Palliative Care Communication in Oncology Nursing

Joy Goldsmith, PhD, Betty Ferrell, PhD, MA, FAAN, FPCN, Elaine Wittenberg-Lyles, PhD, and Sandra L. Ragan, PhD

Oncology nurses consistently exhibit distress when communicating about end-of-life topics with patients and families. Poor communication experiences and processes correlate with emotional distress, moral distress, and work-related stress. The National Consensus Project (NCP) for Quality Palliative Care developed clinical practice guidelines to establish quality standards for the practice of palliative care. NCP’s guidelines are expressly intended as an interdisciplinary document and are representative of the inherent interdisciplinary nature of palliative care. Communication’s value to palliative and oncology nursing is unique because those two specialties include a high frequency of challenging interactions for patients, families, and healthcare professionals. The COMFORT communication curriculum, a holistic model for narrative clinical communication in practice developed for use in early palliative care, is posed as a resource for oncology nurses with a series of practice case examples presented against the backdrop of NCP’s eight domains of quality palliative care.

Palliative care prioritizes patient pain and symptom management, emphasizes communication with patients and their families, and establishes coordination of care. Given the prevalence of cancer and the high need to manage symptoms of this often advanced illness, researchers have proposed that palliative care should be integrated into standard oncology care (Periyakoil & Von Gunten, 2007; Smith et al., 2012). With emerging research showing the benefits and feasibility of combining palliative care and oncology (Smith et al., 2012), questions remain about how to successfully integrate both services. One step toward integrating palliative care and oncology is to provide clinicians with communication training to meet patient and family needs. The COMFORT communication curriculum has been presented for nurse communication training in early palliative care (Goldsmith & Wittenberg-Lyles, in press; Wittenberg-Lyles, Goldsmith, Ferrell, & Ragan, 2013; Wittenberg-Lyles, Goldsmith, & Ragan, 2010; Wittenberg-Lyles, Goldsmith, Richardson, Hallett, & Clark, 2013). COMFORT is an acronym for seven holistic principles of palliative care communication including narrative clinical practice (Communication), health and cultural literacy (Orientation and opportunity), presence in practice (Mindful presence), the role of family caregivers (Family), transitions in care (Openings), patient and family needs (Relating), and teamwork (Team). The COMFORT model also is now a component of the End-of-Life Nursing Education Consortium communication module and is available at www.clinicalcc.com. For more details of the COMFORT model, see Wittenberg-Lyles, Goldsmith, and Ferrell (2013).

Clinical guidelines establishing quality standards for palliative care practice were developed through the National Consensus Project for Quality Palliative Care ([NCP], 2009). The NCP guidelines define each domain, but ultimately establish the necessary elements of quality palliative care (see Figure 1). The NCP guidelines direct the interdisciplinary team, but also hold special significance to nurses as the providers most often interacting with patients and families across all settings of care. To demonstrate the pertinence of COMFORT to quality palliative care, this article highlights corresponding NCP domains and fictive practice examples with specific communication tools. COMFORT and the NCP guidelines illustrate how essential palliative care communication is to every aspect of quality oncology care.

Communicating

A basic axiom of COMFORT is that every message a person creates consists of task content (educating, advocating, and
inquiring), as well as relational content (caring, connecting, and feeling) (Watzlawick, Beavin, & Jackson, 1967). NCP (2009) Domain 7 describes essential care for the imminently dying. The ongoing presence of the nurse during that time provides opportunity for task and relational communication. Nurses can respond to family inquiries by offering information on the dying process and the family’s role (task), and through nonverbal and verbal communication, nurses also can support, comfort, and reduce uncertainty (relationship). In facilitating the patient and family’s expression of emotion, nurses bear witness to suffering; they honor the voices of the patient and family through active listening and person-centered messages that recognize and legitimize feelings. Helping a dying patient and their family “rewrite” an illness story that focuses on quality of life demonstrates a therapeutic approach to clinical communication and its healing powers.

Case Study: Stan

Stan, a 42-year-old man admitted to the hospital for end-stage leiomyosarcoma and resulting third episode of sepsis, has opted for palliative care and a do not attempt resuscitation order. Stan’s father tells the oncology nurse in the intensive care unit, “This is so much harder to do than I ever imagined.” Stan’s wife then asks the nurse, “What will happen next? What do we do?” The nurse can operationalize communication in the following ways.

▸ Employ verbal analogy or verbal directness: “His body is like a machine that is no longer operating smoothly. His motor will race at times and also slow dramatically. As his organs slow in their functioning, his heart and blood pressure will race, then slow.”

▸ Identify uniqueness in the patient and family: “What do you think is the hardest thing for you? Who else is part of this illness experience?”

▸ Understand life prior to illness: “How has this illness affected your life and relationships? How do you see the future?”

▸ Inquire about psychosocial health: “What people in your life support you? What do you think needs to change?”

Orientation and Opportunity

Convergence is emphasized in the COMFORT model. Convergence describes clinical communication that aligns with the patient and family by adjusting vocal tone, proximity, and/or language without stereotyping or assuming cultural knowledge. Eliciting and documenting the cultural needs, concerns, and background of the patient and family are central to meeting NCP (2009) Domain 6 of quality palliative care, which highlights cultural aspects of care.

Accommodating the infinite range of ritual practice, treatment beliefs, and family disclosure preferences requires determined intention on the part of healthcare professionals. The force of culture, relationships, family, disclosure practices, and the fragility of particular family systems present formidable clinical practice communication challenges.

Case Study: David

David, a 42-year-old Filipino gay man with AIDS and associated malignancies, presents in the oncology clinic. David, estranged from his family for many years, has recently reconnected with his sister, Nanette. At the clinic, the nurse explains a new protocol and potential side effects to them. Once alone, Nanette shares her strong belief with David that a local Filipino doctor could offer alternative herbal treatments. As the nurse reenters the room, she detects high tension and a change in mood. The nurse can operationalize orientation and opportunity in the following ways.

▸ Identify observable cues indicating accommodation needs for culture and health literacy: Does a general state of withdrawal exist? Is the patient or family difficult to engage? Does the patient or family’s behavior demonstrate that information is being withheld?

▸ Ask questions specific to illness and changes in treatment: “How can we help you live in the best way possible? Do you have fears or worries? What makes life worthwhile? What kinds of treatment are not acceptable to you?”

▸ Discuss topics specific to cultural diversity: “Tell me more about your family. Where do you go for support? How does your family make health decisions? What would spirituality or religion in your care look like?”

Mindful Presence

Mindful presence, the third COMFORT module, positions nurses as being purposefully attentive to the moment, actively engaged in the present, sensitive to context, nonjudgmental, and empathetic. In comforting patients and families, nurses can provide an emotional climate for the expression of regrets, discussion of spiritual concerns, and the sadness resulting from life’s human shortfalls. Through empathic, active listening and nonverbal attentiveness, nurses can demonstrate the acceptance, patience, trust, and attitude of letting go that will permit the patient and family to express spiritual, religious, and existential suffering and make meaningful connections in the midst of loss. Instrumental to Domain 5 of quality palliative care, nurses are charged with regularly exploring and assessing patient fears, beliefs, preferences, and desires. Simply talking about these concerns is noted as being meaningful to patients and families (Visser & Wysmans, 2010). A nurse’s compassionate presence does not include having the right answers, but rather “being there” for patients.
Case Study: Herb

Herb is a 79-year-old Korean War veteran in a Veterans Affairs long-term care facility with a diagnosis of advanced small-cell lung cancer. After one round of chemotherapy, he opted to end treatment. Herb is aware of his impending death and cries often. Last night, he went to the nurse’s station and talked with his favorite nurse about his life regrets, three previous marriages, enduring grief from the loss of his son, and his anguish that he “gave up on God.” The nurse can operationalize mindful presence in the following ways.

- Practice effective and empathic listening: Stop other activities, look at the patient and family, listen without interrupting, clarify the patient and family’s feelings, focus on the meaning of the message, observe the patient and family’s body language, and practice saying nothing (i.e., using silence) to allow the patient and family to share.
- Perform self-reflection: What issues were significant to the patient and family? How were they feeling and why? How were you feeling and why? What were the consequences of your actions with the patient and family? What knowledge was most informative? Finally, how did this situation connect with previous patient and family experiences?

Family

Understanding a family climate will aid the nurse in determining burden and targeting appropriate interventions for family caregivers. A family communication environment develops over time and is not created by the event of illness. Two factors contribute to a family communication pattern: conversation and conformity (Wittenberg-Lyles, Goldsmith, Parker Oliver, Demiris, & Rankin, 2012). Conversation refers to the frequency, freedom, and topics a family uses. A low-to-high conversation climate determines how much a family shares, whereas a low-conformity family creates opportunities for changing roles within the family or differentiation of beliefs, and beliefs. A high-conformity family has little tolerance for openings in conversation for nurse intervention.

The ethical and legal aspects of care described in Domain 8 of the NCP (2009) guidelines include descriptions of collaboration between clinicians and family that honor a family’s decision-making capacity and desired level of involvement. Team intervention must be dependent on family communication patterns.

Case Study: Louis

Louis, a 70-year-old widower, is admitted to the oncology care unit with advanced prostate cancer and intractable back pain. His two children, Ben and Janice, arrive from out of state. Ben insists that Louis be transferred immediately to a comprehensive cancer center, while Janice is adamant that their father would rather be at home instead. Janice sits clutching Louis’s hand, sobbing, and says to the nurse, “I will have my husband fly in and carry Dad out of here!” The nurse can operationalize comforting the family in the following ways.

- Use inclusion questions to ask each member of the family to speak and elicit involvement: “Who is most upset in your view?”
- Use reflexive questions to invite the family to reflect on possibilities: “What might be hard about caring for your dad at home?”
- Ask strategic questions that incorporate a solution to guide the family: “What level of pain are you willing to have your dad tolerate before other pain control is included in his care?”
- Pose queries to the family in finding a care plan: “What else is going on in your family? What has helped in dealing with previous family crises? What do you remember from those experiences? What values did you learn that are still important to you now? Tell me about your family. Who is close to whom? Did your dad ever tell you what he wanted for himself? Who is supporting you now?”

Openings

The COMFORT model offers clinical communication tools enabling nurses to engage patients and families at moments of observable tension in the course of care. The social aspects of care in NCP (2009) Domain 4 include a responsive plan of care specifically accounting for the social needs of the patient and family. Social needs encompass a family system, cultural network, social support, meetings involving as much family as possible, and appropriate referrals to facilitate social needs during illness. The social domain also addresses the financial impact of illness. Those and other needs create moments of intense pressure and conflict during transitions in care and can serve as openings in conversation for nurse intervention.

Case Study: Silva

Silva, an 80-year-old Armenian woman recently widowed, moved to California to live with her daughter, Azril. Silva was diagnosed with peritoneal cancer two weeks after arriving in the United States. In a rehabilitation facility following surgery, Silva shows little interest in walking or eating. Azril insists that vigorous rehabilitation be attempted. Azril confided to her mother’s nurse that she could not bear the possibility of losing both parents in such a short time. She has declined having her mother complete an advance directive as Azril considers it a bad omen. The nurse can operationalize openings in the following ways.

- Recognize transition in illness prompting tension, including initial diagnosis, treatment choice, family disagreement,
Consider strategies for engagement: Ask gentle questions:
“Are you ready to talk today?” Rephrase: “You said you want to talk.” Make statements: “You’ve mentioned the death of your father. I’m here if you want to talk about it.”

Employ useful language in light of tension: Clarify goals:
“I understand you may be anxious about the upcoming chemotherapy.” Identify needs: “Do you want to talk about what’s going on?” Connect goals with care needs: “It sounds like you want to be with your family. We can help them care for you at home.” Explore distress: “Tell me about your sadness.” Reassure: “Whatever you decide, I will be here as your nurse.”

Relating and the Physical Aspects of Care

Interdisciplinary team members are united by psychospiritual care to meet the needs of patients and families who experience terminal illness, which often brings psychological suffering and spiritual distress (Steinhauser et al., 2008). Physical pain management is most effective when clinicians employ the best evidence and skills to support patients and families. For example, patients’ reluctance to discuss pain management can be challenging, and pain may become fully debilitating not only for the patient, but also the family. Nurse communication training can move beyond what is said to interpret what patients and families mean. Informed by relational history, the nurse clinician can explore and address the meaning driving speech acts.

Case Study: Elena

Elena, a 12-year-old girl with advanced sarcoma, is seen by pediatric palliative care services. Her cancer is metastatic with protracted bone pain. Elena has two younger siblings, and her mother also cares for an aunt with Alzheimer disease. Both the nurse and social worker have observed that when Elena’s mother is present, Elena does not complain of pain and minimizes her symptoms. The nurse can operationalize relating in the following ways:

Respond to the patient and family if they want to talk about life, dying, or death; show signs of protecting privacy or each other; or shift anxiety from treatment concerns to existential matters.

Increase clinician understanding of the patient and family: Adapt communication by giving the patient and family time and space if they are not ready to talk about or make decisions. Note how the patient and family handle an issue. Do not force information that the patient and family have difficulty managing; suspend the need to achieve a decision. Use the team and family by taking advantage of team talents and employing existing dynamics of the family.

Team Structure and Processes of Care

Nurses often serve as leaders during team meetings, and that role has tremendous influence on group communication patterns. The COMFORT model teaches nurses to recognize structural barriers and opportunities affecting group and team communication. Interdisciplinary team members are united by psychospiritual care to meet the needs of patients and families who experience terminal illness, which often brings psychological suffering and spiritual distress (Steinhauser et al., 2008). Psychospiritual care is complex, ambiguous, and cannot be attended to best by any one team member. COMFORT explicates the model for interdisciplinary collaboration and highlights the nurses’ need to use interpersonal relationship skills to establish mutual respect and trust with other team members.

Domain 1 of the NCP (2009) guidelines emphasizes the importance of creating structures that will support each of the subsequent domains to collectively promote palliative care. Clinical communication necessitates interdisciplinary collaboration among palliative care professionals to develop holistic care plans addressing the psychosocial aspects of treat (Domain 3). Without a structure for care in place, the psychosocial aspects of patient and family health cannot be effectively addressed.

Case Study: Ron

Ron, a nursing director of a National Cancer Institute-designated community cancer center, recently relocated from a multisite comprehensive cancer center. Almost immediately, Ron recognized major problems with processes of care in his new setting. He is particularly concerned that only e-mailed messages rather than a verbal report are provided by the evening or weekend on-call nurses to the primary nurse. He also questioned recent budget cuts eliminating social worker and chaplain involvement in weekly interdisciplinary team meetings, restricting their attendance only to monthly participation. Ron observes that interdisciplinary team meeting communication is limited to the medical director commenting on new patient summaries or complex symptom issues as presented by the charge nurse. Contribution from other nurses or team members is limited.

Geraldine, a chaplain with the palliative care service, stopped Ron to share concerns about a 72-year-old patient with liver cancer who lost his wife to lung cancer two months ago. Geraldine described the patient’s previous history of depression. Ron wonders how this complex case will be addressed appropriately by a team that is not functioning as a collaborative unit. He can operationalize team structure in the following ways:

Examine the team: What are the professional roles on the team? Is the hierarchy defined? Is including all team members
Implications for Practice

- Oncology nurses encounter a high rate of stressful and difficult end-of-life conversations with patients and families.
- Patient- and family-centered communication skills training that places an emphasis on palliative care would benefit oncology nurses.
- The COMFORT communication curriculum is a resource that specifically provides nurses with communication skills training on patient and family needs at the end of life.

In meetings a priority? Does everyone understand what others do, as well as their preparation? How does the team approach conflict? What is the structure of the meeting itself? Are controversies ignored? Are all perspectives heard? What should change about the team and its function?
- Avoid groupthink (when the desire for harmony overrides realistic appraisals): Elicit different perspectives, share problems, list reasons for a particular decision, identify pressures that might compromise a decision, and expect team members to engage in new opportunities to serve patient and family goals.

Implications for Practice

Nurses caring for patients with cancer and their families often are uncomfortable discussing prognosis, hospice care, advanced care planning, and spirituality (Noble & Jones, 2010; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005; Zhou, Stolzhus, Houldin, Parks, & Swan, 2010). The COMFORT model and its instructional materials provide a practical resource for integrating palliative care and oncology. Palliative care involves multiple disciplines, settings, and transitions, as well as enormous cultural variation. Ultimately, nurse communication training employing the COMFORT curriculum can enact the domains of quality palliative care and ease burdensome transitions in oncology, enhancing patient and family-centered practice.

References


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