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Caregiver Activation and Home Hospice Nurse Communication in Advanced Cancer Care

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Abstract

Background—Activated patients have the skills, knowledge, and confidence to manage their care, resulting in positive outcomes such as lower hospital readmission and fewer adverse consequences due to poor communication with providers. Despite extensive evidence on patient activation, little is known about activation in the home hospice setting, when family caregivers assume more responsibility in care management.

Objective—We examined caregiver and nurse communication behaviors associated with caregiver activation during advanced cancer patients' home hospice visits using a prospective observational design.

Methods—We adapted Street's Activation Verbal Coding tool to caregiver communication and used qualitative thematic analysis to develop codes for nurse communications that preceded and followed each activation statement in 60 audio-recorded home hospice visits.

Results—Caregiver communication that reflected activation included: demonstrating knowledge regarding the patient/care, describing care strategies, expressing opinions regarding care, requesting explanations of care, expressing concern about the patient, and redirecting the conversation toward the patient. Nurses' responded by: providing education, reassessing the patient/care environment, validating communications, clarifying care issues, updating/revising

care, and making recommendations for future care. Nurses prompted caregiver activation through focused care-specific questions, open-ended questions/statements, and personal questions.

Conclusions—Few studies have investigated nurse/caregiver communication in home hospice and to our knowledge no other studies focused on caregiver activation. The current study provides a foundation to develop a framework of caregiver activation through enhanced communication with nurses.

Implications for Practice—Activated caregivers may facilitate patient-centered care through communication with nurses in home hospice thus resulting in enhanced outcomes for advanced cancer patients.

Introduction

The American Cancer Society¹ estimates that in 2015 approximately 1.6 million new cases of cancer will be diagnosed in the U.S. A diagnosis of cancer constitutes a major life event for both the person diagnosed and his/her family and caregivers.² Reflecting on the impact of her mother, grandmother, and six aunts' experience with breast cancer in her book "Refuse",³ author and environmentalist Terry Tempest Williams (1991) discerns, "an individual doesn't get cancer, a family does" (p. 214). Similarly, research indicates a cancer diagnosis can have a greater impact on family members than on patients.^{4–9}

Improvements in early screening, diagnosis, treatment, rehabilitation, and supportive interventions have contributed to increases in cancer survival.^{10,11} As a result, many patients and families live with the ongoing challenges of managing cancer as a chronic illness.^{11,12} Cancer experts have recommended using the Chronic Care Model¹³ as a framework for care and suggest self-management in cancer requires partnership building between providers, patients, and families over the entire cancer-care continuum.¹¹ As described by the Institute of Medicine,¹⁴ the cancer-care continuum extends across six major phases: prevention, early detection, diagnosis, treatment, survivorship, and end of life.

Successful self-management in chronic conditions including some types of cancer requires activated patients who have the knowledge, skills, and behavioral repertoire to manage their health¹⁵ across the entire care continuum. Studies indicate activation is associated with better health outcomes and better overall care experiences, lower hospital readmission, fewer medical errors and adverse consequences due to poor communication.¹⁶ In addition, activated patients are more likely to prepare questions for providers, seek out healthcare information, make changes in lifestyle behaviors, perform consistent home care, obtain regular chronic care, and experience fewer problems with care coordination for chronic illnesses.^{17–25} Further, when assessing activation one must consider how patients and their caregivers communicate with healthcare providers.^{26–28} It is also important to include family caregivers of cancer patients in studies addressing activation to ultimately improve the health of the patient as well as the caregiver.

Along the cancer-care continuum, the responsibilities of caregiving are particularly increased at the end of life. Patient care needs intensify with advanced cancer as the physiologic changes result in diminished capacity for patients to manage their own care and

normal activities of daily living.¹¹ While goals of care focus on maintaining independence and autonomy, the responsibilities of care and life management often inevitably transition to caregivers on behalf of the patient. Patients who have been activated and engaged in self-managing their cancer become reliant on caregivers to be activated in taking on the responsibilities of care during this crucial time. In many cases, caregivers report taking on the role as an extension of family responsibility, with little choice or preparation, having continued caregiving for a number of years equivalent to a full time job.²⁹ Studies indicate an increased burden when family caregivers have to administer medications (including pain medications), use complex equipment, and perform activities of daily living such as bathing, toileting, dressing, feeding (and preparing special diets), positioning and turning, and transporting patients/family members.^{30,31}

While a substantial body of evidence exists focused on self-management and patient-activation, little is known about caregiver activation. Activation in caregivers is particularly salient in end of life care, such as home hospice, when family caregivers assume more responsibility and care provision. Therefore, the purpose of this study was to examine caregiver activation during home hospice care for advanced cancer patients. The specific aims were:

1. Identify and describe caregiver communication associated with activation/active participation during visits with home hospice nurses.
2. Identify and describe nurse communication behaviors that preceded and followed activated caregiver communications.

Methods

Design and setting

An analysis of 60 audio-recordings from a larger prospective observational, multi-site study of audio-recorded hospice nurse home visits was conducted to explore caregiver activation and hospice nurse communication³² (NIH P01CA138317). Hospice nurses wore small digital recorders to capture naturally-occurring conversations during home visits. Nurses, patients, and their designated caregiver participants were recruited and consented from hospice agencies from 4 locations across the U.S. For the current study, audio recordings from consented caregivers within the caseloads of 45 consented hospice nurses were randomly selected for analysis. Eligibility criteria for caregivers included caring for a patient diagnosed with advanced stage cancer, patient age 45 or older, English-speaking and writing. This study was approved by the university Institutional Review Board and the hospice agencies involved.

Hospice nurses were instructed on how to use the digital audio recorders and wore them around their neck during home hospice visits. Before entering the home of a consenting caregiver, hospice nurses turned on the recorder and stated the date and time, their study nurse identification, and the patient and caregiver identifier. Before beginning the visit, nurses were required to remind the patient, caregiver, and other individuals present in the home that the visit was going to be recorded and to obtain verbal consent from those present who were not study participants. If no objections were voiced, recording continued

throughout the home hospice visit. If at any time anyone in the home requested that recording be stopped, the nurse was instructed to turn off the recorder immediately. Once recordings were complete, research assistants retrieved and downloaded audio recorded data directly to an encrypted, password protected laptop computer. The data were then uploaded to a password-protected drive on a secure university server. Once downloaded, the audio recorded visits were erased from the recorders which were returned to the nurse to be used again.

Coding caregiver communication

Digital audio recordings of home hospice visits were coded by three coders (CD, DL, KD) using Noldus Observer XT 11.5 event logging software for observational data. Though the recordings reflected the fluid exchange between the caregiver and nurse, consistent with Specific Aim 1, caregiver communications were analyzed first. To address the specific aim: Identify and describe caregiver communication associated with caregiver activation, codes were developed directly from listening, reviewing, and discussing the audio recorded visits. The codes were then entered directly into the specialized direct-entry software.

Conceptual framework for code development—Two frameworks served to broadly operationalize communication behaviors and guide code development for this study – patient activation and Street’s Activation Verbal Coding Tool.

Activation: We used the definition for activation developed by Hibbard and colleagues¹⁵ which equates patient activation with understanding one’s role in the care process and having the knowledge, skill, and confidence to manage one’s health and health care. Those who are activated believe they have important roles to play in self-managing care, collaborating with providers, and maintaining their health. They are able to accomplish self-management because they **know** how to manage their condition, maintain functioning, and prevent health declines and have the **skills** and **behavioral repertoire** to manage their condition, collaborate with health providers, maintain their health functioning, and access appropriate and high quality care.¹⁵ We applied the definition of activation to caregivers in this study based on the significant care responsibilities they take on in home hospice. In operationalizing activation for coding, we identified communications that reflected the primary elements of activation, **knowledge, skills, and behavioral repertoire** to provide care in the home setting.

Street’s Active Participation Verbal Coding Tool: Street and colleagues²⁸ developed a communication coding scheme used to identify active patient participation in communication in healthcare settings that was also validated in other cancer settings.^{26, 33–35} In a study examining physician/patient communication, Street et al²⁶ measured the “degree to which patients were active participants” by adapting a self-report measure (Lerman’s Perceived Involvement in Care Scale (PICS))^{36, 37} to make it appropriate for observer coding. We used the resultant verbal coding scheme and applied the items to caregivers to serve as a guide for the code book for this study. For example, the item, “The patient asked the nurse to explain the care/treatments,” was modified to “The CG asked the nurse to explain the care/treatments” (See Table 1). In addition, Street and colleagues²⁸ suggest active participation

coding integrates three types of verbal communication - asking questions, being assertive, and expressing concerns. These types of communication are considered “active” because they can influence a clinician’s behavior, perceptions of the patient, and treatment decisions.

We found significant conceptual congruence between the components of activation and Street’s Active Participation constructs. Therefore, the framework integrating the operational definition of activation and Street’s Active Participation Verbal Coding served as a guide to develop codes that reflected specific content (knowledge, skills, and behaviors) and processes (asking questions, being assertive, expressing concerns) for this study. Table 1 provides a summary of the guide used for code development that integrates the definition of activation and Street’s Active Participation Verbal Coding.

An iterative process of listening to the recordings multiple times, individual and collaborative coding, extensive discussion, and consensus building was used to develop and refine codes. Twenty audio recordings served as the basis to develop and pilot test the code book. During this process some codes were expanded while others collapsed into meaningful units that best reflected the conceptual framework for the study.

The final code book integrated the elements of activation and Street’s Active Participation Verbal Coding²⁸ tool and resulted in codes, operational definitions, and sample communications taken from actual audio recordings which served as exemplars for coding. Researchers co-coded 15% of the total audio recordings throughout the coding process to ensure consensus and prevent coder drift. In addition, the researchers met regularly to discuss the coding process and findings in order to enhance reliability and validity in coding.

Coding nurse communication—In order to identify and describe nurse communication behaviors that precede and follow activated caregiver communications, we followed a multi-step process of qualitative thematic analysis and code development. Using open coding, we did not develop a priori codes, but rather generated them inductively. Three researchers (CD, DL, KD) independently reviewed the recordings specifically focused on nurse communication that preceded and followed caregiver communication that was previously identified and coded as activation. Initial codes were developed independently, then discussed to determine common elements and themes. In addition, recordings were reviewed and coded together to provide an opportunity for discussion resulting in further agreement. Consensus was reached after in-depth discussions. Key words and themes identified from repeated review of the recordings served to form the initial codes that were clustered into families of codes and conceptual categories. The conceptual categories were broad, inclusive and focused on general communication themes and processes. The qualitative analysis continued until data saturation was reached and no new themes emerged. The codes developed from this initial qualitative analysis were then used as the basis for coding the remaining audio recordings using Noldus Observer XT 11.5 software.

Qualitative rigor was assured by ongoing peer debriefing throughout the process, collaborative coding among the researchers, continual comparative analysis, and in-depth discussion. An audit trail included detailed notes of the discussions and ongoing process documenting the process of code development and analysis decisions. In addition, meetings

with the inter-disciplinary research team from the larger parent study provided ongoing consultation and a broader context to the coding process and findings.

Analysis

The integration of data analysis was facilitated as the coded caregiver communication provided direction for the qualitative coding of nurse communication. As caregiver communications that reflected activation was first coded, it was then used as a guide to identify and qualitatively code the nurse communications that preceded and followed. The final dataset included coded caregiver communications that reflected the identified elements of activation and coded nurse communication behaviors that both preceded and followed. Data were downloaded into a computerized spreadsheet and included the codes, speaker, time stamp, and an open cell for notes. Descriptive statistics were calculated for the communication codes revealing frequency, measures of central tendency, and percent of visits in which each code occurred. Patient, nurse and caregiver descriptive demographics were also calculated. Qualitative analysis was conducted as described above.

Results

Demographics

Patients/caregivers—The average patient (N=60) age was 70.2 (SD=11.2) with a range from 53 to 92 years. The majority were Caucasian (98%) with 3 patients indicating they were Hispanic. The most common cancer diagnoses were lung, prostate, brain, and breast cancer. The most common co-morbid conditions were hypertension, diabetes, arthritis, and heart disease with 83% of patients reporting one or more co-morbid condition. The median time from hospice admission to date of death was 6.85 (SD=11.2) weeks. Caregivers (N=60) tended to be spouses (65%) or adult children (30%), mostly female (70%), primarily Caucasian (92%), and had a mean age of 59.5 (SD=14.4). They reported an average of 2.5 health problems (SD=1.3) including hypertension, arthritis, mental health problems, cancer, and diabetes. Nearly half of the caregivers in this study worked outside the home with 32% employed in full time jobs. (Table 2)

Hospice nurses—Nurses (N=45) were primarily female (91%), Caucasian (91%), had an average age of 41.4 (SD=10.36), and had been practicing as a registered nurse for an average of 13.4 years (SD=13.3). The mean time employed as a hospice nurse was 4 years (SD=4.5), however 40% had been employed in this specialty for one year or less. The majority had graduated from an associate degree or diploma program (64%) and over half (58%) of those nurses had a bachelor's degree in another discipline. Sixteen percent were certified in hospice/palliative care. (Table 3)

Communication

Analysis of 60 audio-recordings for distinct nurse-caregiver-patient visits yielded a total of 4379 coded caregiver and nurse communication events. The average length of time per visit was 43 minutes (SD=14.19) with an overall range of 20 to 81 minutes. Figure 1 depicts a graphic representation of the overall study findings and reflects the fluid and collaborative nature of communication between caregivers and nurses in home hospice.

Findings for specific aim 1. Identify and describe caregiver communication behaviors associated with caregiver activation

A total of 1805 caregiver communication behaviors were coded. The most commonly identified/coded caregiver communications that reflected activation included: demonstrating knowledge regarding the patient and or his/her care (present in 93% of visits, $M=7.5$ ($SD=4.9$)), describing care strategies (present in 92% of visits, $M=6.75$ ($SD=4.4$)), expressing opinions regarding care (present in 87% of visits, $M=3.28$ ($SD=3.1$)), requesting explanations of care (present in 78% of visits, $M=2.2$ ($SD=2.2$)), expressing concern about the patient (present in 75% of visits, $M=2.5$ ($SD=2.5$)) and redirecting the conversation toward the patient (present in 60% of visits, $M=1.9$ ($SD=2.5$)). (Table 4 provides a summary of findings and related quotes.)

Demonstrating knowledge—Many caregivers were able to demonstrate *knowledge* regarding the patient and care in a variety of ways. They had knowledge about the patient's health and overall condition and were able to inform the nurse about past medical or social history that was pertinent to ongoing care planning. For example, one caregiver alerted the hospice nurse to a past allergic reaction when the nurse brought up a possible treatment. Caregivers were also knowledgeable about the patient's current condition and provided updated information including changes related to patients' activity and energy level, level of consciousness (alertness vs. confusion), oxygenation status, appetite, intake and output, bowel status, and pain. They communicated knowledge about the patient's care including appointment schedules with providers; information related to over the counter and prescription medications; and equipment and supplies.

Nurse: "Is she still taking her Lasix?"

CG: "No they discontinued that because she is hardly drinking enough. She hasn't really ate in three days, maybe 4. And now she doesn't really drink anything at all." (CG # 07: 51 year old daughter)

Describing care strategies—Caregivers described care strategies that reflected components of activation. In some cases the care strategies had previously been implemented and in other cases caregivers described strategies they planned to implement. They communicated planning for care by scheduling around family members' availability and use of home care aides; making changes in the home to provide a safe care environment (rearranging rooms/furniture, removing obstacles, integrating equipment); anticipating needs for adequate supplies; methods for medication administration in the home; appropriate food preparation; turning and positioning for comfort; strategies to assess and treat symptoms (pain, constipation, anxiety); and ways to balance patients' need for assistance while preserving their sense of independence.

1) CG: "I usually put her oxygen up a little bit before I get her into the bathtub. We've kinda figured when her oxygen gets low is when she passes out. Sometimes that tubing gets clogged up or bends.... right now it's on 3.... but we have to watch for that. Be sure it doesn't get clogged." (CG # 01: 24 year old granddaughter)

2) CG: “She used to take 1 mg tablets but now that it’s the liquid I measure it out in the - little cup so that it’s the same as the 1 mg like before. Then I give it to her with juice.” (CG # 19: 62 year old husband)

Expressing opinions regarding care—The conversations also reflected that many caregivers were able to communicate their opinions regarding patient care. They expressed their opinions related to the effectiveness of various treatments and medications, their interpretation of patient responses, and their view of interactions with other hospice team members.

1) CG: “I don’t think that is helpful whatsoever. She’s had that Haloperidol since the weekend. I don’t see any difference.” (CG # 07: 51 year old daughter)

2) In a conversation regarding the possibility of starting a medication that would require a trip to the hospital for follow up lab work: CG: “I think taking “K” into the hospital drains his energy but if it helps with pain control then it may be worth it.” (CG # 43: 63 year old wife)

Requesting explanations—Caregivers communicated with nurses asking questions that facilitated explanations of care. Caregivers requested explanations by asking questions about care processes (prescription refills, ordering medications), the meaning of medical terminology, procedures involved in specific care, reasons for specific medications, the interpretation of symptoms, and what to expect as the patient’s condition deteriorates.

1) CG: “Why are his hands so clammy?” (CG # 12: 64 year old wife)

2) In a conversation with the nurse about possibly using Patient Controlled Analgesia: CG: “What does that mean – pump? Is it something inserted or ... how does that work?” (CG # 10: 74 year old sister)

3) CG: “I just wonder if his health is deteriorating. Can you tell if it is going down?” (CG # 00: 70 year old wife)

Concern about patient—Caregivers communicated general and specific concerns about the patient. Some concerns related to very specific care issues while others focused on changes in the patient’s condition or problems they anticipated that could potentially affect the patient. In addition, some of the concerns related to safety of the patient in the home (such as falling).

CG: “He’s hardly eaten since Saturday morning. He’s hardly drinking anything too. Just with his pills and then he don’t drink enough to get them down.”

Nurse: “So his appetite is down and he’s not drinking enough?”

CG: “No he’s not drinking enough really.”

Nurse: “His appetite might be up and down.”

Nurse: “How do you feel about that?”

CG: “It’s OK about him not eating but I think he should be drinking. That makes me worried” (CG # 07: 51 year old daughter)

Redirecting the conversation toward the patient—At times caregivers communicated in a way that redirected the discussion toward the patient in an attempt to draw the patient back into the conversation. Examples of this included asking the patient specific questions in the presence of the nurse, encouraging the patient to communicate with the nurse, and reminding the patient of issues they had discussed to bring up with the nurse. In addition, caregivers redirected the conversation by reinforcing to the patient what the nurse said regarding his/her care.

1) CG: “The other night you (patient) had some anxiety and some agitation. Do you remember that? We were saying we were going to tell...(referring to the nurse).” (CG # 28: 69 year old female partner)

2) CG: “She’s saying we should switch to the liquid if the pills are too hard to swallow.” (CG # 39: 76 year old husband)

Findings for specific aim 2) Identify and describe nurse communication behaviors that precede and follow activated caregiver communications

Nurse communication prior to activated caregiver communications—Analysis of nurse communications that preceded caregivers’ activated communication behaviors revealed a total of 615 coded nurse statements. These nurse communications were considered as triggers or prompts that were operationalized as a distinct change of subject, direction, or opening to a discussion. As conversation is a dynamic reciprocal process and communication interactions both precede and follow activation behaviors; preceding codes were used when there was an opening of the conversation or change in the topic or flow of the discussion by the nurse. The visits contained an average of 10.25 (SD=7.97) prompts with a minimum of 8 and maximum of 37. In addition, caregivers activated communications were unprompted an average of three times per visit (SD=2.2). In other words, caregivers introduced specific issues without any prompting by the nurse – they initiated communication independent of the nurse asking. Nurses communicated using broad open-ended questions/statements (12% of total prompts), focused care-specific questions (75% of total coded prompts), and personal questions (13% of total coded prompts) Table 5 lists examples of each type of nurse prompt.

Nurse communication after caregiver activated communications activation statements—Analysis of nurse communication statements that followed caregivers’ activated communication statements revealed a total of 1959 coded nurse responses. Nurses’ responded to caregiver’s activated communications by providing education (present in 90% of visits, M=8.6 (SD=5.5)), reassessing the patient/care environment (present in 85% of visits, M= 3.2 (SD=2.2)), validating communications (present in 83% of visits, M=4.2 (SD=2.6)), clarifying care issues (present in 83% of visits, M=2.8 (SD=2.6)), updating/ revising care (present in 73% of visits, M=2.2 (SD=2.1)), and making recommendations for

future care (present in 63% of visits, $M=1.6$ ($SD=1.6$)). (Table 6 provides a summary of nurse communications)

Providing education: Nurses provided education in response to caregivers' activated communication. Some instances focused on instruction regarding specific care processes (such as medication administration, turning and positioning, dietary issues, dressing changes), how to interpret patient symptoms, and what to expect during patients' disease trajectory.

1) In a conversation about if pain is being managed well, nurse explains what "well" means. Nurse: "If you are having pain that is more than 4 out of 10, then it's not being managed well."

2) Nurse: "So I would give him the full syringe of the morphine and the full syringe of the Haldol... you can do that every 4 hours... if you think after say an hour or so he's still not comfortable... you can try giving the Lorazepam... and give me a call."

Reassessing the patient/care environment: Nurses reassessed the patient or the care environment in response to caregivers' activated communication. At times the nurse reassessed subjective symptoms or responses, examined the patient to further assess the physical condition, or reassessed the home environment including equipment and supplies.

1) CG: "Do you have any of that barrier cream? I've been using that." (CG # 01: 24 year old granddaughter)

Nurse: "Yeah, I think I have some out in my car. I'll go get it... but let me take a look at that (reddened area on the patient's back) first. I better take a look."

2) CG: "R" do you want an Ativan?" (asking patient in nurses' presence) (CG # 01: 24 year old granddaughter)

Nurse: "R" do you feel anxious? I mean like on a scale of 0 – 10 how anxious do you feel?"

Validating communications: At times nurses responded to caregivers by providing validation. Through validating statements nurses affirmed caregivers' concerns, responded to their description of care strategies, and acknowledged their opinions.

1) CG: "With the confusion, I just started to do the pain medication like the quick acting hydrocodone on schedule." (CG # 07: 51 year old daughter)

Nurse: "That's absolutely appropriate."

2) In a conversation in which the nurse is explaining signs of active dying the caregiver says: CG: "Oh I know. They explained this to me. I still find it frightening." (CG # 00: 70 year old wife)

Nurse: "It is frightening, but just know that we are here for you."

Clarifying care issues: Nurses also responded by seeking clarification of caregivers' communications. They asked for more information, attempted to reiterate what was said, and asked for clarification of the caregivers' statement to better understand the issue or problem.

1) In a conversation regarding other potential caregivers the nurse attempts to clarify the primary caregiver's perspective: CG: "And there's also "B" too, but ... God she's a mess too.... She has good intentions, but she just doesn't know what pills do what and what's for what... (CG # 04: 24 year old daughter)

Nurse: "Well and you don't feel she's that helpful?"

2) CG: "Well it still is - because 8:30 to 8:30 is still 12 hours. So he's taking one (pill) in the morning at 8:30 then 2:30 then 8:30 at night... so that's three times... (CG # 21: 56 year old wife)

Nurse: "OK so basically you're doing every 6 hrs while waking and you're going 12 hrs at night."

Updating/revising care: In response to caregiver communication nurses revised or updated patient care. In some cases this took the form of contacting the physician to request changes in medication prescriptions or treatments, coordinating additional care with the hospice team, making referrals, communicating with various pharmacies to relay information related to medication or supplies, and revising specific procedures or updating equipment.

CG: "He gets the patch tomorrow. Changes every 3 days and it's usually the day before he changes it that he experiences problems..." (CG # 03: 80 year old wife)

Nurse: "So I wonder if it's not lasting 3 days then. So is that pretty consistent, it lasts 2 days but then the day before it needs to be changed he starts up..."

CG: "Yes, the day before he needs a little more..."

Nurse: "Generally its changed every 3 days it's supposed to be good 3 days, but maybe in some people.... let me just check."

CG: "Usually it's that second day when he experiences more (pain). But then you (directed to the patient) had quite a bit last night, didn't you..... of the pain?"

Nurse: "Now we might have stretched it too far in between (referring to between dose times). So I can talk to Dr. X about that - that it's not as effective the second day. To see if he'd increase the dose or change the frequency."

Making recommendations for future care: Responding to caregiver's activated communication, nurses made recommendations for future care. Often nurses recommended actions that caregivers could take should a specific patient scenario occur again, if certain symptoms worsened, or if new problems developed. The recommendations encompassed medication administration, care and comfort strategies, symptoms to report, and possible resources to access.

1) In a conversation in which the CG is describing a recent experience of tachycardia: Nurse: “If her heart rate continues to go up like that again she could be in some pain. So one thing you could do is ... you might want to start a little bit of (pain) medication next time. Try giving her that liquid morphine.”

2) Nurse: “When we get to that point we will teach you how to do some repositioning to make sure his skin doesn’t break down (when patient is bedbound). I can get a pad that fills up with air that helps move him around and that helps.”

3) Nurse: “If she seems to be having trouble breathing in the future, one thing you could do is just sit her head up in bed.”

Discussion

In this study we describe elements of caregiver activation assessed in naturally occurring conversations with home hospice nurses. Our analysis revealed most caregivers were engaged with their hospice nurse and communicated in ways that demonstrated their personal knowledge, skill, and behaviors related to caregiving. Fifty eight out of the 60 audio recorded visits had caregivers that communicated some level of activation during the home hospice visit and varying elements of activation. In the two that did not, the caregivers both had minimal contact with the nurse and did not engage during the home visit. While assumptions related to the reason for the two caregivers not engaging in the visit cannot be made, it is useful to note that in the other 58 visits, caregivers were present and conversant throughout the entire audio-recording. In instances when patients were experiencing increased symptoms and or worsening consequences of disease, the caregiver tended to speak more than the patient

Our findings demonstrate the integral role of the caregiver in the course of the patient’s care and the vital partnership between nurse and caregiver in end of life home care. In nearly three quarters of the visits, nurses made revisions/changes in the plan of care based on communications with caregivers. These changes focused on adding new medications or revising the dose/frequency of ongoing medications; revisions in treatment/interventions, equipment/supplies; and referrals for additional care. While nurses most often facilitated activation through broad general open-ended questions, care-focused questions, and personal questions; caregivers introduced specific care-related issues independently an average of three times per visit. The actions taken by nurses based on communication with caregivers may likely affect patient’s experiences in home hospice and possibly outcomes, which is central to patient and family-centered care. This is also consistent with Street and colleagues²⁸ contention that communication is considered “active” because it can influence a clinician’s behavior, perceptions of the patient, and treatment decisions.

Our study findings are consistent with current literature related to caregivers. Recent studies indicate that family caregivers require high level of knowledge and skills to provide care and reduce their own distress.^{38, 39} Schumacher and colleagues³⁸ suggest family caregiving skill is the ability to engage effectively in care processes, characterized by goal-directed, organized behaviors acquired through practice and requires psychomotor, cognitive, and

psychological skills. However little evidence exists focused on the knowledge and skills family caregivers need to provide care and the predominant strategies of working with caregivers relies on providing information only.⁴⁰ In reality, caregiver skills include monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system; all of which requires complex reasoning and the opportunity to receive guidance and direction from nurses to rehearse what they learn so they can develop skills over time.^{38,40} Our focus on knowledge, skills, and behaviors in activation is well-aligned with current caregiving literature depicting the challenges family caregivers face.

Patients, caregivers, and healthcare providers consistently acknowledge that effective communication is critical in end of life care, yet a paucity of systematic research exists focused on interactions between caregivers and home hospice nurses^{41–44} with much of the health communication research focusing on the role of physicians.^{45–47} A recent analysis of U.S. thought leaders in hospice nursing revealed key areas of focus should include the role of communication and the importance of assessing the caregiver's ability to provide safe and responsible care.⁴⁸ However, few studies have investigated caregiver communication in home hospice and to our knowledge no other studies focused on caregiver activation. Our study focuses on communication and activation in the natural setting of home hospice and seeks to provide insights into the world of cancer caregiving at the end of life.

Using activation and active communication as a framework, our study findings could serve as a foundation for developing and testing evidence-based communication strategies for caregivers that enhance activation and facilitate successful caregiving. Complementary communication skill-building strategies could be developed for nurses to encourage and respond to activation in caregivers. Understanding activation in home hospice caregiving is an important step in informing nurses to help support caregivers and anticipate problems that may arise. Our findings also underscore the importance of supporting caregiver activation earlier in the cancer care continuum so that the transition to hospice can be less stressful for the family and more informed for the hospice team. A family-centered individualized approach focused on facilitating activation in family caregivers could assist healthcare providers to better determine the type and amount of health services and instrumental support needed to ameliorate burdens associated with caregiving. Recognizing strengths and limitations in activation can encourage and empower caregivers to get the assistance and support needed.

Limitations/Future directions for research

Several limitations apply related to the study sample. The lack of racial and ethnic diversity is a primary limitation and decreases the overall generalizability of this study. Future studies including a more diverse sample of patients, caregivers, and nurses would provide a broader view of communication and elucidate cultural differences that could inform culturally sensitive practices in home hospice. In addition, the majority of nurses graduated from associate degree or diploma programs and most were not certified in hospice/palliative care. Research focused on nurse characteristics may reveal important differences in caregiver/

hospice nurse communication and activation. A larger study sample would provide the opportunity to explore differences in the study findings based on nurse demographics such as education, certification, and time in specialty.

Expanding our data source from audio to video recordings would provide a broader view of the home visits with the integration of non-verbal communication and other observational data. This study examined behaviors evident in caregiver/nurse communication and did not reflect activated caregiving behaviors that may not have been mentioned in the conversations. While we focused on discovering communication that reflected activation in caregivers, we did not attempt to determine the level of activation (e.g. low vs. high) or what level was sufficient for optimal caregiving. In addition, considering that caregivers in this study reported an average of 2–3 chronic health problems, an examination of activation as it relates to the caregivers' own health would be revealing; however our preliminary findings suggest this is an infrequent occurrence. Other future directions for research include a longitudinal design to determine if caregiver activation changes over time, examining the outcomes of caregiver activation and communication for home hospice patients and caregivers, determining the caregiver activities/behaviors associated with different levels of activation, and the development of activation-enhancing education/coaching for caregivers and nurses.

Conclusions/Implications for practice

Despite these limitations, our study provides an initial exploration of activation in caregivers during a crucial time in the cancer care continuum – end of life home hospice care. Family caregivers are critical to the care of cancer patients receiving home hospice care; often expected to coordinate health services, manage complex symptoms, and provide much of the physical and emotional care of the patient that was once provided by nurses in the home. Caregivers report they need more consistent professional advice and coaching in bedside nursing skills to increase their self-confidence and ability and they worry about carrying out the practical aspects of home care competently and safely.³⁰ Hospice nurses are uniquely situated in the home setting, with opportunities to provide coordination and coaching for patients and family caregivers, as well as facilitate access to the interdisciplinary hospice care team. Activated caregivers may facilitate patient-centered care through communication with nurses in home hospice thus resulting in enhanced patient outcomes. The current study can provide a foundation to develop a framework of caregiver activation through enhanced communication with nurses in home hospice. Transformative nursing practice focused on communication processes that facilitate caregiver activation in home hospice can potentially affect patient and caregiver outcomes in end of life care.

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Figure 1.
Caregiver (CG) and nurse communication findings

Table 1**Guidelines for Caregiver Communication Coding**

Street's Patient Active Participation Coding (Content) Applied to CGs

- 1 The CG asked the nurse to explain the care/treatments and procedures in greater detail.
- 2 The CG asked the nurse for recommendations for care/treatment.
- 3 The CG asked the nurse about options for care/treatment
- 4 The CG let the nurse know what he/she liked and disliked about the care/treatment options.
- 5 The CG told the nurse which form of care/treatment the patient preferred.
- 6 The CG felt free to express any concerns and worries the patient might have about care/treatment.
- 7 The CG expressed his/her opinion about care/treatment.
- 9 The CG told the nurse about the concerns he/she has about the patient's health even when he/she does not ask.

Types of Verbal Communication (Process)

- 1 Asking questions
- 2 Being assertive (offering opinions, stating preferences, making requests)
- 3 Expressing concerns (worries, fears, negative feelings)

Definition of Activation (Content)

Communication demonstrating: knowledge, skills, and behavioral repertoire to manage care in the home setting

Abbreviation: CG, caregiver.

Table 2**Summary of Patient and Caregiver Demographics**

Patient Characteristics (N=60)					
	Min	Max	Mean	SD	n %
Male					31 52
Female					29 48
Race/Ethnicity					
Caucasian ^d					59 98
Age	53	92	70.2	11.12	
Weeks from hospice admission to date of death	2.0	52	10.85 6.85 median	11.2	
Enrolled 6 weeks					24 40
Cancer diagnoses					
Lung					18 30
Prostate					9 15
Brain					6 10
Breast					6 10
Other/combinations					21 35
Co-morbidities	0	5	1.75	1.61	
1 or more co-morbidity					50 83
Hypertension					22 37
Arthritis					13 22
Diabetes					11 18
Heart disease					7 12
Kidney disease					3 5
Lung disease					5 8
Other					28 46
Caregiver Characteristics (N=60)					
Gender					
Male					18 30
Female					42 70
Race/Ethnicity					

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	Min	Max	Mean	SD	n	%
Caucasian					55	92
Hispanic					3	5
Native American					1	2
Asian					1	2
Relationship to patient						
Wife					27	45
Husband					12	20
Adult children					18	30
Adult grandchildren					1	1.6
Other					2	3.3
Age Range	24	89	59.5	14.4		
Employment status						
Unemployed/retired					34	57
Employed part-time					6	10
Employed full-time					19	32
Number of health problems						
	0	5	2.5	1.3		
Hypertension					18	30
Arthritis					18	30
Mental health					11	18
Cancer					8	13
Diabetes					6	10
Heart disease					4	7
Fatigue syndrome					2	3.3
Other					26	43
At least 1 health problem					51	85

^aIncludes 3 Hispanics.

Table 3

Summary of Nurse Demographics (N=45)

	Min	Max	Mean	SD	n	%
Female					41	91
Age range						
< 30 years of age	25	58	41.4	10.4	7	15
30–39 years of age					13	30
40–49 years of age					13	30
50–59 years of age					11	25
Race/Ethnicity						
Caucasian ^a					41	91
African American					4	9
American Indian/Alaskan Native					2	4
Asian					2	4
Education						
BSN					15	33
MSN					1	2
ADN or diploma ^b					29	64
Years as nurses	2	36	13.4	13.3		
2 years					4	9
3–5 years					16	35
6–8 years					9	20
14–27 years					7	15
30+ years					9	20
Years as hospice case manager	1	16	4	4.5		
1 year					18	40
2–4 years					11	24
4–10 years					11	24
10+ years					5	11
Certification in hospice/palliative care					7	16

^aIncludes 1 Hispanic

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¹⁷ had other BA/BS degrees
q

Abbreviations: ADN, Associate Degree in Nursing; BSN, Bachelor of Science in Nursing; MSN, Master of Science in Nursing.

Table 4

Activated Caregiver Communications (N=1805)

Activated Caregiver Communication	M/SD	% of Tapes in Which Communication is Present	Caregiver Quotes
Demonstrating knowledge of patient & care	7.5/4.9	93	She was kind of tired yesterday, but the day before that she was really alert. That's the water pill. It was started for his heart. In the hospital once they started using those "clear ones" we didn't have no problems. But using those others - that's when she started blistering.
Describing care strategies	6.8/4.4	92	And I've given him XX of the morphine - one half. And he was still anxious so I gave him alprazolam. He did go in and lay down after the morphine a little bit. Then he said he was hurting so I gave him another oxycodone. Coughing and choking becomes a problem if I don't think ahead enough to give him a liquid to dunk anything dry in. Somebody brought us cookies and that didn't go down so well, but then he dunked them in his coffee and that was fine. We hang that sign up on the wall (referring to the DNI/DNR sign) so that even when aides or anybody comes in it's noticeable and they all know. Strategically we are ones who want to have things here before it's actually needed so we have it when it is.
Expressing opinions regarding care	3.3/3.1	87	My sense of the e-kit (emergency kit) is that I wouldn't use that unless I speak to the triage people I expected that extended release sleeping pill to work better, longer and was surprised his pills didn't work as well. The classical music has been good.... instead of like the TV, great sounds, calm...
Requesting explanations	2.2/2.2	78	How did her tests come out? Is her potassium low? Do you think his confusion is linked to the cancer? Why did she take the inhaler? Did you tell her to?
Expressing concern about the patient	2.5/2.5	75	But it was the breathing part that kind of was alarming.... because he was almost gasping. Yeah, he had a sort of anxiety attack and that is a concern.... really concerning. When he walks over there to the bathroom, he's kinda tripped over that hose, I'm really concerned about it. She was sitting up in bed, I was so nervous because she was so agitated and so confused It's more the moving, getting up and... That's where I'm more concerned. He could fall.
Directing conversation toward patient	1.9/2.5	60	Here is the nurse mom, you need to tell her about the pain, show her where your pain is Just don't feel hungry do ya?

Table 5

Nurses Prompts/triggers Preceding Caregiver Activation Communication (N=615)

Communication category	% of Total Prompts	Quotes
Open-ended questions/statements	12	“So you said things are good?” “Any changes I need to be made aware of?” “How are things going?”
Focused care-specific questions	75	“How about feedings? How are they going?” “Any problems urinating?”
Personal questions	13	“Good morning Joan. How’ve you been, you look tired. What’s going on?”

Table 6

Nurses Responses to Caregiver Communication (N=1959)

Nurse Responses	M/SD	% of Tapes in Which Communication is Present	Nurse quotes
Providing education	8.6/5.5	90	Often we need less medication if we are ahead of the distressing symptom rather than when we are just chasing it It's a proton pump inhibitor- anyone on a steroid- it can cause a little GI bleeding So it's important to take that ... it will protect your stomach when you take a steroid. It's the progression of the cancer and you need more sleep. When you're body's fighting off cancer you need more sleep. Do you notice how she (patient) stops breathing sometimes. She's starting to mottle a little bit. That's a good indication (she is dying).
Reassessing the patient/ care environment	3.2/2.2	85	Are you talking about the kind of purple area. I do see what you mean about the swelling on the... It (equipment) won't go down any further? Ok let me check on that then. Oh OK, well let me take a look at that bottle so I can put it in my computer to be sure there's no drug-drug interactions. That's the thing we worry about, but if this helps you feel better, then that's wonderful. (Nurse was responding to: this statement by the CG: And I also put her back on her dandelion root pills because its been giving her energy and it helps with liver support.)
Validating	4.2/2.6	83	And that's definitely a good practice. You really got that laxative stuff down to a science, you do. I understand... I can just imagine.
Clarifying care issues	2.8/2.6	83	Oh, is that a normal thing for you then? The morphine does? Tastes bad and makes him feel bad? The multiple myeloma - the cancer? Is that what you're thinking of?
Updating/revising care	2.2/2.1	73	We can increase the dose- we like to start low, but if it doesn't work, we can always increase it. I will talk to the doctor and we can increase the amount ... by far, if it's not having the effect. Ok I will give "T", he's our social worker, a message about this. He is out of town now but he'll call you back. Ok I've sent a volunteer referral through and he will be contacting you and you can chat about what you need and when they can come... what we can offer, and I think it's right up our alley I called my office, they are going to have someone come out and look at the bed, see if they can get it figured out. They are going to call the equipment company. I'm going to go by your lead. If you say this is getting miserable, then we'll get somebody to look at it
Making recommendations for future care	1.6/1.6	63	If we get to where his symptoms just get uncontrollable or if you (CG) can't manage, then we'll need to think about moving to a home with a higher level of care. I'm thinking we need to move his pain med to an opioid when the cancer pain progresses. I'd recommend methadone. When we get to the point where we have too much trouble with the tablet, we can use the syringes