

End-of-Life Communication

Nurses Cocreating the Closing Composition With Patients and Families



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Communication is imperative for end-of-life decision-making; however, descriptions of key strategies used by nurses are missing. A phenomenological approach was used to interpret interviews from 10 hospice/palliative nurses. The overarching pattern is the closing composition. Key communication strategies/patterns include establishing context, acknowledging through attentive listening, making it safe for them to die, planning goals of care, and being honest. Essential is the awareness that nurse, patient, and family all hold expertise in the subject matter. It is imperative that pre-/postnursing licensure curriculum be expanded to include training in mutual influence communication practices and mentoring in the skill of orchestration. **Key words:** *advance care planning, communication, end-of-life care, nurses, palliative care, phenomenology, relationships*

HEALTH care professionals in Westernized societies are challenged in initiating crucial conversations with patients and families experiencing life-limiting illnesses. These patients and families grapple daily with

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the knowledge that they may or may not be responding to treatment. Amid patients' and families' fervent search for the latest "cure," health care professionals may struggle communicating that cure is no longer possible.¹ For these patients and families, health care professionals often are a beacon of hope—"yes, you can fight this, yes, you can win." Yet, in the face of a terminal diagnosis, instilling hope in this way limits opportunities for patients and families to truly understand the realities of the disease and openly review, without judgment, their goals and wishes for end-of-life (EOL).² Within the health care team, nurses are well positioned to navigate advance care planning decision-making. While bearing witness to patients' and families' stories, nurses have the opportunity to sensitively present reality to preempt unnecessary treatment and suffering.^{3,4}

Advance care planning discussions about EOL can be heart-wrenching, painful, and difficult for patients, families, and some health care professionals. The reality of mortality underscores the imperative for dialogue specific to EOL goals and wishes. A recent survey of

Statements of Significance

What is known or assumed to be true about this topic:

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What this article adds:

This article adds a real-life, unscripted documentation of the communication practices used by hospice/palliative care nurses when engaging patients and families with life-limiting illnesses in EOL decision-making. This study extends the knowledge of EOL communication practices by revealing the importance of orchestration and mutual influence, which are crucial for shared decision-making.

physicians specific to EOL discussions and advanced care planning with patients and families revealed that 46% of physicians are uncertain what to say when initiating these conversations and only 29% indicated receiving formal training specific to advanced care planning.⁴ Nurses identify several barriers to EOL conversations, such as logistics, inadequate education on the topic, and cultural differences,⁵ resulting in futile care versus palliative and/or hospice care at EOL.

These critical conversations are the natural domain of nurses, who have the most contact with patients and families,⁶ and physicians, who typically lead the medical care.⁷ However, the uncertainty and barriers reported by both physicians and nurses signal a need to more specifically explore and identify components reflective of optimal communication around palliative and EOL care

decision-making. To address these communication concerns, this study sought to understand the communication practices used by rural and urban, hospice/palliative care nurses when engaging patients and families in decision-making at EOL.

BACKGROUND AND SIGNIFICANCE

Palliative and EOL care defined

Palliative and EOL care encompass a myriad of physical, psychosocial, and spiritual changes, which necessitate ongoing intervention and evaluation.⁶ Palliative care focuses on the patient with serious advanced illness, and their family, and seeks to enhance quality of life throughout the illness trajectory by "addressing physical, intellectual, emotional, social, and spiritual needs."^{8(para1)} Palliative care is an interdisciplinary, simultaneous care model, where a specialized palliative care team, alongside the patient's primary provider, addresses the multifaceted concerns of patients and families.⁶ The World Health Organization adds that palliative care relieves patient and family suffering through "early identification and impeccable assessment."^{9(para1)} End-of-life care is supportive care when a person is dying, which can be provided "days, weeks, and even months before death."^{10(para2)} Hospice, similar to palliative care, provides comprehensive symptom management; however, hospice is for persons with a life-limiting/terminal prognosis and includes the family.¹¹

Dying in America

In 2014, the Institute of Medicine (IOM) issued the report, *Dying in America*,¹¹ in which experts from across the United States identified grave concerns with the current state of health care delivery for persons at EOL. These concerns recognized the aging US population, a lack of knowledge about the palliative and hospice care, confusion regarding the role of advance care planning, and a lack of trained hospice/palliative

care professionals.¹¹ The report offered recommendations; communication was one of the key areas identified to support patients/families at EOL.

Since the release of this report,¹¹ health care professionals have noted some progress toward improving EOL care, yet barriers remain. Survey respondents identified modest improvements in care delivery (54.2%), communication, and advance care planning between providers and patients (59.1%), and palliative/EOL care education (64.9%).¹² Yet even with these reported improvements, the respondents shared that communication deficit among health care professionals, families, and patients was the most important barrier in delivery of palliative/EOL care. This was followed by poor public awareness of advance care planning with EOL care options, limited palliative/EOL care education and training opportunities, lack of palliative care knowledge, and challenges in discussing EOL concerns.¹² It is evident that in the United States, despite IOM recommendations, significant gaps continue in health care professional knowledge and use of effective EOL communication practices with patients and families.

Communication and decision-making at EOL

Throughout the care trajectory of advanced illness to terminal prognosis, patients desire shared decision-making¹³ and are best served when health care communication envelops the elements of clinician expertise, patient and family goals and concerns, and medical evidence.¹¹ A systematic literature review identified registered nurses' roles of information broker, supporter, and advocate when engaging patients/families in EOL decision-making.¹⁴ These roles are echoed in Dahlin and Wittenberg's¹⁵ descriptions of critical communication competencies for the generalist nurse, where honest and transparent communication is the central component.¹¹ This communication at EOL is patient centered where nurses bear witness to personal

suffering by employing multiple communication techniques, such as presence, listening, silence, and humor.¹⁵

The necessity for nurse presence, practice expertise, and communication excellence is well established within the palliative and EOL nursing literature.¹⁶ Nurses are the faithful and stable presence for patients and families at pivotal lifespan moments, particularly near or at the EOL. Nurses must be skillful and empathetic communicators, yet they report challenges in communicating with patients and families in areas such as engaging persons from differing cultural backgrounds, having discussions related to spiritual or religious concerns, and initiating a conversation following the delivery of "bad news."^{17(p169)} Furthermore, novice nurses, as well as nurses employed in critical care, pediatrics, geriatrics, and rural regions, identify additional communication challenges and barriers with patients and families at EOL.^{5,7,18-22} Examples of these challenges and barriers include (a) years of experience,^{7,18,19} (b) bearing witness to perceived unnecessary treatments,¹⁸ (c) managing difficult family dynamics,²¹ (d) poor provider communication with patients and families,^{5,20} and (e) blurring of professional/personal roles in rural nursing.²²

It is clear that nurses recognize the importance of their role as advocate, supporter, and information broker for patients and families at EOL; however, many struggle with how to implement these roles. In addition, recent evidence suggests that, despite the *Dying in America*¹¹ report, barriers remain in the ability of health care professionals to initiate these crucial EOL care discussions.¹² Furthermore, few studies have explored the practices used by hospice and palliative care nurses when discussing EOL wishes with patients and families.¹⁴ Thus, the purpose of our study was to understand the shared communication practices of rural and urban, hospice/palliative care nurses when engaging patients with a terminal diagnosis and their families about EOL decision-making.

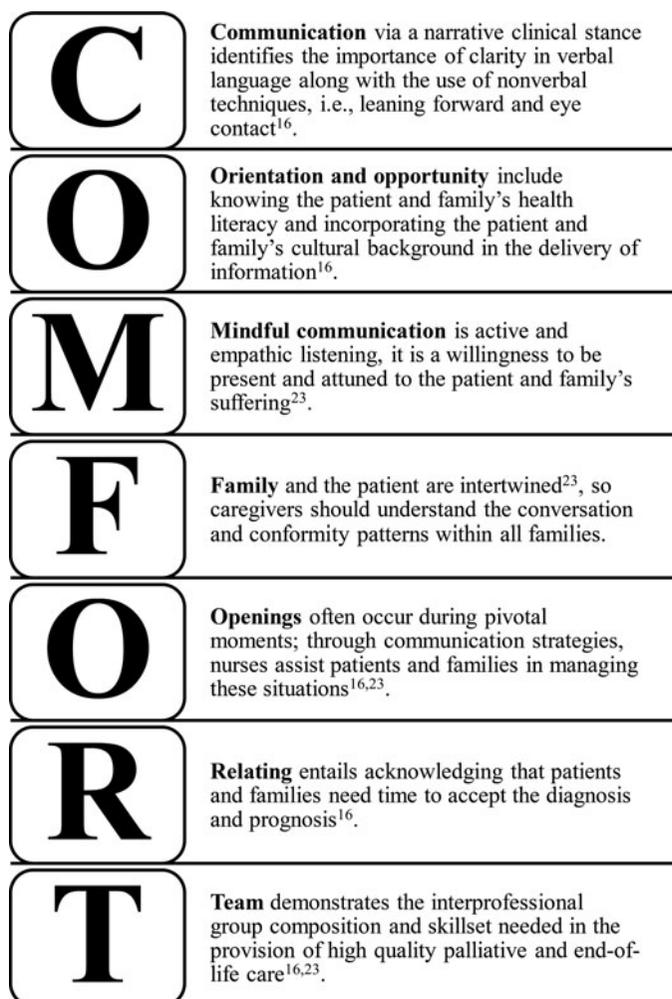


Figure. COMFORT model.

Relevant theory

Communication skills are particularly crucial in the context of a life-limiting disease trajectory; however, a lack of health care professional comfort in EOL discussions leads to flawed outcomes.¹¹ These poor outcomes can be attributed to the traditional sender-receiver approach of dispensing health care information. In contrast, the COMFORT model is a patient-centered, palliative care communication framework designed to address communication challenges across the health care continuum.¹⁶ This model, specific to EOL communication, is grounded in narrative

nursing practice²³ and represents mutual influence where nurse and patient/family are simultaneously and reciprocally engaged.^{16,23} COMFORT comprises 7 key principles—Communication, Orientation and opportunity, Mindful communication, Family, Openings, Relating, and Team—and is further described in the Figure. The linear fashion of the model does not imply an algorithm; instead it is a way of reflectively embodying day-to-day interactions with patients and families. Although the model did not guide this study, it served as a backdrop for relevance of the narrative analysis to nursing practice.

The COMFORT model is useful across practice settings, yet health care professionals continue to struggle communicating with patients and families about EOL. What can be useful for health care professionals is to envision communicating with patients and families about EOL decisions as orchestration. Orchestration is an amalgamation of the professional roles and duties associated with providing EOL care. For example, the nurse surreptitiously serves as information broker, supporter, and advocate while arranging and directing the essential elements of best practice alongside patient/family goals,¹³ as if orchestrating a symphony.

All nurses manage competing demands, but for hospice nurses this management or orchestration becomes even more critical because of the time constraints of imminent death. The orchestration conducted by hospice nurses includes a high priority on communication, which attends to patient/family needs, seeks interdisciplinary input, and juggles organizational constraints. This phenomenon of orchestration is not rushed despite the anxiety often associated with dying. Hospice/palliative nurses personify the orchestration of the day-to-day elements in delivering patient-centered care amid the reality of impending death and are uniquely poised to share their experiences. This interpretive phenomenological study extends our understanding of EOL communication practices through the descriptive lens of hospice/palliative nurse narratives.

METHODOLOGY AND METHODS

This article reports the hermeneutical analysis of interviews from a broader multimethod study. Hermeneutic phenomenology, influenced by Heidegger and Gadamer, was the methodological approach used by the research team. Hermeneutics reveals phenomena that are often concealed or overlooked in everyday human experiences or practices, returning the forgotten phenomenon to visibility.²⁴ Revealing phenomena and sharing

the experience in a new way extend knowledge about what was previously known.²⁵

Methods

After approval by the institutional review boards at Avera Health and South Dakota State University, the principal investigators contacted and discussed the study protocol with the health system's home health/hospice agency nurse managers. The location of the nurse managers included rural and urban facilities. The nurse managers identified nurses who met the inclusion criterion of at least 2 years' experience working with hospice patients and families. After the nurses agreed to participate, the nurse managers shared the potential participants' e-mail addresses with the principal investigators, who then contacted each participant to establish the date, time, and location for the face-to-face interview. The nurse managers were not informed which participants elected to participate. All participants elected to be interviewed at their work location. Because of a prior commitment, 1 rural nurse was interviewed using a secure Skype connection.

During the informed consent process, each nurse was notified that study participation was voluntary and withdrawal could occur at any time. After giving consent, the participants provided general demographic information and selected a pseudonym, which was then used throughout the transcribed notes. To help the participants prepare for the semistructured interviews, the questions noted in the Table were sent out via a secure e-mail server 1 week before the scheduled interviews. Each interview began with the same 3 questions, with the researchers gently probing by saying, "tell me more about" or "can you describe a situation?"

Following a Heideggerian/Gadamerian hermeneutic approach,²⁶ the researchers began each in-depth interview mindful of their personal nursing backgrounds—one as a former hospice nurse the other a former parish nurse.²⁷ These views specific to EOL communication guided the researchers in

Table. Interview Questions

1. Tell us about a time where you helped a patient and family with advanced care planning decision-making. If possible, describe the time frame and the decisions within which you assisted the patient and/or family.
2. Describe your specific communication strategies when talking with patients and/or families about end-of-life planning.
3. Tell us your communication approach when working with patients and families in advanced end-of-life decision-making.

their clarification and probing questions with the participants. Furthermore, the researchers' prior review of the literature and nursing experiences facilitated their thoughtful contemplation, as they bore witness to the participants' stories.²⁷

At the completion of the interview, each participant received a \$50 gift card. All participant information was stored in a locked file, with all narrative data shared through a secure university-based online storage system.

Sample

A total of 10 hospice/palliative nurses participated in this study. All were employees of the same health care organization, female, between the ages of 30 and 60 years, and had 10 to over 30 years of nursing experience. Upon hire, all participants received specialized training on the basis of the End-of-Life Nursing Education Consortium (ELNEC) curriculum.²⁸ The 5 rural nurses cared for patients in the home, acute care, and nursing home settings. The 5 urban nurses cared for patients in a hospice house.

Analysis

Each interview lasted 45 to 60 minutes, was digitally recorded, and transcribed verbatim by a qualified transcriptionist. Before the research team began their analysis of the narratives, they addressed their preconceived

views. The interpretive team consisted of the authors and a bachelor's prepared educator with an emphasis in fine arts. The authors are nurse educators and researchers with over 30 years of combined clinical experience, are certified in hospice and palliative nursing, and have received specialized training in EOL care.

One team member, a skilled hermeneutic phenomenologist, guided the other members of the interpretive team through the analytic process, as described by Crist and Tanner.²⁹ Familiarization with the data began by reviewing the transcriptions for accuracy while relistening to the audio-recording and simultaneously reading the text, making minor revisions as needed. Each member conducted an in-depth analysis by independently reading and rereading the texts, seeking common themes among and within the narratives, and identifying initial paradigm cases.²⁹ Over a period of 2 months, the team compared their initial themes, cases, and shared meanings. As they debated the overarching pattern, a growing awareness emerged that the narratives went beyond a description of EOL communication practices to reveal the phenomenon of orchestration. The team envisioned the orchestration of these communication practices as the nurse cocreating with the patient and family an EOL symphony.

To illustrate the orchestration, the team recognized that the use of an alternative platform would be helpful. Janesick³⁰ articulates the importance of intuition and creativity within the analytic process, thus the team incorporated interpretative metaphors to describe the overarching and subsequent patterns. This approach reveals an overlooked but common experience/practice and expands understanding and awareness³¹ by illuminating the phenomenon through a metaphoric lens.

Rigor

Throughout the entire process, the researchers addressed rigor and trustworthiness.³² Credibility was maintained

by establishing a safe environment for nurse participants to share personal stories about EOL care communication. Transferability is evident in the descriptions of the setting and the participants. The researchers maintained dependability using the participants' verbatim examples.³³ The researchers conducted member-checking, by sharing their interpretations with participants and receiving no comments for correction.³² Dependability and trustworthiness were maintained by the sharing, discussing, and refining their interpretations via Skype and the participant narratives provided.³²

FINDINGS

Communication practices

Captured in the touching narratives of these 10 hospice/palliative care nurses was their genuineness and candor. They openly shared their struggles and communication practices when orchestrating EOL decision-making with patients and families. These nurses recognized the patient and family's inherent need for these critical conversations. They did not shrink away from the potential dissonance, but rather through authentic presence created an opening for these difficult discussions. Furthermore, these nurses acknowledged that patients do not have the luxury to practice or rehearse their dying experience. Infused throughout the narratives was the profound sense of the nurses' unhurried and un-harried orchestration of the following communication practices (patterns): establishing context, acknowledging through attentive listening, making it safe for them to die, planning goals of care, and being honest. The nurse's orchestration of these communication patterns guides the patient and family in cocreating the closing composition (overarching pattern) for the EOL symphony. To reveal the communication patterns, a musical metaphor is used as a mechanism for conveying the communication practices as shared by these hospice/palliative nurses.

Establishing context

Within the closing composition, establishing context often begins simply with these nurses hearing the background music, seeking to understand what the patient and family have undergone before their initial meeting. This begins with a review of the patient's medical record, where the nurses come to know the disease trajectory from the perspective of the health care team. When they meet the patient and family for the first time, noting the tempo and the pitch of the vocals and who the key performers are, what was once background music is now a live performance. Each of the nurse participants identified that requisite in this first gathering is "meeting them [patients and families] where they're at," where these nurses do not attempt to sway the patients or families' views, but rather bear witness to their song.

Each nurse identified similar ways of initiating these critical conversations. Phrases such as "Tell me what you know about your illness" or "How did you get to this point?" were often the only invitation needed. In her role of supporter, Heidi shares her approach with patients and families entering hospice:

When people have just come on hospice and they have just turned that corner—using those words with people. "Wow, you just turned a huge corner. This is big. This has been tough." And you get the outpouring of the tears . . . the opportunity for them to express that grief . . . I don't have a big agenda, actually, other than just to be present . . . It might depend on the situation, but it might be something like, "Do you want to talk to me about how that's [aggressive therapy] going and how you see things going?"

Kate recognizes that for patients and families this first discussion about hospice signals that "things are just starting to unravel in their world." When possible Kate addresses the patient first saying,

"You're the man of the hour." I acknowledge the patient as that being the most important . . . I've seen too often . . . the patient is ignored. It's really about dignity for the patient . . . I will use the phrase hospice, but I will often say, "It's a big word

and I don't want it to scare you" . . . I often use the word goals instead of hospice . . . [I] acknowledge that they have had a very difficult road. "I've read your chart. My goodness, you've had a heck of a few months. You guys must be tired. You've been through a lot."

Acknowledging the challenges, maintaining patient dignity, and listening and hearing their perspectives of their illness journey are all key practices these nurses employ when first meeting patients and families. Essential in this initial gathering is not attempting to change their perceptions but to create a dialogue and build trust and rapport in their fragile world.

Acknowledging through attentive listening

Establishing context provides the scaffold necessary to begin the process of creating the melody, harmonies, and rhythm of the closing composition. Nurses must learn the patient's rhythm to "meet them where they are at." For example, the patient's rhythm can be specific for how he/she expresses physical, spiritual, or emotional concerns. Only when the rhythm is learned can the nurse begin to hear the patient's melody and work with the patient to form the music for this closing phase. It is also vital to pay careful attention to the various harmonies of family members, helping to align the wishes of the family with those of the patient. Integral to the composition is recognizing when someone other than the patient begins to take over the melody, such as a spouse or child, but also being attentive to which voices are silent. It is important for nurses to be mindful of the tempo set by the patient and family, and to be comfortable in silences. After all, the great composer Claude Debussy once pointed out, "Music is the space between the notes."³⁴(p147) Heidi illustrates this in the following excerpt:

I don't have an agenda, other than to be present. And presence in the larger definition of walking through it with them, doing active listening, being able to listen to what it is that is on their hearts that day.

Theresa feels that establishing continuity with patients and families is essential. When conducting daily rounds in the hospital, she generally starts a conversation by asking, "How are you doing today?" and "What can I do for you?" Through this brief daily visit, she establishes rapport and demonstrates her availability. Theresa remarks:

It might only be two minutes one day, but it might be the next day where they'll [the patient] say, "I didn't sleep very good last night." And instead of saying, "Oh, I'm sorry to hear that," I'll sit down and say, "Why didn't you sleep good last night?" or "Let's talk about why you didn't sleep good last night." . . . Sometimes there's one little thing that they'll offer you that you'll pick up on . . . You do end up covering all kinds of things because you're taking the time to listen to them.

Theresa's consistency helps to develop the rapport needed for patients to feel comfortable sharing their deepest concerns. She is attentive to the subtle language the patient uses. Instead of disregarding what could appear as a superficial complaint, through her posturing (sitting down) and deeper questioning she provides an opening for disclosure of what is often a deeper issue. Phrases like "I didn't sleep well last night" or "I don't know what to do about this" are often a signal of deeper physical, spiritual, or emotional suffering.

Nancy incorporates many of the same techniques while also recognizing the importance of being cognizant of the nonverbal cues she may be sending to patients and families. She is carefully aware of whether her presence is creating space for them to share or is furthering the dissonance. She remarks:

I think the big thing is that I need to be seated. I need to be on the level with the patient and not standing over them during an assessment asking questions about spirituality or anxiety or fears while I'm listening through a stethoscope because, guess what? That gives them the impression that what they're saying isn't important, and that's more important than anything I'm going to find out by listening to heart sounds or lung sounds. So, making sure I've had that time to sit and just make eye contact and talk about the nonverbals [*sic*] I might

be seeing . . . So many patients will say, “No, I’m not having pain,” and I’ll say, “Well, I’ve noticed that your hands are in a fist and your . . . furrowed brow, and you’ve kind of been rolling your head back and forth. Are you uncomfortable?” Sometimes the word pain is . . . it’s not pain unless your right arm is cut off. But if you use the word, “Are you uncomfortable?” they’re more willing to share . . . “Well, I just ache all over.” Well that’s not pain to some of these people, that’s just not being comfortable.

Sasha demonstrates attentive listening to patients by acknowledging their losses. She shares:

. . . letting the patient know you heard them. List those losses . . . “You’ve been through a lot with the loss of your wife, moving from your home to the facility,” or just recognizing that you feel that they’ve had changes and a lot of loss . . . I think honoring and saying it aloud that you recognize that as a loss even if the patient hasn’t been able to express it as a loss . . . They feel like they’ve been validated, they’ve been heard.

These exemplars offer ideas and practices for deepening conversations with patients at EOL. These nurses tune into their patients’ nonverbal rhythms and phrases that may seem off-pitch by asking for clarification. Yet, these conversations are also necessary with families. Noelle talks about how she observes families when she is speaking.

I watch how much are they able to really be focused on what I’m saying. If somebody is sitting there . . . head in their hands, crying, maybe not really even to listen to what I’m saying, they’re probably not going to be a key person to go to right now. But if you’ve got somebody intently sitting there and listening to every word and maybe . . . nodding, they let you know that they’re hearing what you say . . . You key in on those, and . . . if somebody opens the door and asks a question like, “Do you think this could be as fast as just a few days?” I say, we never know, but I sure think that’s a possibility . . . I think it’s only fair . . . I don’t think it’s fair to let them think they’re going to be here longer than what they are.

These nurses reveal that often the patient and family do not communicate well over choices, such as pursuing aggressive therapy

or resuscitation status. They share that when this occurs it is important, when possible, “to get everybody in the same room so that you don’t have all these other conversations going on.” In her role as advocate, Sasha describes how she approaches patient/family discord.

What I’ve utilized with families is having that patient say out loud what it is they really want . . . [In a particular situation] the patient and the wife were sure that they wanted to be a Do Not Resuscitate, and the daughter had said, “Oh, but dad, they can do CPR and technology is so good . . . They bring people back all the time.” That was her perception, but both the husband and the wife were like no, we don’t want that, we’re okay. “If God wants to take me, I’m okay with that. I don’t want them to beat on my chest or have a tube and I don’t want to be on the ventilator.” But in that particular case it was setting up for the daughter, just to say now I want your dad to answer this question, and I just want you to listen to what he has to say. And I just said, the patient’s name and said, “Tell your daughter what you shared with me earlier about why do you want to be a Do Not Resuscitate.” She had a hard time being still and not interrupting him, but I think with him saying that, you could tell that she still disagreed with what her father was saying, but she needed the set-up to hear him say it himself. She still wanted to talk over him and disagree with his decision. I don’t know if that was the right approach or not, but that was one tool of letting them hear it for themselves. Then she also got to share with him why she felt so strongly that he should receive CPR or be intubated because she felt like he had a lot more life left. I don’t know that they had ever expressed that to each other in the same room.

These nurses demonstrate attentive listening by sitting, commenting on the patient’s nonverbal cues, probing further on seemingly off-hand comments, acknowledging the losses, and being aware of their own body language. Imperative within attentive listening is realizing that

if we [nurses] are directing the conversations instead of letting them [patients] direct the conversation, it is two different conversations. So to really ask questions trying to pull out what’s important to them and then having the discernment and the wisdom to see what you can pull out that’s

really important out of that conversation. It takes listening.

Through attentive listening, which is simultaneous and reciprocal (mutual influence), the nurse can recite the melodies and the harmonies patients and families share, ensuring all voices are heard.

Making it safe for them to die

The end of someone's life cannot be timed to a death march or a funeral dirge; death is often off-beat, disorderly, and syncopated. This syncopation, with its variation in rhythms and chords, can be frightening because it feels disorganized and unmanageable. Nurses, working within this closing composition, must prepare patients and families, as they approach death for these moments of modulation in pitch, key, and cadence. This preparation through establishing trust and providing education helps them to anticipate, recognize, and respect the syncopation. They become comforted in knowing that during this deceptive cadence they will not be alone, and their wishes will be honored. When the care team eases the tension and suspense felt during the deceptive chords of the dying process, patients and families now have an environment where it is safe to die.

Noelle exemplifies the importance of establishing a trusting relationship and an environment of safety in a story of a middle-aged woman diagnosed with metastatic lung cancer whose desire was to "go someplace where they'll keep me out of pain and keep me from being scared." According to Noelle, the outlook from the beginning indicated a very limited timeline. Noelle recognizes that trust and safety must first be established before she assumes the role of information broker. She tells:

Sometimes you have those patients that you just "cook with," and we did right from the beginning. She was just full of questions . . . We talked about how this [dying] might play out and what kinds of symptoms she might have and what we were going to do.

Noelle describes setting up her morphine drip, adjusting the basal rate, and nurse administration of bolus doses during the night, noting that each day the patient required more morphine.

Every day we'd sit, we'd talk, and she'd say, "Well, you know, I could hardly take a shower this morning . . . that's a lot different than what it was two days ago." She would open up and just be very aware of the changes taking place, so then we talked about what do we do when you get to a point that . . . [She would ask,] "What do I do when I can't take a shower?" I said, "Well that's what we're here for. We'll keep you clean, we'll keep you bathed." [She was] very private, didn't want any help with anything. I said, "How alert do you want to be when the end comes?" She said, "I don't want to know what's happening, and I don't want to be scared." I said, "Well, then I think we're at that point where we already need to talk about us putting you to sleep when we see that the time is here." . . . We ended up talking about and getting consent for palliative sedation.

Noelle continues the story by sharing that they had not yet started the palliative sedation, but she could see that time was getting close:

So I could just tell from Friday morning to Friday night, Saturday morning to Saturday night, and I said to her on Sunday, "We're maybe getting to the point where we might want to talk to the doctor about when to start this sleep medicine." She said, "Well, I'm going to have supper. My boys are bringing in supper tonight . . . I want to eat with them." . . . But that never happened. I put her to bed at 3:00 and at 6:30 when the boys came back they came out to the desk. I think she had a 5:00 med, something, I can't even remember what, something I considered not important, so I didn't wake her. I thought she needs this nap, you know, before they come so that she's got energy. Well then they came and came out and said, "We can't wake her." I said, "Oh really? She went right to sleep after you guys left." I went down to the room, and I couldn't wake her. I said, "I think she's just that exhausted. I was in here when you guys walked out and I watched her give herself a bolus . . . I don't think it took her 15 seconds to be asleep. We can wait and see, maybe she'll wake up, but maybe this is going to just take care of itself on its own." Both boys were very understanding

of their mom's wish to not know when the time came, and they said, "So you think it could happen this quick?" I said, "It could, and it did." She died the next day, never woke up again.

Noelle's story depicts the syncopation of dying. The dying process for this woman proceeded at a rapid tempo, yet through trust and education about the process, this woman's wishes were honored. Noelle simply states, "You know, we have to do that. We owe it to people to make it safe for them to die . . . and if they're scared . . . there has to be that assurance."

Planning goals of care

Dying is ubiquitous, but the process remains intensely personal and unique for each situation. Within the syncopation of dying is the refrain of patient wishes and goals of care. Nurses need to understand advance care planning, advance directives, palliative care, and EOL decision-making. This understanding equips them to keep time with the unique rhythm of the patient/family-centered goals of care. The refrain of wishes and goals of care may occur up until the final stanza of life, where patients and families may need help in understanding what is meant by goals of care. The word "goal" could mean a task or a to-do list, but well-timed nursing probes such as "What is it that you want, What can I do to help your care," or most concretely, "Is there something you would like to do while you are still physically able?" represent words affording patients an opening to cocreate their melody of care.

Although written directives may be in place, family members may have never seen the document, and the patient may not even remember the contents as articulated by Nancy:

It was amazing, there was something in writing, but the kids hadn't seen it, and it was locked in the safe back home, so there wasn't a copy of the advanced directive in the current nursing home chart. I said, "Well, what does it say?" and even the patient couldn't remember what she had decided

from her advanced directive and it was probably done within the last 10 years.

The nurse-facilitated dialogue that ensues when wishes are openly discussed within the patient's current context is crucial for EOL decisions. Aggressive heroic measures may seem appealing when death is imminent and the loud clang of a do-not-resuscitate order disturbs whatever rhythm a family may have. Ingrid uses an economy of words and a sensitivity to timing:

Who is the CPR going to benefit, the patient or the family? And they just like, the look on their face, they sat back and they're like, oh . . . us. Yeah it's not helping her. So it was just a matter of the right words at the right moment.

Just as sensitivity to timing is imperative for a well-played opus where movements are distinctly unique, so also is a nurse's sensitivity to timing important as goals of care are revisited in response to changes in the patient's condition. Rapport and trust, like the bass and treble clef of an opus score, string together meaningful tones heard in probes such as "What do you think is going on? or What kinds of changes are you seeing?" which welcome patient input for EOL decision-making. Ingrid describes it this way:

Hospice might not pay for it but that doesn't mean you can't do it if those are your wishes. Then to say the next time they are having issues, "Is that still what you want?" and not try and be judgmental one way or another or steer them one way or another, but really let it be patient centered as to what their goals are.

The autonomy of patient decision-making may be in harmony or discord with family wishes as echoed by Sasha:

I think part of it is asking the family member, "How do you think it is going?" So I think the biggest piece is seeing the patient bigger than just the individual, that it's the whole family and what's going on with the person in bed is affecting everybody in the family. Learning to use the family as, tool is not a good word, but use them as a unit rather than just seeing the patient as an individual laying in the bed and using the family as a whole.

Conversation is scored within tones of compassion, presence, and calm. Ingrid describes:

A calm conversation is a calm voice with being compassionate about their loved ones and not necessarily say[ing], “I know how you feel,” but to say that this is their story and knowing it’s all about them and not necessarily what we want or what us professionals want for the situation.

And there are the repetitive notes, or hints, as Sonia explained about a patient transitioning from home hospice to skilled care:

He listened to what we had to say, and he just didn’t think he was ready for that, didn’t want to do that. That happens occasionally, you know, it’s a lot to take in. So then it was probably about a week later we came back, and he said he was ready, he wanted to sign for hospice services . . . In that conversation we always ask at admit, a good one that opens up, I think a lot of ideas of what they think hospice is . . . He was very accepting of us coming and didn’t want to do nursing home, didn’t even want to talk about it. But then as his condition changed we had to adjust his plan of care, and he wasn’t able to ambulate as often but was still refusing . . . So as the hospice nurse and the social worker, we made more visits, we had daily nurse aide visits, communicated with his wife who was the contact person, then he had some sons and a daughter that came too to help. Then he got to a point where he was accepting of being able to move . . . So sometimes, it takes, you know, if you can at least hint at the idea, it doesn’t mean you have to go . . . You have to kind of hint at them or approach them as their needs arise too.

Especially poignant is the patient’s awareness upon learning she has a voice in directing her care as shared by Sasha:

. . . you’ll ask the open ended what is your goal or what is it you want? And they’ll say, “I don’t know.” So one [is] classic. She was at least 85 years or older . . . and she says “I don’t know, nobody’s ever asked me.” And so she needed time to think about that. You could just tell she had never even fathomed that, that she would have the opportunity to say what it is she wanted. She was being the good patient. But she did come up with something, you know, but she had to think about it for awhile.

Delicate interludes occur with the changing nuances of the patient’s wishes and goals of care—interludes captured with the mutual influence of patient and family. The nurse, as an information broker and advocate, deftly orchestrates these interludes with a measured pace and understanding that the patient’s wishes are the worthiest refrain in the closing composition of the EOL symphony.

Being honest

Requisite to a goals of care conversation is the need for factual information. But just as black and white piano keys exist side by side on a keyboard, the black and white facts of patient conditions are merely solitary pieces of information and do not represent the nuances inherent in each situation. The hospice nurse’s honest arrangement of these facts is garnered through shared time and dialogue with the patient and family. Sasha represents being honest within the context of decision-making:

And then what would be some of the things, what if you don’t put the tube in, and a lot of that was reframing the same things that the physician had told the family, but they hadn’t talked it out loud yet, so I know I didn’t give different information than the physician, but as the physician talking to a family, I remember it just being very black and white. Well you, know there is a risk of infection, he could still aspirate, he could still get a pneumonia. They were black and white facts, you know, that were listed. And then we talked about that, just in general, what would that mean and what would that mean if dad didn’t have a tube feeding and he wasn’t able to eat or drink anymore.

A tone of honesty ringing through the participants’ narratives is also closely aligned with transposing reality into understandable phrases from which family and patient are able to make EOL decisions and prepare for the dying process. For Nancy, as information broker, being honest means:

. . . if I see changes and I see things that are telling me things are changing and getting closer, I’m

going to be honest with them and not say, “Oh yeah, things are about the same.” I’m going to say, “You know what? I am seeing this . . . his blood pressure is starting to drift down, his heart rate is faster, I am seeing mottling on his knees. I really do think that if there’s family that wants to see him, or he needs to see someone, I think we need to do it soon” . . . I am going to say it over and over again to the patient and the family if I see things that make me think we need to start making sure you’re aware of how close things might be.

The repetition of messages of reality is rooted in a compassionate awareness that “they can only grasp so much, and then they might need it repeated.” Nancy describes her technique:

. . . oftentimes there’s more family coming in and out, and so you say sometimes the same thing over and over again. You might shorten the sentences, you might try and get more in depth if that’s what they seem to be looking for, but sometimes it’s just saying the same thing in different ways over and over to try and explain what is physically going on with their condition.

The repeated delivery of information is similar to a musical refrain, where the nurse may say the same thing but in a different way. The measured approach of the nurse as an information broker must be in harmony with the nurse as a supporter. For example, with each refrain the patient and family may not be hearing the same message; thus, the nurse must gauge patient/family readiness for difficult conversations. Ingrid’s honesty is transparent, sensitive, and in tempo with patient/family readiness. Ingrid states:

You know, maybe when someone, especially at admission comes in and they are very quiet, and they don’t have a lot to say. You know, you can try and sit and talk to someone, and they don’t offer much conversation. That to me says . . . that they’re not quite ready to hear everything. I acknowledge that I’m sure this has been a really tough road, that you’ve made some really hard decisions especially to get to this point. Then I always acknowledge that we’re here for them and their loved ones, I mean in talking with the patient, we’re here for you and your family, and just to let them know it is a family focused place, and that we’re honest and, you know, we’re here for questions or any con-

cerns or I said if there’s anything that’s bothering you and you want help, because we want to make this a good experience for you given the difficult circumstances they are in.

These hospice nurses validate the pivotal transition from life to death. This transition is treated with honesty and sensitivity to the tempo of patient/family readiness. Honesty fosters EOL decision-making because it incorporates the nurse’s expertise and application of clinical evidence, in concert with patient/family wishes. Thus, each patient’s closing composition in his/her EOL symphony is original, unapologetic, and conducted at a seemingly steady and unhurried pace.

The closing composition

Hospice nurses enter into spaces where other health care professionals are often hesitant. They recognize that the imminence of death creates an urgency to address patient and family comfort, as well as attend to the completion of a life. Integral to EOL care interactions is effective communication. For our participants, each distinctive patient/family interaction is orchestrated with the skillful interplay of the following communication patterns: *establishing context*, *acknowledging through attentive listening*, *making it safe for them to die*, *planning goals of care*, and *being honest*. These communication patterns are the nurse’s mechanism for attending to the completion of a life, and are the overarching pattern—the closing composition.

A musical composition may be considered as the process of creating music. Similarly, the closing composition is the process of creating a supportive space for patients with life-limiting illnesses and their families to plan and decide their EOL wishes. This creative process features the hospice nurse’s (conductor) artistry in orchestrating the communication patterns. In this orchestration, the nurse is attuned to the pitch and tones (the story) of the patient and family. Although the pitch and tones have clinical similarity at EOL, the nurse recognizes the singularity of each patient’s melody as well as

anticipates changes in the patient's rhythm. The nurse is crucial in preparing the patient and family for any dissonance created by changes in rhythm as death approaches. The syncopation of dying is modulated by the nurse through advanced care planning where the patient has expressed his/her final wishes. Honesty is interwoven throughout the orchestration of the closing composition; repetition of information (the refrain) is a necessity. The nurse's exquisite orchestration of these communication patterns throughout the closing composition coalesces into the EOL symphony.

DISCUSSION

Current emphasis on provider initiation of EOL care communication³⁵ overlooks the integral components of orchestration and mutual influence. This study extends the knowledge of EOL communication practices by revealing the importance of orchestration and mutual influence, which are crucial for shared decision-making. Our participants' narratives demonstrated how they guide patients and families with EOL decision-making through the orchestration of communication patterns.

The patterns include the nurse's expertise as an information broker, patient advocate, and supporter, as well as the fundamental communication concepts of trust, honesty, attentive listening, presence, context, and repetition. Clearly, the manner in which the participants embodied their roles and the communication practices suggests a difference in nursing comportment to orchestrate EOL care. What does it mean to orchestrate?

Orchestration in nursing is described as going beyond management of care to include the ability to harmoniously combine the various aspects of patient care.³⁶ In addressing the complexity of EOL care, our participants demonstrate orchestration by addressing the multifaceted concerns and needs of patients and families while also serving as the hub

of the multidisciplinary team. Through their skillful orchestration, a supportive space is created where patients and families safely explore "what end-of-life looks like."

Crucial to this exploration by patients and their families is a sense of mutuality, which is to say that the nurse and patient influence each other's communication.¹⁶ The quality of mutuality provides a sharp but needed contrast to the traditional sender-receiver communication model, an approach which impedes discussion.³⁶ Skillful orchestration achieves what patients and families consistently identify as most important at EOL (ie, effective communication, shared decision-making, and expert care).³⁷ Of utmost importance is the awareness that the nurse, patient, and family all hold expertise in the subject matter.³⁸

Our nurse participants' EOL communication practices matured from training through the ELNEC curriculum, observation of and mentoring by seasoned palliative/hospice nurses, and experience. Specialized EOL care training for prelicensure students results in improved knowledge and attitudes toward care of the dying.³⁹⁻⁴¹ However, these results do not explicitly improve communication in clinical practice.⁴² Specialized EOL care training must include an EOL communication model, accompanied with experiential learning, debriefing,⁴³⁻⁴⁵ and an emphasis on the mutual influence of patient, family, and nurse.

Postlicensure training in ongoing EOL communication is essential for accurate, timely, and sensitive tailoring of patient and family goals.⁴⁶ However, an all-too-common waiting game ensues in discussing palliative and EOL decisions, as any or all parties wait for the other to address the "elephant in the room" topic(s).¹¹ The nurse's skill in gently and effectively orchestrating, initiating, and guiding communication is undeniably imperative; there will be no opportunity for a do-over of the dying experience. Advance care planning discussions ideally occur at the onset of a life-limiting illness and must be mutually nurtured

throughout EOL decision-making,⁴⁷ as the focus shifts to the final days and moments.⁴⁸

Study limitations

Our sample of nurses was limited to one major health care institution, although the settings included rural and urban facilities. There are demographic limitations with the sample. However, the limited diversity is representative of the majority of employed nurses in the region.

REFERENCES

- Center to Advance Palliative Care. America's care of serious illness: 2015 state-by-state report card on access to palliative care in our nation's hospitals 2015. <https://reportcard.capc.org/>. Accessed April 21, 2017.
- Mattes MD, Sloane MA. Reflections on hope and its implications for end-of-life care. *J Am Geriatr Soc*. 2015;63(5):993-996.
- Ferrell BR, Coyle N. *The Nature of Suffering and the Goals of Nursing*. New York, NY: Oxford University Press; 2008.
- Fulmer T. Talking with patients about end-of-life care: new poll reveals how physicians really feel. <http://www.jhartfound.org/blog/talking-with-patients-about-end-of-life-care-new-poll-reveals-how-physicians-really-feel/>. Published 2016. Accessed June 22, 2016.
- Aslakson RA, Wyskiel R, Thornton I, et al. Nurse-perceived barriers to effective communication regarding prognosis and optimal end-of-life care for surgical ICU patients: a qualitative exploration. *J Palliat Med*. 2012;15(8):910-914.
- Coyle N. Introduction to palliative nursing care. In: Ferrell BR, Coyle N, Paice JA, eds. *Oxford Textbook of Palliative Nursing*. 4th ed. New York, NY: Oxford University Press; 2015:3-10.
- Hebert K, Moore H, Rooney J. The nurse advocate in end-of-life care. *Oschmer J*. 2011;11(4):325-329.
- National Hospice and Palliative Care Organization. Palliative care: an explanation of palliative care. <http://www.nhpco.org/palliative-care-4>. Accessed March 20, 2017.
- World Health Organization. WHO definition of palliative care. <http://www.who.int/cancer/palliative/definition/en/>. Published 2017. Accessed April 13, 2017.
- National Institute on Aging. End of life: helping with comfort and care. <https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/introduction>. Published 2016. Accessed March 20, 2017.
- Institute of Medicine of the National Academies. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2015.
- National Academy of Medicine. Assessing progress in end-of-life and serious illness care. <https://nam.edu/event/assessing-progress-in-end-of-life-and-serious-illness-care/>. Published 2017. Accessed April 13, 2017.
- Alston C, Paget L, Halvorson G, et al. *Communicating With Patients on Health Care Evidence* [discussion paper]. Washington, DC: Institute of Medicine; 2012.
- Adams J, Bailey D, Anderson R, Docherty S. Nursing roles and strategies in end of life decision making: a systematic review of the literature. *Nurs Res Pract*. 2011;2011:1-15.
- Dahlin C, Wittenberg E. Communication in palliative care: an essential competency for nurses. In: Ferrell BR, Coyle N, Paice JA, eds. *Oxford Textbook of Palliative Nursing*. 4th ed. New York, NY: Oxford University Press; 2015:81-109.
- Wittenberg-Lyles E, Goldsmith J, Ferrell BR, Ragan S. *Communication in Palliative Nursing*. New York, NY: Oxford University Press; 2013.
- Malloy P, Virani R, Kelly K, Munevar C. Beyond bad news: communication skills of nurses in palliative care. *J Hosp Palliat Nurs*. 2010;12(3):166-174.
- Hendricks-Ferguson V, Sawin K, Montgomery K, et al. Novice nurses' experiences with palliative and end-of-life care communication. *J Pediatr Oncol Nurs*. 2015;32(4):240-252.
- Moir C, Roberts R, Martz K, Perry J, Tivis L. Communicating with patients and their families about palliative and end-of-life care: comfort and educational needs of nurses. *Int J Palliat Nurs*. 2015;21(3):109-112.
- Dillworth J, Dickson V, Mueller A, Shuluk J, Yoon H, Capezuti E. Nurses' perspectives: Hospitalized older

CONCLUSION

Without hierarchy, nurse, patient, and family simultaneously partner in creating the closing composition of EOL. Absent in nursing education and practice is an emphasis on the role of the nurse in orchestrating the communication patterns within EOL care. It is imperative that pre-/postnursing licensure curriculum be expanded to include training in mutual influence communication practices and mentoring in the skill of orchestration.

- patients and end-of-life decision-making. *Br Assoc Crit Care Nurs*. 2016;21(2):e1-e11.
21. McAndrew N, Leske J. A balancing act: experiences of nurses and physicians when making end-of-life decisions in intensive care units. *Clin Nurs Res*. 2015;24(4):357-374.
 22. Pesut B, McLeod B, Hole R, Dalhuisen M. Rural nursing and quality end-of-life care: palliative care . . . palliative approach . . . or somewhere in-between? *Adv Nurs Sci*. 2012;35(4):288-304.
 23. Goldsmith J, Ferrell B, Wittenberg-Lyles E, Ragan S. Palliative care communication in oncology nursing. *Clin J Oncol Nurs*. 2013;17(2):163-167.
 24. Harman G. *Heidegger Explained: From Phenomenon to Thing*. Vol 4. Chicago, IL: Open Court Publishing Company; 2007.
 25. Vandermause RK, Fleming SE. Philosophical hermeneutic interviewing. *Int J Qual Methods*. 2011;10(4):367-377.
 26. Ironside P. Introduction: thinking beyond method. In: Ironside P, ed. *Beyond Method: Philosophical Conversations in Healthcare Research and Scholarship*. Vol 4. Madison, WI: The University of Wisconsin Press; 2005:ix-xix.
 27. Plager KA. Hermeneutic phenomenology: a methodology for family health and health promotion study in nursing. In: Benner P, ed. *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness* Thousand Oaks, CA: Sage; 1994.
 28. American Association of Colleges of Nursing. End-of-Life Nursing Education Consortium (ELNEC). <http://www.aacn.nche.edu/el nec>. Published 2017; Accessed May 2, 2017.
 29. Crist JD, Tanner CA. Interpretation/analysis methods in hermeneutic interpretive phenomenology. *Nurs Res*. 2003;52(3):202-205.
 30. Janesick VJ. Intuition and creativity: a pas de deux for qualitative researchers. *Qual Inq*. 2011;7(5):531-540.
 31. Carpenter J. Metaphors in qualitative research: shedding light or casting shadows?. *Res Nurs Health*. 2008;31(3):274-282.
 32. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Newbury Park, CA: Sage; 1985.
 33. Roberts R, Priest H, Traynor M. Reliability and validity in research. *Nurs Stand*. 2006;20(44):41-45.
 34. Hoff B. *The Tao of Poob*. New York, NY: Penguin Books; 1982.
 35. Nedjat-Haiem FR, Carrion IV, Gonzalez K, Ell K, Thompson B, Mishra SI. Exploring health care providers' views about initiating end-of-life care communication. *Am J Hosp Palliat Med*. 2017;34(4):308-317.
 36. Kennedy H, Shannon M, Chuahorm U, Kravetz M. The landscape of caring for women: a narrative study of midwifery practice. *J Midwifery Womens Health*. 2004;49(1):14-23.
 37. Andrews T, Nathaniel A. Awareness of dying remains relevant after fifty years. *Grounded Theory Rev*. 2015;14(2):3-10.
 38. Kuhl D. *What Dying People Want: Practical Wisdom for the End of Life*. Canada: Anchor Canada; 2002.
 39. Jafari M, Rafiei H, Nassehi A, Soleimani F, Arab M, Noormohammadi M. Caring for dying patients: attitude of nursing students and effects of education. *Indian J Palliat Care*. 2015;21(2):192-197.
 40. Conner N, Loerzel V, Uddin N. Nursing student end-of life care attitudes after an online death and dying course. *J Hosp Palliat Nurs*. 2014;16(6):374-382.
 41. Frommelt K. Attitudes toward care of the terminally ill: an educational intervention. *Am J Hosp Palliat Med*. 2003;20:13-22.
 42. Heyland D, Barwich D, Pichora D, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med*. 2013;173(9):778-787.
 43. Dame L, Hoebke R. Effects of a simulation exercise on nursing students' end-of-life care attitudes. *J Nurs Educ*. 2016;55(12):701-705.
 44. Bloomfield J, O'Neill B, Gillett K. Enhancing student communication during end-of-life care: a pilot study. *Palliat Support Care*. 2015;13:1651-1661.
 45. Twigg R, Lynn M. Teaching end-of-life care via a hybrid simulation approach. *J Hosp Palliat Nurs*. 2012;14(5):374-379.
 46. Caswell G, Pollock K, Harwood R, Porock D. Communication between family carers and health professionals about end-of-life-care for older people in the acute hospital setting: a qualitative study. *BMC Palliat Care*. 2015;14(35):1-14.
 47. Walczak A, Butow P, Tattersall M, et al. Encouraging early discussions of life expectancy and end-of-life care: a randomised control trial of a nurse-led communication support program for patients and caregivers. *Int J Nurs Stud*. 2017;67:31-40.
 48. American Nurses Association. Call for Action: Nurses Lead and Transform Palliative Care. <http://nursingworld.org/CallforAction-NursesLeadTransformPalliativeCare>. Published 2017. Accessed May 2, 2017.

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