Positive emotion	Distress Emotional response Physical care information Physical care questions Positive emotion
	Nurse	Nurse	Nurse
	Physical care information Physical care questions Partnering Emotional response	Physical care information	Partnering