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Author manuscript
Nurse Educ Pract. Author manuscript; available in PMC 2016 July 26.

Published in final edited form as:
Nurse Educ Pract. 2016 January ; 16(1): 193–201. doi:10.1016/j.nepr.2015.07.007.

Oncology nurses' communication challenges with patients and families: A qualitative study

Smita C. Banerjee[a,*], **Ruth Manna**[a], **Nessa Coyle**[a], **Megan Johnson Shen**[a], **Cassandra Pehrson**[a], **Talia Zaider**[a], **Stacey Hammonds**[a], **Carol A. Krueger**[a], **Patricia A. Parker**[a], and **Carma L. Bylund**[a,b]

[a]Memorial Sloan Kettering Cancer Center, USA

[b]Hamad Medical Corporation, Qatar

Abstract

The benefits of effective communication in an oncology setting are multifold and include the overall well-being of patients and health professionals, adherence to treatment regimens, psychological functioning, and improvements in quality of life. Nevertheless, there are substantial barriers and communication challenges reported by oncology nurses. This study was conducted to present a summary of communication challenges faced by oncology nurses. From November 2012 to March 2014, 121 inpatient nurses working in the oncology setting participated in an online pre-training qualitative survey that asked nurses to describe common communication challenges in communicating empathy and discussing death, dying, and end-of-life (EOL) goals of care. The results revealed six themes that describe the challenges in communicating empathically: dialectic tensions, burden of carrying bad news, lack of skills for providing empathy, perceived institutional barriers, challenging situations, and perceived dissimilarities between the nurse and the patient. The results for challenges in discussing death, dying and EOL goals of care revealed five themes: dialectic tensions, discussing specific topics related to EOL, lack of skills for providing empathy, patient/family characteristics, and perceived institutional barriers. This study emphasizes the need for institutions to provide communication skills training to their oncology nurses for navigating through challenging patient interactions.

Keywords

Communication challenges; Communication skills training; Death and dying; Empathic communication; End-of-life; In-patient nursing; Oncology nursing

Introduction

Nurses play a pivotal role in accompanying the patient and family through their cancer journey. As outlined in the 2010 Institute of Medicine's (IOM's) report, nursing practice covers a broad continuum of care, from health promotion to disease prevention, to coordination of care, to cure (when possible) and to palliative care when cure is not possible

*Corresponding author. Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Ave., 7th Floor, New York, NY 10022, USA. Tel.: +1 646 888 0011. banerjes@mskcc.org (S.C. Banerjee).

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(IOM, 2010). Given the frequency and continuity of contact that nurses have with their patients and their families, nurses are in an ideal position to assume important role in health care delivery processes (Baer and Weinstein, 2013). Cancer patients and families have a high prevalence of psychological stress and need emotional and social support; therefore, the importance of adequate communication about the diagnosis, prognosis and treatment alternatives cannot be over-emphasized (Hack et al., 2012).

The benefits of effective communication are multifold, and include the overall well-being of patients and health professionals. Effective communication positively influences the rate of patient recovery, pain control, adherence to treatment regimens, psychological functioning, and quality of life (e.g., Gattellari et al., 2001; Uitterhoeve et al., 2009; Vogel et al., 2009). Alternatively, ineffective communication can leave patients feeling anxious, and is associated with increased uncertainty and dissatisfaction with care (Hagerty et al., 2005), increase lack of compliance with recommended treatment regimens (Jin et al., 2008; Martin et al., 2005), and elevated rates of depression and anxiety (Donovan-Kicken and Caughlin, 2011). As well, ineffective communication may negatively affect the nurses by increasing stress, lack of job satisfaction, and emotional burnout (e.g., Emold et al., 2010; Potter et al., 2010).

Despite the numerous benefits of effective communication between patients and nurses, it is not uncommon for oncology nurses to report substantial barriers and communication challenges within their practice. In a recent study examining outcomes of a two-day interactive communication skills course on self-reflection of senior registered nurses, two main areas of communication challenges and specific skills development identified by the nurses included: dealing with patients with difficult questions and dealing with angry patients and relatives (Pilsworth et al., 2014). In another study that explored communication barriers as reported by seven nurse managers revealed an imminent need for nurses is to learn how to manage their intermediary role between patients, families, and physicians (Wittenberg-Lyles et al., 2013).

Prior studies demonstrate that oncology nurses face a plethora of communication challenges, primarily surrounding patient emotions, and challenging family dynamics around end-of-life (EOL) issues. What is still missing, however, is an iteration of specific forms of communication challenges (e.g., not knowing how to respond to a crying patient, or lack of supportive words when patient is EOL, etc.) that will reliably summarize the range of communication challenges faced by oncology nurses in an inpatient setting. Accordingly, this qualitative study will guide the development of communication skills courses that help nurses learn communication strategies to recognize, address, and overcome the communication challenges. These challenges require skills that go beyond simple supportive techniques such as empathy and listening. Teaching advanced communications skills that address specific problems identified and enumerated by nurses may be useful for addressing the communication challenges that interfere with patient-supported care. This study was conducted as a needs assessment survey that would inform the delivery and refinement of a one-day nurse communication skills training programme which provides an experiential and hands-on training to oncology nurses to increase proficiency in dealing with communication challenges. The aim of this study was to present a summary of specific forms of

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communication challenges faced by oncology nurses in a large cancer hospital, particularly focused around challenges related to empathic communication and EOL care issues.

Methods

Participants and procedure

From November 2012 to March 2014, 121 inpatient nurses working in the oncology setting at Memorial Sloan Kettering Cancer Center (MSKCC) in United States participated in an anonymous online pre-training survey that focused on understanding specific forms of communication challenges faced by MSKCC's inpatient oncology nurses. Nurse leaders from acute care, pediatrics, critical and urgent care selected potential nurse participants (N= 146) to participate in one of 13 communication skills trainings, offered between November 2012 to March 2014. MSKCC's Institutional Review Board approved this educational study and the publication of this data.

Approximately two weeks prior to their training, all nurse participants received an invitation and a web link to complete online survey using Qualtrics software; see http://www.qualtrics.com/). The response rate was approximately 83%, with 121 inpatient oncology nurses completing the survey.

Measures included a combination of qualitative and quantitative questions. On a 5-point Likert-type scale with 1 (Strongly Disagree) and 5 (Strongly Agree), nurses were asked to rate their confidence in communicating empathically with patients, and discussing death, dying and EOL goals of care. Additionally, nurses were asked two open-ended questions to understand their specific types of communication challenges: "What are the challenges in communicating empathically with your patients?" and "What is the most difficult aspect of discussing death, dying and EOL goals of care with patients?"

Data analysis

After the online questionnaires were completed, results were provided to the study team in SPSS®, version 18.0. Using descriptive analysis, mean scores for self-confidence ratings in communicating empathically with patients and in discussing death, dying and EOL goals of care were calculated.

Consistent with prior qualitative work and current analysis methods, the analysis of the open-ended question responses was performed through a thematic text analyses approach (Patton, 2002) that involved a rigorous review and interpretation of the data. A coding team consisting of the first four authors on this paper analyzed the data. When reviewing the data, the team focused on describing and interpreting participant comments regarding their challenges in communicating empathically with patients and discussing death, dying and EOL goals of care. The analysis strategy involved a combination of independent and collaborative analysis. As a first step, the coding team generated a code book consisting of descriptive and interpretive concepts identified during review of the open-ended data. To achieve this, they proceeded through an iterative process of open coding of a subset of the transcripts. Each coding team member independently developed codes capturing their interpretation of the underlying meaning of participant comments. After each team member

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completed their coding of a sub-topic, the team met to review the coding, mutually agreed to codes and their definitions, and reached consensus about how to apply the created codes to the data. This process of independent coding continued, and was followed by consensus work until the two sub-topics were coded (Patton, 2002).

Results

Self-reported confidence in communication

The mean rating for nurses' self-reported confidence in communicating empathically with patients was 4.12 ($SD = .64$) and in discussing death, dying and EOL goals of care was 3.43 ($SD = .97$).

Challenges in communicating empathically with patients

Six challenges in communicating empathically with patients were discussed: 1) dialectic tensions in providing empathy; 2) burden of carrying bad news; 3) lack of skills for providing empathy; 4) perceived institutional barriers in providing empathy; 5) challenging situations; and 6) perceived differences. Further, each type of communication challenge included a subset of challenges described below. Table 1 summarizes themes and sub-themes for challenges in communicating empathically with patients, and provides additional supporting quotes.

1. Dialectic tensions in providing empathy—Dialectic tensions refer to the contradictory impulses of the nurse–patient relationship. Nurses in this study referred to two types of dialectic tensions. Firstly, the tension between knowing and not knowing about the illness experience was noted as a challenge to providing empathy. Although nurses' professional experience gave them extensive knowledge of what patients experience while in the hospital, without a direct personal experience to draw from, many nurses felt inadequate to comment or offer a valid perspective on a patient's difficulties. As one of the nurses noted,

> "A challenge to empathizing with my patients would be my own personal lack of experience with being an in-patient. I can only imagine what the loss of control and frustration feels like, but don't have a personal frame of reference."

Secondly, balance between attachment and detachment was noted as a challenge to providing empathy, when the nurse felt caught between one's own emotions of feeling attachment to the patients and their families and the need to practice a degree of detachment from their patients and families. For instance, one of the nurses shared,

> "I think the biggest challenge is keeping a safe distance and not becoming too involved with certain issues, so that you can be supportive without becoming sad or upset yourself."

2. Burden of carrying bad news—In a hospital environment, nurses are typically privy to information about the patient's medical status. Holding information that has not yet been disclosed to the patient is described as a significant challenge to empathic communication. In this study, nurses discussed three aspects of the stress and burden they

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feel when they have more information than the patient and/or family members. Firstly, nurses felt uncomfortable in having difficult conversations when the patient and family bring up difficult topics much in advance, leaving the nurse in a situation where he/she felt inadequately prepared to answer questions. For instance, one nurse noted,

> "… bringing up end of life topics before patient is actively dying."

Secondly, nurses discussed the challenges in communicating information when the patient and family have not been accurately apprised of the patient's disease status, prognosis, or change in treatment. Nurses elaborated upon the stress they feel when they have an ongoing relationship with the patient, but are unable to disclose the accurate medical information they have because the oncologist has not yet revealed the information. For instance, one nurse described,

> "… differences in what I know/expect for a patient and how much/honest a doctor has been with the family & patient."

Thirdly, nurses described the discomfort and lack of communication skill in communicating empathically during transitions to palliative care when providing only emotional comfort could feel insufficient, such as "when there is nothing else the medical team can offer for care; " as well in initiating and carrying out EOL discussions, including discussions surrounding "advanced directives," "personal/last wishes," and "natural death."

3. Lack of skills for providing empathy—Communication of empathy requires skill in using the correct words and phrases to demonstrate an understanding of the patient's situation and reassuring the patient that their emotional response to a situation is valid and reasonable. Nurses described five different types of specific communication challenges that arise due to lack of skills in providing empathy. Firstly, nurses shared the lack of skills in knowing what the right response should be in certain situations. For instance,

> "I never know what to say … I know I just need to listen sometimes but find it hard to say the right thing to let them know they can vent or share concerns."

> "A challenge I feel is when they know they are dying and have just given up hope what to say to them."

Secondly, some nurses shared the lack of skills in choosing the appropriate words that communicate empathy, and not "sympathy," or "pity." They also described the fear of sounding superficial, or using clichéd language that feels insincere, such as

> "Knowing if what your saying is understood by patient. Knowing that in the end everything you say can't change the bad news. I feel like I'm just spewing clichés."

Thirdly, some nurses expressed the lack of skills in communicating empathy when the patient and/or their family is unresponsive or unwilling to listen to the nurse, such as,

> "Will they understand I am being empathetic? Am I conveying this to them? They don't verbalize this kind of thing."

A fourth theme dealt with the lack of skill in understanding unique needs of patients and caring for them at their unique level. A couple of nurses responded that it is hard yet

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extremely important to realize that as nurses, they have seen many patients with emotional distress or other issues. However, for the patients, it may be their first time going through hospitalization for cancer. Therefore, for nurses, giving every patient their unique attention and providing empathic communication may be hard at times, and the nurses want to be well-equipped to do so. Finally, a few of the nurses expressed that lack of medical knowledge made them uncomfortable in really understanding the issue at hand and providing empathic support.

4. Perceived institutional barriers in providing empathy—Another theme that arose in challenges with empathic communication was nurses' own perceptions of institutional barriers. In particular, two barriers were discussed. Firstly, lack of time to sit with the patients created a hindrance in providing empathic support. This was voiced by many nurses and stood out as one of the key obstacles. For instance,

> "Challenges in communicating empathetically with my patients include a lack of time, for example, if it is a busy night on the unit and time spent with patients is limited."

Secondly, a few of the nurses also discussed the differing expectations of them by both the medical team and the patients and families making it difficult for them to provide empathic support. One of the nurses discussed her inability to have empathic communication with patients because the priority of the medical team on her floor was always on treating the clinical symptoms. Therefore, she found it awkward to communicate with the patient when other members of the team do not value communication and prioritize clinical issues.

5. Challenging situations—Nurses described four types of challenging situations that made empathic communication difficult: angry patients/families, disrespectful patients/ families, when patients/families are unable to accept EOL and are very distressed, and families that are struggling with their own issues and are not open to having communication with the nurse. The following excerpts exemplify these communication challenges respectively,

> "When patients and families are stand-offish and aggressive at times."

> "… it can be more difficult to empathically communicate with a patient when they are verbally abusive and impatient."

> "… they are not emotionally ready to let go of dying family member."

> "Family members with conflicting views."

6. Perceived differences between nurse and patient—Nurses reported that perceived differences between themselves and the patients make communication of empathy challenging for them. Specifically, nurses mentioned age, personality, and cultural differences as providing a road-block for empathic communication to occur.

Challenges in discussing death, dying and end-of-life goals of care

Five challenges in discussing death, dying and EOL goals of care were discussed: 1) dialectic tensions in EOL discussions; 2) challenges in discussing specific topics related to

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EOL; 3) lack of skills for empathic communication during EOL care; 4) patient/family characteristics; and 5) perceived institutional barriers in EOL care. Table 2 summarizes themes and sub-themes for challenges in discussing death, dying and EOL goals of care, and provides additional supporting quotes.

1. Dialectic tensions in end-of-life discussions—As described previously, dialectic tensions refer to the contradictory impulses of the nurse—patient relationship. Nurses responding to the questions about EOL challenges referred to two types of dialectic tensions: balance between attachment versus detachment and balance between telling the family versus withholding information. Firstly, balance versus attachment and detachment, where some of the nurses noted that they develop relationships with their patients and often get very emotional during conversations about end-of-life. These conversations trigger their own fears of dying or lead to counter-transference, when the nurse gets very caught up with the patients' fears, worries, sadness, and other emotions. For instance, this quote from a nurse exemplifies the dialectic tension:

> "Another difficult aspect is when you love your patient, as we get to know some of our patients we become almost like friends but only meet up in the hospital and I remember having a conversation about death with one of my patients at the end of my shift and we were just both blood shot in tears (eyes were blood shot). It is really hard and as I go on I am scared of becoming hardened or too close."

The next dialectic tension focused on finding an optimum balance between telling the family versus withholding information because the physician has not revealed the information to the patient or the family. A few of the nurses described scenarios when the physician's personal discomfort in having EOL conversations prevented them from carrying out these discussions with patients and families. This reluctance from the physicians also prevented the nurses from initiating EOL conversations, even in situations where the prognosis seemed bleak necessitating the need for the physician to initiate EOL conversations. For instance,

> "The practitioner's own unease and avoidance of talking about the potential or the inevitable prospect of death."

2. Challenges in discussing specific end-of-life topics—EOL conversations require skill in using the correct words and phrases to describe the "transition to palliative care," the concepts of "natural death," "comfort care," and "EOL goals." Nurses described four different types of specific communication challenges that arise due to lack of skills in discussing specific topics related to EOL. Firstly, nurses shared having a lack of skills in communicating the reasons behind transitioning to palliative care/comfort care, and answering patient and family emotions and questions about the transition phase. For instance,

> (Challenges in …) "explaining to the family that it is about keeping the patient comfortable. Explaining why we are stopping lots of meds."

The second theme focused around the challenge of assessing patient/family expectations and readiness to have EOL conversations, and initiating the conversations. For instance, one

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nurse noted the challenge of checking-in with the patient to see if he/she was aware of the poor prognosis, and one nurse discussed the challenge in starting an EOL conversation,

> "Getting to know the patients expectations – are they aware of the poor prognosis?"

> "Where to even begin. Can't assume that they don't ever want to talk about death. Just getting the conversation started and knowing when the right time is for the patient."

Thirdly, particular topics related to the concept of "natural death," as well as EOL goals, imminent death (approaching death), and timing of death were described as a challenge by some of the nurses. A few of the nurses described feeling awkward when the patient or the family members ask very pointed questions about their death, particularly "when?" and "how?" Nurses revealed that that these conversations were very challenging and the concepts of "body shutting down," and "natural process of dying," were difficult to explain. For instance,

> "It's hard to explain to family members when a patient is dying that this is natural or how the body works at the end of life …"

Finally, a couple of the nurses reported feeling uncomfortable in discussing topics related to grief and bereavement, such as:

> (Challenges in …) "What love ones can do after the loss to help them cope."

3. Lack of skills for providing empathy during end-of-life care—Nurses described three challenges in providing empathy in EOL scenarios: not knowing what to say, addressing fear and other emotions, and providing empathy appropriately. Firstly, nurses described experiencing a total loss of words in emergent situations (such as, "not knowing what to say," or "choice of words …") when patients and family members want to know the current state and prognosis. Secondly, challenges in addressing patient emotions, such as fears about death, anger, frustrations, and disappointments make it difficult for them to communicate effectively. Anticipating patients' emotions that arise when the doctor provides some news, and in managing patient emotions at EOL were also noted by some of the nurses as challenging. One nurse noted that the "look on their face" makes it very hard for her to provide empathy to patients. Another nurse shared,

> "The most difficult aspect is how they are going to receive the message and react, because everyone sees death differently."

Thirdly, the challenges in expressing appropriate levels of empathy, so as to not appear as sermonizing or pitying was described as challenging by some of the nurses. For instance,

> "How do I talk matter-of-factly while still expressing sympathy? Should I express sympathy or will that seem like pity?"

4. Patient/family characteristics—Patient/family characteristics refer to specific aspects of patients and families that make communication challenging for the nurses. Four types of patient/family characteristics were enumerated, and included: pediatric patient settings, young patients with small children, families not ready to let go, and cultural beliefs

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of the patient. Firstly, nurses noted the challenges in communicating effectively within a pediatric patient setting. The next two excerpts highlight the challenges,

> "Discussing them with families of children dying, and children themselves."

> "Discussing it with a young patient, or with their parents."

Secondly, owing to the age and vulnerability, some nurses noted the challenges in communicating with a young family, where the patient has a young partner or young children. Thirdly, quite a few of the nurses discussed the challenges of communication when the patient/family is not willing to let go, or has not yet accepted the reality of imminent death. For instance, one nurse described the challenges in communicating when the family seemed to be in denial, and not willing to let go so early,

> "It's also very difficult to discuss dying with patients who were completely unprepared or did not think they'd be facing death so soon (or pts/families who are in denial)."

Finally, a couple of nurses noted that the difference in cultural beliefs and social values (without providing any specific examples) of the patient and themselves made communication challenging.

5. Perceived institutional barriers in end-of-life care—A last theme that arose in challenges with EOL communication was nurses' own perceptions of institutional barrier, and they described two types of institutional barriers. Firstly, tangible barriers such as perceived lack of time or lack of space in the hospital to have private conversations about EOL made communication challenging. Secondly, some nurses discussed the challenge in communicating when they could not make autonomous decisions about having certain kinds of conversations with patient/family because they did not have the consent from the medical team, such as,

> "The feeling that the consent of the medical team has not been granted to nursing staff to discuss these issues."

Discussion

Overall summary of findings

This paper provides a qualitative account of in-patient oncology nurses' challenges in communicating empathically with patients, and discussing death, dying and EOL goals of care. Although prior research has identified challenges and obstacles faced by oncology nurses in communicating with patients and families (see Tay et al., 2011 for systematic review findings), most of the work has been quantitative focusing on nurses' responses to pre-designed questionnaire items. The present study is qualitative in nature and presents a more in-depth account of specific communication challenges faced by oncology nurses. This study provides direct implications for a communication skills training to address the specific challenges enumerated by the nurse participants. As well, this study adds to the pool of the few other qualitative studies (e.g., Turner et al., 2007) that not only describe the specific communication challenges faced by oncology nurses, but also provides direct implications for tailoring communication skills training for maximizing benefit for the learners.

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Addressing communication challenges in providing empathy

Overall, the results revealed six themes that best describe the challenges in communicating empathically with patients. Whereas these findings corroborate prior research regarding important challenges and obstacles for oncology nurses in communicating empathically with patients and their families (e.g., Morgan et al., 2010; Sivesind et al., 2003; Turner et al., 2007), the present study also reveals some important distinct communication needs of inpatient oncology nurses. The themes that emerged from the qualitative data analysis suggest that nurses need training in providing empathy, particularly in these areas: (a) identify and acknowledge their own emotions when caring for patients with cancer; (b) learn how to assess the communication needs of the patient and family members; (c) participate in communication skills training to learn skills for communicating empathy (i.e., skills such as encourage expression of feelings, acknowledge, validate, and normalize) in order to address the problem of "not knowing what to say; " and (d) practice use of communication skills in difficult and challenging interactions, i.e., within the context of EOL conversations, with angry, frustrated, and disrespectful families, and when the nurse is aware of the prognosis but the information has not yet been communicated to the patient/family. Developing a communication skills training programme that focuses on addressing the aforementioned issues will not only address relevant communication challenges but also highlight the commitment of the institution to encourage and support communication between nurses and patients, therefore, focusing on patient-centered care.

Addressing communication challenges in end-of-life care

The results for nurses' self-reported challenges in discussing death, dying and EOL goals of care revealed five themes. These results support prior work that highlights the need for training to support EOL conversations between nurses and patients/families (e.g., Beckstrand et al., 2012; Gagnon and Duggleby 2014; Sivesind et al., 2003). The present study highlights specific needs to develop communication skills training for oncology nurses to: (a) help nurses learn effective communication about discussing transitions to palliative care; (b) explaining the concepts of natural death and addressing patient and family questions regarding the timing of death, and (c) providing empathic responses to worried, frustrated, scared, and sad patients and families.

Thematic similarities in empathic communication and end-of-life care challenges

A number of similarities existed in nurse-reported themes related to challenges in communicating empathically with patients and discussing death, dying, and EOL goals of care. Firstly, it was clear from the responses that nurses often struggled with their own emotions while providing for the patient in a caring, comforting, and empathic manner. Teaching nurses to use reflection, self-awareness, and mindfulness-based stress reduction techniques to regulate their stress more effectively could be crucial to reducing nurse emotional exhaustion and burnout (Traeger et al., 2013). Secondly, nurses highlighted the need to learn optimal ways of communicating empathy because they often felt at a "loss for words," "not knowing what to say," or "how to deliver my thoughts." Learning how to communicate in an empathic manner will not only help nurses express themselves, but also give them confidence when they attempt to address patient fears or other emotional issues,

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and encourage patients' expressions of feelings if patients' emotional cues are acknowledged and responded to by the nurses (Sivesind et al., 2003). Finally, institutional support is key to motivating nurses to have in-depth communication with their patients. Perceptions such as lack of time, lack of support from the medical team, and limited utility and autonomy to have conversations with patients may inhibit supportive communication by the nurses. Institutional communication skills training programmes can help communicate the commitment of the institution and nursing leadership to support nurse-patient communication, and diminish negative perceptions regarding institutional barriers to supportive communication.

Limitations

Several limitations are worth noting. This study was carried out at one cancer center in the North-East United States, and results may not be generalizable to other cancer hospital settings. However, the qualitative aspect of the study encouraged various concerns and challenges to surface and present communication needs of the nurses. The online survey may have inhibited some nurses from responding in a more elaborate manner, particularly to describe examples of scenarios where communication obstacle prevented quality patient care; therefore suggesting a need for in-depth qualitative interviews. However, it is also important to remember that this study was conducted to help refine a curriculum on empathic responding and communicating about death, dying, and EOL goals of care. The challenges enumerated by the nurses in this study will be used to derive exemplars and role play scenarios for the communication skills training for inpatient oncology nurses.

Conclusion

In conclusion, this study provides an in-depth description of challenges experienced by inpatient oncology nurses and provides implications for training programmes to tailor content to challenges faced by nurses at a given institution. The challenges enumerated by nurses also corroborate findings from other studies; therefore, describe key barriers to supportive nurse-patient communication. Prior research highlights that oncology nurses have limited opportunities to receive communication training (Krimshtein et al., 2011) and report a greater need for more education on communication (Helft et al., 2011). Developing, delivering, and evaluating communication skills training programme for oncology nurses is a much needed requirement of modern day medicine and a step towards helping nurses provide patient-centered and supportive care to patients and their families.

Acknowledgments

This work was supported by the following sources of support: The Geri and ME Fund, funds from Memorial Sloan Kettering Nursing Education, The Fridolin Charitable Trust, and a grant from the National Cancer Institute (T32-CA009461). We would also like to thank the MSKCC nurse leaders for their support in recruiting for and helping facilitate inpatient nurse training.

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Table 1

Nurses' pre-training responses: Challenges in communication empathically with patients.

Themes and sub-themes (No. of nurses)	Supporting quotes (select few)
Dialectic tensions in providing empathy	
Balance between knowing versus not knowing (8)	- "I think it is hard to imagine exactly what my patients are going through especially during a cancer diagnosis." - "I have not been in their position, so at times I feel that they look at me like I don't actually know what they are going through." - "A challenge to empathizing with my patients would be my own personal lack of experience with being an in-patient. I can only imagine what the loss of control and frustration feels like, but don't have a personal frame of reference."
Balance between attachment versus detachment (9)	- "I think sometimes we are so attached to our patients, that we feel that if we are too empathetic in our communications, we will become too emotional, so we try to detach." - "I think the biggest challenge is keeping a safe distance and not becoming too involved with certain issues, so that you can be supportive without becoming sad or upset yourself." - "I think my challenges with communicating empathically with my patients are that when I tend to be empathetic, I have a difficult time separating myself from work when I leave the hospital and become upset bothered by issues have dealt with during my shit at home."
Burden of carrying bad news	
Having pre-emptive/early discussions (2)	- "… bringing up end of life topics before patient is actively dying." - "Also, it is difficult sometimes bringing it up initially to the family."
Being aware of "bad news" before the family is told (4)	- "Many times nurses are aware of a patients test results or poor prognosis well before the patient. Measuring words and tone before the doctor "breaks the news" is stressful especially with long term pts." - "… pt not informed re his/her own medical status, misguided by medical team." - "… differences in what I know/expect for a patient and how much/honest a doctor has been with the family & patient."
Discussing transitioning to palliative care and/or EOL discussions (5)	- "The discussion of end-of-life … advance directives." - "Their personal wishes. What it will look like when they die." - "The discussion of … comfort care." - "When there is nothing else the medical team can offer for care."
Lack of skills for providing empathy	
Not knowing what to say (11)	- "Not knowing what is the best thing to say and how they will respond." - "I never know what to say … I know I just need to listen sometimes but find it hard to say the right thing to let them know they can vent or share (sic) concerns." - "… how to deliver my thoughts." - "A challenge I feel is when they know they are dying and have just given up hope what to say to them." - "It is not always easy making them feel better or comforted because they might feel very hopeless."
Approaching empathy-rejecting patient/ family (4)	- "Will they understand I am being empathetic? Am I conveying this to them. They don't verbalize this kind of thing."

Themes and sub-themes (No. of nurses)	Supporting quotes (select few)
	- "Also many patients do not welcome the empathy." - "One challenge to communication empathically is when a patient and/or their family is unwilling to listen to what you have to say."
Using the right words (10)	- "Making sure message is received as empathy not understanding." - "… listening and saying the correct thing, because every situation is different." - "Expressing that I understand." - "Knowing if what your saying is understood by patient. Knowing that in the end everything you say can't change the bad news. I feel like I'm just spewing clichés." - "Allowing patients to accept that I understand their concerns without feeling like I'm "commiserating" (sic) with them rather than understanding."
Assessing individual needs of the patient (2)	- "It is a challenge to assess the specific needs of each individual patient and their families, so that you are able to best provide appropriate emotional support. Also, it is a challenge to remember that each patient's experience is unique, and while they may be going through a process that you as the nurse have experienced many times over, for the patient it is a new, and often overwhelming experience."
Lack of specific medical knowledge or experience (3)	- "Not being sure of their diagnosis and or the prognosis." - "It is challenging having to discuss treatment options and their adverse effects."
Perceived institutional barriers in providing empathy	
Not enough time (10)	- "Challenges in communicating empathetically with my patients include a lack of time, for example, if it is a busy night on the unit and time spent with patients is limited." - "I see time constraints as a challenge. With the busy day-to-day tasks of a RN, there are many interruptions and distractions that can sometimes limit an empathetic long conversation with the patient and family members …" - "Having enough time to give to them to hear their thoughts and explore there feelings without having to rush off and see other patients."
Differing expectations (4)	- "In the UCC, patients are often frustrated due to long wait times for MRI, inpatient beds, results, etc. Most times, there is little to tell the patient and all they can do is wait. This is usually upsetting to patients." - "……where priority is always in the clinical picture."
Challenging situations	
Angry patients/families (3)	- "Sometimes patients are angry because of the circumstances and news they are presented with so they can be aggressive or mean to the people who are taking care of them and more often to their family as well." - "When patients and families are stand-offish and aggressive at times."
Disrespectful patients/families (3)	- "it can be more difficult to empathically communicate with a patient when they are verbally abusive and impatient." - "The biggest challenges that have come with communicating with patients are when they are particularly disrespectful or inappropriate. Mostly it is the times that patients are feeling their most frustrated and the closest "thing" for them to take their frustrations out on is their nurse."
Not ready to accept dying (3)	- "Some challenges can include family's that are not ready/willing to accept their loved one is dying." - "They are not emotionally ready to let go of dying family member."
Conflicting families (3)	- "Family members with conflicting views."

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Themes and sub-themes (No. of nurses)	Supporting quotes (select few)
	- “I do try my hardest, but then other times what’ll also happen is if I don’t feel that strong of a connection with a patient my empathy won’t be as genuine esp if it’s a patient being particularly difficult.”
Perceived differences between nurse and patient	
Age and personality difference (2)	- Age difference” - “Personality dissimilarity”
Cultural difference (2)	- “Understanding how different cultures respond to and deal with the dying process is difficult, because at MSKCC we see so patients from so many different backgrounds.” - “Sometimes cultural differences can be challenging when communicating during difficult patient situations.”

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Table 2

Nurses' pre-training responses: Challenges in discussing death, dying and end-of-life goals of care.

Themes and sub-themes (No. of nurses)	Supporting quotes (select few)
Dialectic tensions in EOL discussions	
Balance between attachment versus detachment (8)	- "My father just recently passed away. The most difficult part for me is to remain professional and not get too emotional when talking about death." - "The avoidance of becoming over-emotional. Balancing tears and sympathy with discretion and professionalism." - "I find, I myself get very emotional when discussing these situations with patients and don't want to make the situation worse if I get upset in the middle of the conversation." - "Another difficult aspect is when you love your patient, as we get to know some of our patients we become almost like friends but only meet up in the hospital and I remember having a conversation about death with one of my patents at the end of my shift and we were just both blood shot in tears. It is really hard and as I go on I am scared of becoming hardened or too close."
Balance between telling the family versus withholding information (3)	- "The practitioner's own unease and avoidance of talking about the potential or the inevitable prospect of death." - "… many drs reluctance to speak about end of life especially if the pt is on a trial."
Challenges in discussing specific EOL topics	
Transitioning to palliative care/comfort care (3)	- "Explaining to the family that it is about keeping the patient comfortable. Explaining why we are stopping lots of meds." - "In the perspective of helping them realize the reality of the situation and how comfort care is upmost of a goal." - "Helping the parents or caregivers accept that there are no more treatment option."
Assessing patient/family readiness to have EOL conversations, and initiating the conversations (5)	- "I think that the most difficult aspect of discussing end of life goals of care is assessing the patient and the family's readiness to learn …" - "Getting to know the patients expectations - are they aware of the poor prognosis?" - "Where to even begin. Can't assume that they don't ever want to talk about death. Just getting the conversation started and knowing when the right time is for the patient." - "I think the most difficult part is initially bringing up the conversation. I think once the conversation has begun, it is easier to talk."
The concept of "natural death," imminent death, and timing of death (16)	- "It's hard to explain to family members when a patient is dying that this is natural or how the body works at the end of life. It's also just really hard to take care of people who were once healthy and you took care of them then and are now at the end of their life." - "For me the most difficult aspect is discussing the natural process of dying." - "The most difficult aspect is telling patients that their increasing uncomfortable symptoms are the result of their bodies shutting down." - "Trying to help patients comprehend and understand end of life goal and death." - "Telling the patient and family that death is coming." - "Discussing the reality of the situation, that death is approaching." - "… their child will die so they should think about the issues surrounding planning for that."

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Themes and sub-themes (No. of nurses)	Supporting quotes (select few)
	- "I find the most difficult aspect of discussing death and dying with family members at the bedside is the timing. Family typically is looking for the nurse to tell them how long the patient with remain actively dying and the nurse cannot provide an answer to this." - "Many times patients family members ask exactly when their family member will die or if we "think" it will happen.."
Grief and bereavement (2)	- "What love ones can do after the loss to help them cope."
Lack of skills for providing empathy during EOL care	
Not knowing what to say (5)	- "Choice of words with patient & family in mind." - "Not knowing what to say."
Addressing fear and other emotions (12)	- "Fear of upsetting patient/family …" - "The fear aspect patients and family have …" - "Fear of dying. Fear of what dying means." - "… the emotional reaction they may have …" - "Managing the emotions that may arise" - "The most difficult aspect is how they are going to receive the message and react, because everyone sees death differently."
Expressing empathy (6)	- "Expressing yourself empathetically. Or saying something that's helpful." - "Relaying information in an honest matter without coming across as un empathetic …" - "How do I talk matter-of-factly while still expressing sympathy? Should I express sympathy or will that seem like pity?"
Patient/Family characteristics	
Pediatric patient settings (4)	- "The fact that I work in pediatrics and my patients are children makes this topic difficult to talk about. Usually we are working with the parents rather than the patients themselves." - "Discussing them with families of children dying, and children themselves." - "Discussing it with a young patient, or with their parents."
Young patients with small children (2)	- "The most difficult aspect of discussing death is when it involves young person …" - "Dealing with really young patients who have children, young spouses …"
Families not ready to let go (11)	- "It's also very difficult to discuss dying with patients who were completely unprepared or did not think they'd be facing death so soon (or pts/families who are in denial)." - "When the family is not ready to let go." - "When families and sometimes the patient have not come to terms with the situation." - "Some families and patients are not willing to listen to a discussion about death and dying. Getting through the denial is the hardest aspect."
Cultural and belief differences (2)	- "Culture." - "The family and patients' beliefs."
Perceived institutional barriers in EOL care	

Themes and sub-themes (No. of nurses)	Supporting quotes (select few)
Tangible reasons (2)	- “Lack of time to effectively discuss the issue.’ - “Lack of privacy …”
Loss of autonomy to discuss EOL issues without consent of the medical team (3)	- “The feeling that the consent of the medical team has not been granted to nursing staff to discuss these issues.” - “Perceived loss of autonomy in this aspect of nursing care.”

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