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Discussing Death, Dying, and End-of-Life Goals of Care: A Communication Skills Training Module for Oncology Nurses

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Abstract

Background—Effective communication, particularly at the end of life, is an essential skill for oncology nurses, but few receive formal training in this area.

Objectives—The aim of this article is to adapt an end-of-life care communication skills training (CST) module, originally developed for oncologists, for oncology nurses and to evaluate participants' confidence in using the communication skills learned and their satisfaction with the module.

Methods—The adapted end-of-life care module consisted of a 45-minute didactic, exemplary video and 90 minutes of small group interaction and experiential role play with a simulated patient. Using a five-point Likert-type scale, 247 inpatient oncology nurses completed pre-/post-workshop surveys rating their confidence in discussing death, dying, and end-of-life goals of care with patients, as well as overall satisfaction with the module.

Findings—Nurses' confidence in discussing death, dying, and end-of-life goals of care increased significantly after attending the workshop. Nurse participants indicated satisfaction with the module by agreeing or strongly agreeing to all six items assessing satisfaction 90%–98% of the time. Nurses' CST in discussing death, dying, and end-of-life care showed feasibility, acceptability, and potential benefit at improving confidence in having end-of-life care discussions.

Graphical Abstract

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Keywords

death; dying; end-of-life care; nurse-patient communication; transitions in goals of care; communication skills; training

Despite nurses' centrality in the process of the healthcare team communicating with patients, few receive formal education specific to communication, particularly related to end-of-life care (Chant, Jenkinson, Randle, & Russell, 2002; Kruijver, Kerkstra, Bensing, & van de Wiel, 2000; Vydelingum, 2006). However, nurses rank communication as one of the most important competencies to their practice (McCabe, 2004; McGilton, Irwin-Robinson, Boscart, & Spanjevic, 2006). Although nurses generally feel confident in providing care for the physical needs of patients with cancer, they find addressing the patients' emotional concerns to be more difficult (Rask, Jensen, Andersen, & Zachariae, 2009). These reported difficulties in communication exist among hospice nurses as well (Ellington et al., 2008; Ellington, Reblin, Clayton, Berry, & Mooney, 2012).

Nurses' communication skills are crucial to patient care because they provide much of the care and support to patients and their families throughout the disease trajectory. Nurses are also more likely to be present at the time of death than any other healthcare professional (Wiegand & Russo, 2013). In acknowledgment of this reality, the Institute of Medicine (2010) reported that, although physicians have traditionally been responsible for these difficult end-of-life conversations, nurses are taking the lead with the advancement of nursing practice.

Key to improving nurses' involvement in patients' end-of-life care is training them how to communicate these issues to patients and their families. According to the American Nurses Association (2010), nurses have several responsibilities in caring for dying patients, including discussing life preferences and communicating relevant information. Because communication has been shown to be a cornerstone of improving patients' quality of care and quality of life (Wittenberg-Lyles, Goldsmith, Ferrell, & Ragan, 2013), the National Consensus Project for Quality Palliative Care (2013) has emphasized the need for effective, compassionate communication in palliative care.

Nurses have reported that merely learning communication skills on the job is not enough (Humphris, 2002), suggesting the need for formalized training. To address this need, a variety of interventions to improve nurses' communication skills and efficacy has been developed. The majority of communication skills training (CST) has been effective at increasing nurses' abilities to provide psychosocial support to patients, their confidence in handling conflicts and criticism, and communication-related self-efficacy (Langewitz et al., 2010; Sheldon, 2011; van Weert, Jansen, Spreeuwenberg, van Dulmen, & Bensing, 2011; Wilkinson, Linsell, Perry, & Blanchard, 2008). Most CST developed for nurses has focused on general communication, with participants focusing on how to have difficult conversations and break bad news (Baer & Weinstein, 2013). Because of the prevalence of nurses present at the end of life (Wiegand & Russo, 2013) and their increased involvement in end-of-life care discussions (Institute of Medicine, 2010), developing CST modules for nurses that specifically target end-of-life care discussions is critical.

To address this key need, the researchers adapted and modified a physician end-of-life care module for oncology nurses that already had been developed and evaluated by the researchers' institution. In this adapted CST module, the researchers were able to incorporate the communication differences inherent in the nurse–patient relationship and the communication skills necessary to that relationship. The primary aim of this article is to discuss the content and adaptation of the CST module. The secondary aim of this article is to evaluate the module by reporting the results on pilot self-report data on nurses' confidence in discussing death and dying, their intention to use the skills they learned in training, and their overall satisfaction with the module.

Methods

The CST and Research Laboratory, housed in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center (MSKCC) in New York, originally developed a series of modules for physicians, which are described elsewhere (Bialer, Kissane, Brown, Levin, & Bylund, 2011; Brown, Bylund, Eddington, Gueguen, & Kissane, 2010). This curriculum has been shown to lead to improvements in the use of major communication skill sets in clinical settings (Bylund et al., 2010). Based on nursing engagement surveys at MSKCC indicating a need and demand for training oncology nurses in communication skills, the researchers adapted this curriculum to fit the needs of nurses. The researchers' laboratory created a multidisciplinary development committee including nursing experts in oncology nursing and end-of-life care. This article describes one of the modules that was adapted for the nursing CST, namely the "Discussing Death, Dying, and End-of-Life Goals of Care" module.

Framework

The training modules developed in the researchers' laboratory are based on the Comskil Conceptual Model (Brown & Bylund, 2008), which describes clinical consultation communication as being composed of goals, strategies, skills, and process tasks. A communication goal is the desired outcome of a consultation or interaction. Goals are obtained through strategies, which are a priori plans that direct communication behavior

toward the desired communication goal. Strategies are achieved using communication skills, which are defined as discrete, measurable units of speech in which a clinician can further the clinical dialogue. Process tasks are sets of dialogue or nonverbal behaviors that create an environment for effective communication. Each of these components are put in a modular blueprint that details how these components work together for addressing specific topics within a clinical consultation or interaction (see Table 1).

The adaptation of the Discussing Death, Dying, and End-of-Life Goals of Care module for nurses included a series of seven steps used in the researchers' prior work (Brown, Bylund, Gueguen, et al., 2010). These seven consecutive steps included (a) systematic literature review, (b) consensus review meetings (with researchers, communication skill experts, and nurses), (c) modular blueprint development, (d) training methods development, (e) scenario development (for role plays and exemplary video clips), (f) making necessary revisions and adaptations, and (g) assessment of the training module (Brown, Bylund, Eddington, et al., 2010).

Participants

From 2012–2014, 247 inpatient nurses working in the oncology setting at MSKCC participated in this CST module. Inpatient nurse specialties included acute care (n = 169, 68%), pediatrics (n = 39, 16%), critical care (n = 25, 10%), and urgent care (n = 14, 6%). Nurses were selected for this CST by their nurse leaders, with a focus on bedside and clinic nurses. On average, 12 nurses participated in the CST per session to allow all participants to practice during the small group interaction and role play. Nurses who participated in this module also participated in two other modules to complete a day-long curriculum. These additional modules were titled "Responding Empathically to Patients" and "Responding to Challenging Interactions With Families." Each module lasted about two hours. An institutional review board waiver was approved to allow the researchers' laboratory to operate this training as a quality improvement initiative to the nursing CST curriculum. The exempt status allowed the laboratory to conduct CST training as a routine educational practice and permitted release of deidentified data on the effectiveness of this training program.

Modular Content

The overall communication goal for oncology nurses when discussing death, dying, and endof-life goals of care is to support patients and their family members during these discussions and to aid in decision-making processes regarding transitions in goals of care. The previous model for the physician's module focused on clinical information regarding the prognosis of the patients as well as reaching a shared understanding about their wishes at end of life. This module suggests five strategies, along with appropriate communication skills and process tasks, which allow nurses to achieve this desired goal of patient interaction across a number of patient and family interactions.

Strategies 1 and 2 involve establishing a relationship with the patients and developing an accurate, shared understanding of their situation. Endorsing question asking can address concerns or confusion the patient may have, allowing a shared understanding to be reached.

Checking the patients' or their family's understanding of the situation further enables the nurse to correct misunderstandings and increase shared understanding. Questioning skills, such as clarifying, also can help deepen the shared understanding of the patients' situation and its implications. Inviting patients' or their family members' agenda items into the discussion is also an important communication skill that allows patients' and their family members' concerns to be addressed.

Most commonly, bedside nurses are responsible for supporting patients and their family members after having an end-of-life discussion with their physician or advanced practitioner nurse (APN). Strategy 3 focuses on specific communication skills and process tasks that can be used to support the patients and their family members following the physician's or APN's discussion on transitioning from curative therapy to end-of-life care. Taking stock of how the patient is feeling and asking open-ended questions (e.g., "What's going through your mind?") allows patients to tell the story in their own words and to express any concerns, confusion, or distress that they may be experiencing. These open-ended questions should be followed up by checking their understanding and endorsing further question asking to correct any remaining misunderstandings. Questioning skills (e.g., clarifying, restating), can be used to continue to deepen the shared understanding of their situation and emotional state. Sensitivity to patients' emotional responses is an integral part of these conversations.

Strategy 4 represents the core communication skill of responding empathically to patients' emotions. In this strategy, the use of supportive skills (e.g., acknowledging, validating, normalizing patients' emotions) is a practical way to help them feel understood and supported. Acknowledging patients' emotions (e.g., "I can see how overwhelmed you are.") is simply stating the emotion that the nurse observes. Validating patients' emotions (e.g., "This must be so hard.") goes a step further than acknowledging by indicating that the patient has a right to feel this way. Normalizing (e.g., "Most people in your situation feel the same way.") indicates that their emotions are commonly experienced by others in similar situations. Finally, praising patients' efforts (e.g., "I am so impressed by how you have dealt with your illness.") helps to solidify the nurse–patient partnership. When responding to patients' emotions, nurses should allow for times of silence so that patients can process their emotions. When appropriate, physical touch (e.g., a hand on the arm) may help communicate that the nurse is responsive to their emotions.

Strategy 5 closes the conversation with acknowledging that a lot of information has been covered, acknowledging that patients and their family members may be overwhelmed, and reassuring them that the conversation will be continued in the future. As the conversation draws to a close, the nurse again should take stock of their understanding. The focus during these conversations is on things of importance to the patient as his or her life draws to a close. Although not all interactions with patients about transitions in goals of care to quality of life at the end of life can be touched on, each of these strategies and skills can be used across several conversations to help guide patients and their family members throughout the transition to end-of-life care.

Training Agenda and Process

Prior to attending the day-long CST, participants were asked to review three workbooks, one designed for each module. These workbooks served as preparation for the workshop and as a resource for trainees after participation in training. The workbook for the present module included supporting literature and educational materials on effective ways to discuss death, dying, and end-of-life goals of care, as well as frequently asked questions on this topic.

At the beginning of this module, a nursing expert on end-of-life care gave a 45-minute didactic slide presentation summarizing the evidence-based literature on end-of-life care. After this brief summary, the presentation focused on specific strategies, communication skills, and process tasks that could be used to accomplish the communication goals of supporting patients and their family members during discussions and aiding patients and their family members in decision-making processes regarding end-of-life care. Each strategy slide in the didactic presentation included a 2–3-minute video clip of a nurse demonstrating how the communication skills relevant to that strategy could be helpful in a conversation. The name of the specific communication skill being used was clearly displayed at the bottom of the video during the recorded interaction to reinforce the use of each skill presented.

Prior CST research shows that to improve communication skills, training must be participatory and experiential (Parry, 2008). Therefore, following the didactic presentation, nurses participated in an experiential role play in small groups (2–3 nurses) to practice the skills and strategies introduced in the didactic presentation. Two trained facilitators—a nurse paired with a communication specialist—led these small-group role-play sessions. Facilitator training consisted of a three-hour training described elsewhere (Bylund et al., 2008). Prepared role-play scenarios were used to give nurses the opportunity to practice their communication strategies and skills with trained actors who simulated patients. Each scenario depicted a scene in which a physician had just discussed transition to end-of-life goals of care and the nurse stayed with the patient to respond to the patient's emotions and clarify what had been communicated.

Each role-play session lasted about 90 minutes, and the time was divided equally among the 2–3 nurses. Prior to role play, the rules of confidentiality were outlined, anxiety on the part of the nurses was normalized, and the ability to take "time outs" was explained. At the start of role play, learners identified their learning goal for the standardized patient interaction and which communication skills they wanted to practice. During the scenarios, nurses had the opportunity to practice these communication skills. Following role play, nurses first were asked to reflect on their use of communication skills, name any communication skills used, and indicate whether they had met their learning goals. Next, they were given feedback from their peers, the facilitators, video playback, and, at the end of session, the actor in the role of the patient. This workshop followed best practice principles in adult learning of being learner-centered and experiential and involving individualized, targeted feedback (Knowles, 1978).

Evaluation

At the end of the module, participants were given an evaluation form to complete anonymously. It included eight statements about the workshop using five-point Likert-type scales assessing participants' levels of agreement or disagreement with each statement (1 = "strongly disagree" and 5 = "strongly agree"). In addition, a retrospective pre–post method (Hill & Betz, 2005) was used in the first two statements: (a) "Before this module, I felt confident discussing death, dying, and end-of-life goals of care," and (b) "Now that I have attended this module, I feel confident discussing death, dying, and end-of-life goals of care." The remaining items assessed nurses on post-training attitudes toward the skills they learned and asked how they could apply them during routine clinical practice, such as at the bedside.

Results

A paired-sample t-test indicated that participants' confidence in discussing death, dying, and end-of-life care goals increased significantly on the 1–5 Likert-type scale when compared before ($\bar{X} = 3.09$, SD = 1.03) and after ($\bar{X} = 4.07$, SD = 0.69) they attended the module (t246 = -18.66, p < 0.001).

To interpret results from the remaining module assessment items, the researchers remained consistent with their evaluation of prior module assessments (Bialer et al., 2011; Brown, Bylund, Eddington, et al., 2010). Namely, a rating of "agree" or "strongly agree" was considered to be an indicator of satisfaction with the workshop and its effectiveness in teaching communication skills regarding discussing death, dying, and end-of-life goals of care. Table 2 displays the percentages of workshop participants who agreed or strongly agreed with the six post-training items. Participants indicated satisfaction (e.g., agreed or strongly agreed) to all six items 90%–98% of the time.

Discussion

Although effective communication is a core competency for oncology nurses and a variety of CST models have been developed (Langewitz et al., 2010; Sheldon, 2011; van Weert et al., 2011; Wilkinson et al., 2008), a module specifically designed to train oncology nurses on how to communicate issues surrounding end-of-life care has not yet been created. To address this key need, the researchers adapted an end-of-life care module (from the physician module) for oncology nurses. This article outlines the methods used in adapting the module to assist oncology nurses in communicating more effectively with patients and their families when transitioning from curative therapy to end-of-life care.

Results indicated that the present CST module significantly increased nurses' confidence in discussing death, dying, and end-of-life care goals, and video feedback was helpful. In addition, the majority of nurses said that they were satisfied with the course, indicating that this end-of-life care CST module is feasible. Finally, the majority of nurses agreed that the CST module helped them think more about their communication with patients and improved their ability to communicate with patients, suggesting that the communication skills learned in the module would be translatable to nursing practice.

Limitations

Because the CST module has a specific format and structure, it theoretically allows for replication to other institutions and comparison of evaluation results regarding the participants' confidence in discussing death, dying, and end-of-life care goals. However, some institutions and certain settings (e.g., remote or rural cancer clinics) may lack the resources to replicate this training. Therefore, additional research should consider adaptations of this CST module to allow for dissemination across a wider range of clinical settings.

In addition, although the results demonstrated that nurses' confidence in discussing death, dying, and end-of-life care goals increased significantly when compared to those prior to attending the module, self-rated ability and satisfaction do not necessarily correlate with objective measures of performance (Mullan & Kothe, 2010). Therefore, the course cannot be assumed to have improved the communication skills of nurses in clinical practice. Evaluation of the nurses' transfer of communication skills to the bedside is an important next step.

Finally, anonymity of the survey prevented the researchers from conducting longitudinal follow-up with the nurses. Therefore, whether the positive training effects seen in the immediate post-training evaluation would be sustained weeks to months following the CST is not known. In the future, the researchers plan to follow up with nurses to determine the sustainability of using the skills learned in the CST in their clinical practice.

Conclusion

The current study provides a solid framework for the development of a CST module for inpatient oncology nurses when discussing death, dying, and end-of-life care. This is a critical next step in training oncology nurses for specialized communication in cancer care. By equipping nurses to handle these sensitive topics, the quality of patient care surrounding transitions from curative to end-of-life care may be improved.

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Implications for Practice

- Improve confidence in discussing death, dying, and end-of-life goals of care with patients and their family members with targeted communication skills training (CST).
- Combine a brief didactic presentation with experiential role play to practice communication skills learned.
- Adapt CST for discussing death, dying, and end-of-life goals of care to other nursing specialties (e.g., pediatrics) and end-stage patient groups (e.g., those with end-stage renal disease or heart failure).

TABLE 1

Modular Blueprint for Discussing Death, Dying, and End-of-Life Goals of Care

Strategy	Skills]	Process Tasks	
Establish the relationship.	•	Endorse question asking. Check patient and family understanding.	•	Ensure privacy and comfort.
	•		•	Make partnership statements.
	•	Invite patient and family agenda items.		
Develop an accurate, shared understanding of the patient's situation, including disease features, prognosis without treatment, and psychosocial needs and concerns.	•	Check patient and family understanding. Clarify.	•	Discuss expectations.
	•		•	Correct misunderstandings.
	•	Check patient preference information.		
Support patients and their family following the physician's discussion of death and dying and end-of- life goals.	•	 Take stock. Ask open questions. Check patient understanding. Endorse question asking. 	•	Tailor to the patient's preferences for level of detail.
	•			Ask if a discussion of the dying process would be helpful.
			•	Describe the natural dying process
	•		•	Avoid jargon and euphemisms.
	•	Clarify.	•	Consider spiritual or religious needs.
	•	Restate.	•	Address specific cultural needs.
Respond empathically to patient's emotional response.	•	Ask open questions.	•	Allow time to integrate and allow
	•	Encourage expression of feelings.	•	for silence. Offer tissues.
	•	Acknowledge.	•	Touch, when appropriate.
	•	Validate.		
	•	Normalize.		
	•	Praise patient efforts.		
Close the conversation.	•	Take stock.	•	Emphasize the quality of symptom control and goals of care—a peaceful, natural death.
	•	Summarize.		
	•	Check patient •	•	Affirm courage.
	•	Make partnership statements.	•	Remind about team availability.

Note. The goal is to support patients and their family members during discussions and the decision-making process regarding end-of-life care.

TABLE 2

Course Evaluation Results of Participant Agreement Related to Discussing Death, Dying, and End-of-Life Care (N = 247)

	Agree or Strongly Agree	
Item	n	%
I feel confident that I will use the skills I learned today.	238	96
The skills I learned today will allow me to provide better patient care.	243	98
The workshop prompted me to critically evaluate my own communication skills.	240	97
The experience of video feedback was helpful to the development of my skills.	221	90
The skills I learned were reinforced through the feedback I received in the small group.	242	98
The small group facilitator was effective.		98

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