

# Beyond Bad News

Communication Skills of Nurses in Palliative Care

Pam Malloy, MN, RN, OCN, FPCN Rose Virani, MHA, RNC, OCN, FPCN Kathe Kelly, BSN, RN, OCN Carla Munévar, MD

Communication skills are paramount in effective delivery of palliative care. The emphasis in much of the previous literature has been on physician communication and also has been largely focused on the singular topic of breaking bad news. Much less emphasis has been placed on communication as a vital skill of nurses and on the opportunities for nurses, as they are often the key professionals at the bedside after "bad news" is shared. The study was conducted as a survey of nurses (N = 333) attending an End-of-Life Nursing Education Consortium conference. The survey assessed nurses' perspectives of the most challenging aspects of communication in their work and elicited examples of both positive and negative communication. Results of the survey indicate important areas for future research and education to enhance nurses' abilities to communicate effectively and compassionately. Respondents identified several key areas in need of improvement related to communication. Examples of the most difficult areas of communication include discussing bad news, talking with physicians about palliative care issues, discussing spiritual concerns, and talking with patients/families from different cultures. Nurses are the primary, constant healthcare providers across clinical settings, and effective skills in communication are critical to nursing practice and to ensure quality care. Education regarding communication skills is needed in basic and graduate nursing education programs as well as in continuing education for practicing nurses.

#### K E Y W O R D S

communication nurse-patient communication patient communication professional communication

nurse working on the night shift enters the room of a patient newly diagnosed with late-stage ovarian cancer. In the still darkness of the night, the terrified patient asks the nurse, "You don't think I will die of this, do you?" In the same hospital, an anxious spouse who has been waiting in the ICU lobby approaches her husband's nurse to seek her advice as she has been asked to consider ventilator withdrawal for her husband who had a massive aneurysm.

Author Affiliations: Pam Malloy, MN, RN, OCN, FPCN, American Association of Colleges of Nursing (AACN), Washington, DC

Rose Virani, MHA, RNC, OCN, FPCN, City of Hope, Duarte, CA

Kathe Kelly, BSN, RN, OCN, City of Hope, Duarte, CA

Carla Munévar, MD, City of Hope, Duarte, CA Address correspondence to Rose Virani, MHA, RNC, OCN, FPCN, City of Hope, 1500 E Duarte Rd, Duarte, CA 91010 (rvirani@coh.org).

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In the same hospital emergency department, a nurse talks with an overwhelmed son who has just arrived and has been asked to make decisions about care for his elderly mother transferred from a nursing home with an apparent stroke. The son acknowledges understanding the physician's explanation of her medical status but tells the nurse he wants his mother to be a "full code" because he is certain "God will pull her through" and that many people are praying for her. While these are difficult case scenarios, each of these cases illustrates the challenges for nurses in communication related to palliative care.

Effective and compassionate communication is the foundation of palliative nursing care. Clinical assessment and attention to physical symptoms and psychosocial concerns, responses to suffering, listening to expressions of loss and grief, and recognition of ethical or spiritual concerns are all contingent upon good communication. To respond to these needs, nurses providing palliative care across a variety of populations and settings must be trained in skillful communication.

# SACKGROUND/LITERATURE

Communication in nursing practice is not a simple, naturally occurring process, but rather a complex endeavor. Like other skills of professional nursing, communication requires intense education and practice.<sup>1,2</sup> The need for expert communication is universal in nursing care but takes on special importance during intense times such as serious illness and end-of-life care.<sup>3,4</sup>

A significant amount of communication literature in palliative care is related to physician-patient communication, with most of that literature related only to breaking bad news.<sup>5,6</sup> Yet nurses are the constant presence across clinical settings, and it is often the nurse who will spend critical time with patients and families helping them to interpret bad news and listening to their emotional responses to such information.<sup>6-10</sup>

The opportunities for nurses to positively influence patient care through effective communication mirror the phases of serious illness. Most patients/families have fears and concerns about the dying process and death. Patients fear being in pain, unrelieved symptoms, and abandonment. At the initial time of a bad diagnosis, nurses actively participate in providing information, clarifying medical information, and listening to the patient and family responses as they evaluate treatment options. During active treatment such as chemotherapy, nurses are key in listening to patient concerns and symptoms and coaching patients to share these concerns. In recurrent or late-stage disease or for those approaching the end of life, communicating about decisions of significant concern is essential.

There has been significant literature in the field of palliative care regarding communication. A number of authors have developed or used protocols for breaking bad news.<sup>1,11</sup>

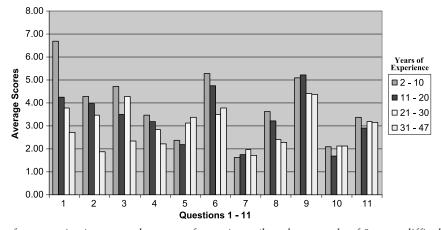


Figure 1. Breakdown of communication scores by years of experience (based on a scale of 0 = not difficult; 10 = very difficult). Survey questions: (1) Talking with patients once they have received "bad news." (2) Talking with family members of seriously ill patients. (3) Talking with patients or families about spiritual/religious concerns. (4) Discussing decisions such as advanced directives, DNR orders, feeding tubes, and so on. (5) Remaining silent and listening to difficult feelings from patients or families. (6) Talking with physicians about palliative care issues. (7) Talking with nurse colleagues about palliative care issues. (8) Talking to patients or families about hospice. (9) Talking with patients or families from different cultures. (10) Talking with patients or families about suffering.



Several authors have proposed that communication skills must be learned and that inclusion of this content in formal curriculum is important. Several authors have addressed the special issues regarding communication with family members.<sup>5,6,12,13</sup> Imparting accurate information so that individuals can make informed decisions is essential. Studies have shown that there are also differences in communication needs between patients and family members. Communication needs of patients include the need for information, assistance in the relief of pain and symptoms, an opportunity to disclose feelings, maintaining a sense of control, and a need for knowing that their life had meaning and purpose. Communication needs of family members include the need for information; permission to speak, and to be listened to as they face the decline and death of their loved one.<sup>14-16</sup> There is growing consensus that formalized procedures such as routine family conferences and effective use of translators for non-Englishspeaking patients can facilitate communication.<sup>12,17-20</sup>

This study adds to the literature by assessing nurse's perspectives on communication in palliative care, which is rapidly a growing field. As our population ages and nurses are increasingly involved in this specialty, this area of palliative care will become even more important. The data provide direction for future educational endeavors and research.

# **\*** METHODS

A survey was distributed to 333 RNs attending one of five End-of-Life Nursing Education Consortium (ELNEC) programs. The ELNEC courses (http://www.aacn.nche. edu/elnec) prepare nurses in essential content areas such as pain and symptom management, communication, culture, ethics, grief, and care at the time of death. Subjects voluntarily completed the survey at the start of the course prior to receiving course content. This article reports on

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Table

Communication Survey Data <sup>a</sup>								
Difficulty of Conversation <sup>b</sup>	Core (n = 162)	Critical Care (n = 47)	Pediatric (n = 34)	Geriatric (n = 90)	Total (N = 333)			
(1) Talking with patients once they have received bad news		3.00	4.22	4.10	3.71			
(2) Talking with family members of seriously ill patients		2.40	3.22	2.55	2.83			
(3) Talking with patients/families about spiritual/religious concerns		2.98	4.25	3.69	3.61			
(4) Discussing decisions such as advanced directives, DNR orders, feeding tubes, etc		2.51	3.87	2.90	3.10			
(5) Remaining silent and listening to difficult feelings from patients/families		2.02	2.85	2.83	2.59			
(6) Talking with physicians about palliative care issues		3.23	3.84	4.12	3.67			
(7) Talking with nurse colleagues about palliative care issues		1.55	1.79	1.80	1.75			
(8) Talking to patients or families about hospice		3.13	3.75	2.74	3.07			
(9) Talking with patients or families from different cultures		4.06	3.53	4.60	4.07			
(10) Talking with patients or families about pain or symptoms		1.94	1.87	1.99	1.94			
(11) Talking with patients or families about suffering		2.36	2.87	3.10	2.81			
No. of years in profession		18.44	20.88	23.21	20.46			
Work setting <sup>c</sup>								
Hospital	87	45	21	30	183			
Hospice	47	2	5	18	72			
Long-term care	6	1	1	36	44			
Home care	6	1	4	7	18			
Other	25	3	6	1	35			

<sup>a</sup>The 4 highest-ranked needs from each course are in bold font.

<sup>b</sup>Based on a scale from 0 = (not difficult) to 10 = (very difficult).

<sup>c</sup>Some participants indicated more than one setting.



survey data collected from these 333 nurses who rated the difficulty of conversations in palliative care and shared their clinical experiences in communicating with patients and families. The project was approved by the institutional review board, and subjects provided consent on the survey for use of the data.

The survey was constructed by the authors and derived from extensive literature review on the topic. The quantitative survey consists of 11 items (Figure 1) asking the nurses to rate common issues in palliative care and nursing communication. The survey items were consistent with aspects of communication identified by key sources including the National Consensus Project for Quality Palliative Care<sup>21</sup> and key literature describing communication.<sup>2,3,7</sup> The survey was reviewed for validity by a panel of nurse experts and pilot tested by nurses attending an ELNEC course. Nurses rated the aspects of communication on a scale of 0 = not difficult to 10 = very difficult. Additionally, the participants were asked two open-ended ques-

tions in which they were invited to share examples of positive and negative experiences they had related to communicating with seriously ill patients or families.

# RESULTS

Study findings are presented in Table 1. The participants were an experienced group with a mean length of time in nursing of 20 years, and the nurses were from diverse practice settings. The nurses' ratings are presented according to which ELNEC course they attended. This included ELNEC specialty courses in pediatrics, geriatrics, critical care, or the general core course. Overall group ratings indicate that the most difficult areas were communicating with patients and families from different cultures, talking to patients after they had received bad news, and talking about palliative care issues or religious/spiritual issues.

Table 1 also highlights some differences across the various courses. It is interesting to note that, in all four

# Table 2

# **Examples From Pediatrics**

- There was a 17-year-old girl, dying in the pediatric ICU of a lung infection, complication from treatment (or bone cancer). I had a good relationship with this patient. She was now on a ventilator.... The family decided to not have further surgeries and changed focus on comfort results. Since she was on a ventilator and unconscious, we couldn't involve her in this decision.... They needed and wanted to tell her what was going on, but didn't know how and asked me to do this since I had a good relationship with her. So, in a quiet, peaceful room, I stood by her side; her mother, aunt, and other family members were there. I told her what was going on medically, what we were doing to relieve her pain and improve her comfort. We were all there with her; her family was there and told her that they loved her very much, learned so much from her, would miss her, and that she would not be alone. It was a very healing moment for the family as we were being so open and honest with this 17-year-old even at her deathbed.
- The time I was with a woman pregnant with her first baby. The baby had not been moving; she came in for a nonstress test. I could not find the heartbeat after much searching. She was nervous. I put my hand on hers and said "At this moment, I cannot find your baby's heartbeat. I would like to call your doctor and ask for you to have an ultrasound. Is that OK with you? She squeezed my hand and said, "That is fine, what do you think?" I told her, "I am concerned that my instrument does not find a heartbeat along with you not feeling the baby move." She did not want to let go of my hand. She was alone. I asked her if there was anyone I could call. She said she would like to call her husband while I called the doctor; I got the order from the doctor; I held one hand while her husband held the other. There was no beating heart. We all knew. The mother screamed and thrashed. Then both mother and father sobbed. I just held both of them with tears streaming down my face. I remained with them several minutes. The mother looked at me and said, "What do we do now?" This couple remained as my patients. After the birth of their stillborn daughter (40 weeks' gestation), I let them drive what they wanted for the baby—pictures, bath, time to hold, etc. I did of course follow up with them. There was a relationship that carried through with them in their next pregnancy and birth of a healthy newborn boy.
- It was not the conversation that made a difference in one patient that I took care of; it was how I spoke to the family and involved them in bedside care. The child was a drown victim and was brain dead. I spoke to the child and bathed him and held him as if he was sleep. My action spoke louder than words. I treated him as if he were still alive, and the parents were truly touched.



groups, talking with patients once they have received bad news and talking with physicians about palliative care issues were rated as key concerns. Talking with patients about spiritual concerns was also rated as very difficult. Talking with nurse colleagues about palliative care and talking with patients about pain or symptoms were rated as not difficult.

Figure 1 illustrates the difference of responses of the nurses surveyed according to years of experience. Nurses

with less experience (2-10 years of nursing) reported more difficulty speaking with patients once they received "bad news" (mean = 6.7 on a scale of 0 = not difficult to 10 = very difficult) versus nursing with more experience (>10 years, mean = 4.3; >20 years, mean = 3.8; >30 years, mean = 2.7). The survey also illustrated that nurses with less experience (<10 years) reported having more difficulties than experienced nurses (>10 years) in the following areas: talking with family members of seriously ill patients

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# T a b l e 3 Examples From Geriatrics

- Several years ago, I worked in a rural acute-care hospital. A resident had just been diagnosed with cancer, and the physician was on his way to the room to let the patient know the results of his tests and the presence of cancer. I knew that this particular physician was not known for his bedside manner, so I made a point of being present for the encounter. The doctor came into the room and simply announced to the patient that he had a "malignancy" and then left the room. After the doctor left, the patient said to me, "What a relief. I thought I had cancer." I immediately excused myself and ran after the doctor to let him know that his explanation had not been understood. He did go back to speak more purposefully with the patient. After the physician left, I stayed with the patient to listen and answer further questions that the patient expressed.
- I have been involved with so many patients and families, it's hard to pick out specific examples—I tend to feel they have all ultimately been positive even if the positive was difficult to get to. Most difficulties have come attempting to educate others that palliative care isn't a "death sentence," that stopping curative measures in favor of comfort is not giving up. The best conversations have been with people who are afraid of dying and being able to give them the ability to be comfortable and find the gifts in death and dying.
- I work with patients with dementia and their families. I think my most satisfying and challenging conversation is about what to expect in the final stage. One family had their father in a nursing home. They couldn't decide on end-of-life care. So I met with them. One child wanted everything possible done. The other didn't. I presented pros and cons of the various treatments, tube feedings, antibiotics, etc, then allowed them to voice their opinions and thoughts. I think they both just needed to be heard and listen to each other. They were able to come up with a plan that worked for both.
- Compassionate listening works every time. Follow-up visits are just as valuable as our actual conference since dying continues to be a process and choices can't be rushed. It's important to share info from family meetings and staff in the hospital and staff where they will be going. Practice what will happen after discharge, that is, pain, symptom management in the hospital before discharge establishes trust in the plan of care if there is time. Maintain a sense of humor; avoid doom and gloom no matter how close death is.
- Last week I lead the team with a young adult son whose father, age 63, was actively dying. I gently explored family spirituality and found they practiced Buddhism. Three days earlier, communication by chaplain had been unsuccessful as family was not open to communication with a chaplain. I work in a Catholic hospital, and the family was Middle Eastern, and we were surprised by family religion. Upon establishing family religious beliefs, the son was able to discuss his father's wish to "be as alert as possible," not be "too sedated," yet desire to be free of pain and SOB. The morning conversation was difficult as all responsibility was with the son, age 21 or 22, and no response from the patient's wife. The morning conversation prepared everyone for afternoon family conference with our medical director and our team.
- Mr C. was 87 years old and had smoked for years. He was diagnosed with lung cancer that had generalized metastasis. He had 2 sons; neither lived close to their father. The elder son contacted me with questions and concerns about his dad and what "should be done for 'dad." For 2 hours, we talked; mostly he talked and I listened. Most of the questions were "Should I make him do this or that?" "Should I bring him here?" And so the questions went rhetorically. Each time, he asked what he should have his dad do, and I asked him what his dad wanted. After about an hour and a half, he said, "I probably should talk with dad to see what he wants." Finally, he was ready to learn to help his father. Mr C. died peacefully in his own bed several months later with both sons and hospice by his side.

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# T a b l e 4 Examples From ELNEC Core

- As a patient was becoming more ill and closer to death, his family was not sure that he knew what was happening and that he was "dying." They asked me if I could ask him if he knew he was "dying." As I swallowed a lump in my throat, I approached the patient and asked him directly if he knew what was happening and that he was dying. He answered that yes, he knew, and then asked me if I knew when it would happen. I assured him that I did not know when it would occur but that I would keep him posted of everything so that he would know. He was satisfied with that and fell asleep with me holding his hand. His family was relieved that the ice essentially had been broken and was then able to discuss funeral arrangements with him before he died.
- The daughter of a patient who was actively dying related to me what a wonderful dad and granddad her father had been. I encouraged all 3 daughters to stay in the room with their dad sharing their stories and memories of treasured moments in their lives. I got them settled in the room and remained with them to make sure they were comfortable and then gave them their privacy for the next hour; the entire family laughed, cried, and shared all of their wonderful memories. After their dad had died, they all thanked me for encouraging them to share their stories. They had told me it had truly made a difference for them and that they considered that last hour a gift.
- Determining whether a conversation went well is difficult. Was it successful in my opinion or in the patient's opinion? Whose goals were met, the patient's or healthcare provider's? Recently, I was providing chemo education to a newly diagnosed pancreatic cancer patient. His wife was in "cure" mode, and the patient was in "quality" mode. We did not get very much done in terms of chemo teaching. However, doors were opened for the patient to discuss with his wife what he wanted in terms of treatment. Oftentimes, patients want/need the nurses, doctors, social workers, etc, to verbalize and physically support their healthcare decisions in front of family members. There is strength in numbers.

(mean = 4.3); discussing decisions such as advanced directives, DNR orders, and so on (mean = 3.5); talking with physicians about palliative care issues (mean = 5.3); and talking to patients or families about hospice (mean = 3.6). However, nurses with less than 20 years of experience had more difficulty speaking with patients or families of different cultures (<10 and 20 years, mean = 5.1 and 5.2, respectively) compared with nurses with more than 20 years' experience (21-30 years, mean = 4.4; 31-47 years, mean = 4.4). In reference to Question 3, an interesting finding was that nurses with less than 10 years and 21 to 30 years of experience had more difficulty speaking with patients and families about spiritual/religious concerns (mean = 4.7 and 4.3, respectively) than nurses with 11 to 20 years of experience (mean = 3.5). Nurses with greater than 30 years of experience reported the least difficulty speaking with patients/families about spiritual/religious concerns (mean = 2.3). Another interesting finding was that nurses with more years of experience (>30 years) found it more difficult to remain silent and listen to difficult feelings from patients or families (Question 5) (mean = 3.4).

Tables 2 to 5 present examples of the narratives provided by the participants as they shared examples of their experiences of bad and good communication with patients and families. Table 2 presents examples from the

pediatric group; Table 3 from geriatrics; Table 4 from the ELNEC core course, which included hospital and hospice nurses; and Table 5 from critical care. The narratives offer rich insight as to the vital roles of nurses in communication with seriously ill patients and their families. Nurses often described instances where they were called on to communicate or validate difficult news. There was one account where a resident from a hospice was dying of a chronic disease. Her son, who was also a physician, was notified and flew in immediately. It had been some time since he had last seen his mother and felt it his responsibility to now have her in his care. Having medical knowledge, he began inquiring about his mother's laboratory work. The nurse gently explained to him that his mother was surrounded by great physicians who had been doing the best for her and that he was her son. This communication provided the son valuable time with his mother. He cried and was with great relief and thanked the nurse for giving him permission to be the son.

Nurses also frequently described how their actions spoke much more than words. Nurses were present, offering their ability to be with patients, to remain present at the most difficult times and to listen. One narrative described how a patient previously had cervical spine surgery and as a result had to wear a neck brace. This particular neck brace provided more comfort since it included heat and



aromatherapy features. While repositioning the patient, her neck brace got caught and tore. The family was very moved as the nurse took the neck brace and sewed it back together. Through this small gesture, the family saw how committed the patient's nurse was to the patient and family. The nurses' narratives often described instances in which they served as advocates for the patients' preferences or as agents when there was conflict. An example of this taken from one of the narratives shares how a nurse caring for one of her patients in the pediatric unit became very close to the patient and family. A child, knowing that he would

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## T a b l e 5 Examples From Critical Care

- I was caring for an 18-year-old boy who was in septic shock after BMT rejection. He was on multiple pressers, was receiving multiple blood products, and was ventilated. When his mother arrived, she was quiet but asking very knowledgeable questions. When the nephrologists came into the room, she had a consent to start CVVH. The nephrologist was shocked when the mother refused to consent. She even stated, "Do you know your son will die if we don't start therapy?" The mother stood firm and stated that she knew her son did not want all the therapies we were delivering. She calmly stated that she was just waiting for the family and friends to arrive before we started withdrawal. I bonded with the woman immediately! What a brave woman!
- With the help of the palliative care team, we developed a plan for withdrawing support. When the family arrived, I crowded all of them in the room! (More than 20!) The family had a chance to remember the young man before he was ill. They told stories and supported the brave single mother. As I started discontinuing therapy, I explained what they may see happen. Fortunately, the withdrawal was smooth, and the young man did not struggle at the end. The family all thanked me for "standing up with them, with the mother's/son's wishes."
- I had the pleasure of working with a patient who was in and out of ICU on a regular basis. His last admission lasted approximately 6 months. In the last month, he started deteriorating even more, and the hope of survival was grim. Eventually, his son made the decisions to liberate him from the ventilator after several interdisciplinary meetings. On the day it was planned, all the family members gathered around him to pray and spend the life's precious last minutes with him. He was started on morphine drip for comfort and was given medications to manage his secretions. He was then liberated from the ventilator. Shortly after, the son started crying because he felt he was killing his father. I took him to his side and listened to him to talk about his father for 5 minutes. After he finished, I told him that by listening to him talk about his father, this was not the quality of life he would have wanted. For the past few months, he had been suffering and had head enough. I told him that his father had asked me on several occasions to remove him from the vent. After talking with him, he found peace in his decisions and was comforted when his father passed within 30 minutes and removed from the ventilator. He came to me afterward and thanked me for my help and for caring for his father.
- I have received a patient from the oncology floor who had been there for over a week with dyspnea. In 1 hour, the MD had written in progress notes she should be DNR but had not talked to her (end-stage lung cancer). That morning, they said if she was really SOB, they could send her to the ICU and vent her. My charge nurse asked me to help so I "jumped in front of the bus." I took report and got respiratory to place her on BiPAP waiting for the pulmonologist then pulled the son I was told was making decisions and explained that, if we intubated, she would be sedated, unable to eat, and talk with her family (it was a large Greek family), and because of her disease, we might have trouble getting her back off the ventilator. I was able to also stop the MD and explain the problems—so we used antianxiety meds opioids, and BiPAP, and she improved, then I had a family meeting (no MDs available). I explained the benefit and burdens, and in the end, by afternoon, we looked for comfort hospice, and she died comfortably with her family, in about a week.
- I work in PACU. We had a patient who came into the ER with a ruptured abdominal aortic aneurysm, he was brought into our room prior to the OR and after the OR. When the family got to the ER, they weren't able to see their husband/dad. I found the patient's family and brought them to the PACU. I spoke with the family and expressed what was happening and what would happen. I encouraged them to touch him and kiss him. They asked if he would die. I reinforced that everything would be done, but he could die. I got spiritual care involved. After surgery, the patient was back in the PACU and very unstable and eager and had the family come in to have an opportunity to see him. I encouraged them to touch and talk to him. His daughter thanked me for allowing them to see him and preparing them for what they would see. We also talked about the possibility that he might die. I was grateful to have the opportunity to help this family.

Abbreviation: CVVH, Continuous Veno-Venous Hemofitration.

be dying soon, became increasingly aware of his spiritual needs and began asking the nurse questions about God and asked her to read from a children's Bible his grandmother had given him. The child would hide the Bible every time the father would come to visit, and later the child explained to the nurse that his father was opposed to him having any religious beliefs. One night, as he sensed that his death was coming soon, he asked the nurse if she could baptize him in the bathtub. She did baptize him, and the boy died the following day. She was pleased to hear his concern and respond to meet his need. Such narratives also illustrate the very complex family dynamics in palliative care.

The narratives generally included communication with family caregivers and illustrate how frequently nurses support families as a key component of care. The narratives illustrate the nurses' frustration in these complex care situations and communication concerns, while many narratives also depicted tremendous satisfaction by the nurses when they felt that they had been able to foster effective communication.

The study was limited to nurses attending palliative care training, and this may have been a select population. Future studies should include more diverse samples of nurses. Intervention studies are also needed to provide communication training and to evaluate the outcomes of that training on patient, family, and nursing outcomes.

# SUMMARY

Communication is a cornerstone of basic nursing practice and a fundamental skill across all settings of care to identify the patient's goals of care. In the field of palliative care, recent literature has emphasized the role of medicine in "breaking bad news" with much less emphasis on the role of nursing in supporting patients and families after bad news has been received and throughout the course of illness and until the time of death.<sup>21-26</sup>

The narratives provided by the participants demonstrate powerful and often emotional accounts of nurses' experiences. The data illustrate the needs for support as nurses have difficult conversations and the need for skills-based learning such as through role play so that nurses can practice their skills.

Results of the study reveal many aspects of communication that are challenging for nurses yet vital for patient care. There are opportunities for addressing communication in both undergraduate and graduate education and for continuing education of nurses in the clinical setting. As patients and families continue to face serious illness, transition to palliative care, and make difficult decisions, nurses will play a critical role and remain as the predominant professionals at the bedside.

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