

RESEARCH ARTICLE

Editorial Process: Submission:12/11/2020 Acceptance:03/04/2022

Nurses' Perceptions of Prognosis-Related Communication

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Abstract

Introduction: Effective communication is an important aspect in providing health care. Communications optimize the patient-caregiver relationship and improve patient care and family and caregiver welfare. The main objective of this study was to explore nurses' experience of prognosis-related communication (PRC). **Methods:** Phenomenological research design was used to do this study. A total of 248 members of the local oncology nursing association were invited to complete this online survey from January 2016 to March 2016. Then, focus groups were held to discuss and improve themes derived from the analysis of online written responses. Five focus groups were performed, each consisting of 6 to 8 participants. No new data were generated by the fifth focus group and data saturation was achieved. NVivo 11 was used to manage data and facilitate the development of themes. **Results:** The participants were almost female, with a mean nursing experience of 13 years and almost 8 years of working experience in oncology ward. Three themes were extracted following data analysis, namely the importance of collaboration, impact of PRC, and communication of prognostic information. One hundred and fifty nurses (60%) reported that they received no formal training or education about PRC. **Conclusion:** There is a need to improve the knowledge and attitude of physician toward engaging nurses in the process of PRC.

Keywords: Perceptions in communication- communication skills- prognosis-related communication

Asian Pac J Cancer Prev, 23 (3), 775-780

Introduction

Effective communication is an important aspect of quality in providing health care. High quality communications optimize the patient-physician relationship and improve patient care, family, and physician's welfare. In the context of a serious illness, communication about values are very important to ensure that patient care is in accordance with the patients and families' wishes (Sanders et al., 2017). Furthermore, an appropriate treatment has been associated with improved quality of life and dying (Curtis et al., 2018).

Health care provider has the responsibility for educating cancer patients and their parents on the cancer diagnosis and treatment. One of the most important conversations for oncologists and patients with cancer is prognostic disclosure. Discussion about prognosis is very important in helping older people with treatment-related decisions and overcoming their disease (Nyborn et al., 2016; Kästel et al., 2011; Mack et al., 2006). Disclosure of patient disease progress and prognosis is considered as one of the responsibilities of doctors, however, nurses are also involved in such discussions. Parents of critically ill children and cancer patients recourse to nurses to improve their understanding of the prognosis and to seek support and guidance (Madrigal et al., 2016; Sisk et al., 2017).

Nurses are willing to become active members in the prognostic discussion with oncology patients, but little is recognized about nurses' viewpoint and experience with the prognosis-related conversation. The exact role and responsibilities of nurses during prognosis-related conversation is not well described. Previous research showed that nurses generally felt uncomfortable to respond questions about life expectancy or diseases prognosis, while many of them preferred to play a supporting role in the prognosis-related communication (PRC) (Helft et al., 2011). Provision of nursing care to patients with life-limiting illness highlights several different roles in the process of prognostic disclosure, including educators, care coordinators, supporters, facilitators, and advocates (Newman, 2016). Many studies revealed that nurses were not included in a discussion related to prognosis (Anderson et al., 2016). In addition, several reports documented the difficulties of having communications (Citak et al., 2013) in palliative and end-of-life care (Hendricks-Ferguson et al., 2015; Montgomery et al., 2017). They found the period of crisis, such as diagnosis or relapse, to be quite miserable when they needed to respond to patient and family questions or to support them during this challenging time. However, most of beginner nurses (less than a year of experience in oncology ward) experienced tension and uncertainty about their role when talking about

palliative and end-of-life care with the patient and family (Hendricks-Ferguson et al., 2015). Thus, further research is needed to better understand the nurses' experience of the prognosis-related communication.

The aims of this research were to find out the nurses' perception and experience of PRC, the aspects affecting their perception and practice, and the perceived effect of PRC and collaboration with physicians on nurses' perception of service quality and ethical distress.

Materials and Methods

A phenomenological research design was used to do this study (Albright et al., 2013). To increase the depth and breadth of understanding of perception and experience of oncology nurses, a qualitative research method was used, followed by focus group technique. This study was approved by the institutional review board of the institution (#ext15223).

Participants

The participants were selected from the membership roster of a local nursing association in Jordan with 2,500 members. All nurses received a notification from Facebook inviting them to participate in the study. The survey included an opening screen, which outlined the components of informed consent. If the respondents were willing to participate, they clicked on the "I Agree" button, and then obtained access to the survey. At the end of the survey, participants were asked to participate in the focus group. Nurses from 5 different institutions and different regions in Jordan were invited to participate in the focus group discussions.

Data Collection

Nurses were invited to complete an online survey included instruments of research and demographic questionnaire. Research instruments measured different variables. As part of the survey, nurses were required to answer three open questions on their experience with prognosis related communication (PRC) in a collaborative relationship with doctors (Question 1), moral distress (Question 2), and quality of care (Question 3) (see Table 1). The survey was open from January 2016 to March 2016.

After completion of this stage, focus groups were held. The purpose of the focus group was to discuss and improve the initial theme derived from the analysis of previous stage. Five focus groups were performed, each consisting of 6 to 8 participants. All of the participants had nursing experience. No new data were generated following the fifth session and data saturation was achieved.

The investigator led the focus groups using semi-structured interviews. The interviews consisted of open-ended questions (Table 2). Audio recording and field notes were used during data collection procedure.

Within each focus group, researcher used instructions for requesting clarification, such as, "What that means?" or "what do you think?" (Karnieli-Miller et al., 2008; Rothwell et al., 2015). In this study, nurses provided first-hand experience on such of these topic.

Data Analysis

Responses to online open-ended questions were transcribed verbatim using NVivo 11, which is used to manage data and facilitate the development of themes. An interpretive-descriptive research method was used to analyze qualitative data (Thorne, 2016).

Data analysis was done using the steps outlined by Polit and Beck 2008. The responses to each of the three questions were analyzed separately. Initially, principal investigator reviewed the first 15 responses to Question 1 to get a sense of them by asking "What's going on here?" and "What did you learn about this?" An initial coding template then was developed. Next, data coding was applied to responses of all the questions asked in the survey. After that, the codes were compared to identify core concepts and themes describing the experience of the patients.

Later, the transcripts of the focus groups were reviewed by the principal investigator and then were exported into NVivo 11 for analysis.

Another researcher, who was involved in the collaborative process, repeated coding and discussion of the entire set of data and identified three themes and six sub-themes.

Various methods are used to ensure rigidity and reduce bias. Validity refers to how well the researcher describes the theme and the results represent the actual phenomenon (Morse, 2015). In this study, validity was ensured through using thick rich description. Descriptions of the theme, sub-theme details, and patients' quote were included, so made the generalizability of the results possible.

Results

Participants

A total of 248 members of the local oncology nursing association in Jordan agreed to participate in the survey (approximately 10% response rate). Only Jordanian nurses were included in this study. Nurses were almost female, with a mean nursing experience of 13 years, and almost 8 years of working experience in oncology ward (Table 3). Most nurses had Bachelor's degree (90%), followed by Master's degree (8%), and PhD in nursing (2%). Most of the nurses worked as a registered nurse (79%), followed by clinical nurse specialist (18%), and nurse coordinator (3%). Nurses were mainly full-time (100%). In terms of place of work, about 90% of the nurses worked in inpatient departments and 10% in outpatient departments.

With respect to rate of answering the open-ended questions, 201 nurses (81%) answered the first open-ended questions on the nurse-doctor collaboration, 230 (3%) completed the second open-ended questions on the impact of communications regarding prognosis, and 218 (88%) described the prognosis-related communication (Table 4).

Thirty nurses from five different institutions participated in the focus groups. Table 3 summarizes the demographic characteristics of these participants. The participants' average nursing experience was 9 years (ranging from 1 to 13 years) and their average nursing experience in the oncology ward was 5 years (ranging from 3 to 8 years).

Table 1. Open-Ended Survey Questions

"Question 1. Can you please tell me about what about your experience in related communications prognosis with physician?
Question 2. Give an example of a situation where you are having trouble because of the prognosis related communication with patient, and / or colleagues physician.
Question 3. How the process of prognosis related communication done to patients have a cancer?"

Table 2. Semi Structured Focus Group Questions

"1. Let's start by talking about some experiences You have been talking to patients and family about their diagnosis and prognosis.
2. What do you think is the role of nurses in this discussion?
3. Describe the collaboration that occurs between physician and nurse on your unit.
4. Explain the process about ensuring all members of the medical team are aware when this conversation happened or has happened and what the content of that speech.
5. What is the most stress about this conversation?"

One hundred and fifty of the nurses (60%) reported no formal training or education on PRC. All the five institutions had Joint Commission International Accreditation.

Three themes were identified following data analysis (Table 4). Each theme included a subtheme. Theme with subthemes are presented below with supporting quotations from the participants.

The Importance of Collaboration

The first theme was importance of collaboration, reflecting the significance of teamwork in prognostic discussion. This theme included two sub-themes, namely benefits associated with collaboration and the consequences of excluding nurses from PRC.

Benefits of Collaboration

Nurses believed that better outcomes could be achieved

when there was a collaboration between the physician and them regarding PRC. Nurses felt that participating in PRC developed the trust in their relationships with patients and their families. In this regard, one the participants said:

"As a nurse, and now as a clinical nurse specialist, I find it most useful when I understand what has been said by the physician. When I am involved, I will be able to answer the patient and family's questions."

Nurses Consequences' Exceptions

Nurses expressed challenges arose when they were not included in the official prognostic conversation between the physician and the patient and family members.

Nurses felt frustrated and depressed when they were left out of the official conversations between the physician and the patient and family members. They also believed that without this information they could not meet their role as educators, advocates, and supporters, and constantly

Table 3. Online Survey and Focus Group Attribute

	Online Survey N = 248		Focus Groups N = 30	
	M* (SD**)	N (%)	M* (SD**)	N (%)
Age (years)	31.7 (0.68)		30.8 (0.66)	
Years as an RN	13 (0.54)		9 (0.49)	
Years as oncology Nurse	8 (0.4)		5.3 (0.35)	
Gender	Female	195 (78)		19 (63)
	Male	53 (22)		11 (37)
Highest education level	Bachelor's degree	229 (90)		26 (88)
	Master's degree	21 (8)		2 (6)
	Doctoral degree	4 (2)		2 (6)
Primary position	Registered Nurse	201 (79)		18 (60)
	Clinical Nurse Specialist	43 (18)		10 (33)
	Nurse Coordinator	4 (3)		2 (7)
Practice setting, n (%)	Inpatient	229 (90)		28 (93)
	Outpatient	25 (10)		2 (7)
Formal training in prognosis related communication	Almost none	150 (60)		17 (57)
	A little bit	50 (20)		7 (23)
	Moderate amount	25 (11)		3 (10)
	Great deal	23 (9)		3 (10)

*M, Mean; **SD, Standard Deviation

Table 4. Open-Ended Survey Questions

	Online Survey N*** = 248 n (%)
The Importance of Collaboration	201 (81)
The Impact of Prognosis related communication	230 (93)
Communication of Prognostic Information	218 (88)

N***, Sample

felt they were catching a ride.

Nurses feared that they would say something contradicting what was said by the physicians, confusing the patient and family. Nurses believed that they could be regarded as incompetent and disinterested when they were not aware of prognostic information discussed with the patients and their family. Nurses feared that their lack of awareness could cause patients to lose their trust in them.

The Impact of Prognosis related communication

The second extracted theme was the impact of PRC, showing the perceived influence that the process of PRC had upon nursing practice as well as patient and family outcomes. This theme included two sub-themes, including patient and family misunderstanding and nurse distress.

Patient and Family Misunderstanding

Nurses believed that patients and their family had an inaccurate understanding of their conditions or prognoses, which they thought was sometimes due to lack of honest, full disclosure, or the presentation of conflicting or confusing information by the members of the health care team. Nurses provided examples where patients seemed to have misunderstandings regarding their conditions. For instance, a nurse said:

“The patient and his/her family thought that metastatic disease was a chronic disease like diabetes.”

Another nurse stated:

“I saw the patient and their family kept talking about how they were going to a restaurant once he was better and not requiring platelets so frequently. This was not going to happen and we all knew it but the physician never made the family aware.”

Nurses believed that lack of accurate understanding limited the patient and his/her family decision-making and prevented their realistic care planning.

Nurse Distress

The nurses described how PRC, at times, resulted in patient and / or parents' distress.

This suffering was difficult for nurses to observe and was distressing to them.. The devastation that ensued among patients and families when the team shared the news of a new cancer diagnosis or relapse was hard for nurses. One nurse said:

“A teenager who graduated from college, had scholarship, and played baseball in the college was given a poor prognosis”

Furthermore, nurse described how the parents could

not grasp the reality of this child's prognosis and tried to proceed as if the prognosis is better than it really is. Nurses reported that they believe that this resulted from procedures and tests were performed, which cause suffering to children.

Communication of Prognostic Information

Since physicians are primarily responsible for conveying prognostic information, nurses focused their discussion on the way they delivered prognosis-related information. Two subthemes, including perceptions of positive communication and issues regarding communication, formed this theme.

Perceptions of Positive Communication

Nurses listed several positive aspects of communication regarding prognosis. A gentler tone was described as allowing the patients and their family to come to terms of death smoothly. This tone along with language that embodied the transition of goals of care from cure to comfort and the provision of non-abandonment language were commended. Additional measures to ensure good communication and treatments included collaborating with other physicians and organizing conferences.

Issues Regarding Communication

Most nurses believed that the communication regarding prognosis of the disease was the responsibility of the physicians, and they were at times troubled by the way in which prognostic information conveyed to patients.

Nurses reported that on occasion physicians were not direct enough or realistic when providing parents with prognostic estimates especially when patients presented with diagnoses that portended poor prognoses.

Nurses felt inconvenience with such a sensitive conversation, especially when the disease-directed treatment was stopped. One nurse stated:

“I cannot inform the patient and his/her family that he/she is going to die. I have to use another word such as never give up”.

It is very difficult for patients and families to change their treatment from curative to palliative, because they may assume that the health care provider does not agree with decision of giving up.

Discussion

The nurses' perception and experience of the prognosis-related communication, the aspects affecting their perception and practice, and the perceived effect of PRC and collaboration with physicians on nurses' perception of service quality and ethical distress were investigated in this study. The nurses had a great appreciation of the need for team collaboration when delivering prognostic information. Nurses depend on their physician colleagues to lead the conversation. The nurses participated in this study believed that when they were not included in PRC from the beginning, they could not play their role adequately. Obstacles such as uncertainties, disconnect, discomfort, and perceived risk may disturb PRC (McLennon et al., 2013).

Similarly, our participants reported distress and disconnect as they believed that patients and their family needed accurate prognostic information, especially when they refused to accept or acknowledged the poor prognosis. The nurses said that when there were not involved in PRC, the patients considered them as a problem of the treatment and viewed them as an additional suffering due to investigations and procedures done on the patient. Nurses also felt that this suffering prevented family and their patient from deciding about enrollment in palliative care or planning a peaceful death. Limited nurses to protect their patients' rights and interests (Khowaja-Punjwani et al., 2017) and to provide them with complete and reliable treatment (McLennon, Uhrich, et al., 2013).

Diagnostic and prognostic information disclosure is an emotionally challenging process. Physicians generally bear the responsibility of sharing terrible news to patients and families. Bad news disclosure is a difficult task for oncologists (Bousquet et al., 2015).

Nurses must recognize and respect this responsibility, which is put on the physician. On the other hand, physicians should recognize the burden on nurses once such information have disclosed to the patient given that patients and families will start to share medical information with nurses to check the development of their patient's disease (Boyle et al., 2017).

The nurses in this study addressed the importance of their involvement in the conversation when diagnostic and prognostic information was disclosed. In addition, the nurses believed that true interprofessional collaboration was required regarding diagnostic disclosure and prognostic information to optimize and ensure quality patient care. Interprofessional collaboration has been described as the relationship between two or more health professionals working together to solve problems or provide services (Barr et al., 2008) or in this case, to tolerate the burden of the disclosure.

Interprofessional collaboration is characterized by common goals, decision-making, and responsibilities (Petri, 2010). Nurses have the opportunity to partner and collaborate more closely with their physicians in PRC, and they do not have to wait for an invitation. Nurses need to demonstrate to their physician colleague the value and benefits of collaborative partnerships as they play more prominent role in this process (D'Amour et al., 2005).

More active involvement in the process of PRC will require a paradigm shift. Nurses should be more proactive in preparing and engaging in conversations about diagnosis and prognosis. Physicians need to recognize and accept the compliment and the leadership role that nurses can apply, and health care organizations need to support and help nurses in developing novel approaches for communication and collaboration and then spreading the model in practice (Institute of Medicine, 2011). This shift will require further education and training of nurses, physicians, and other health care providers (Tang et al., 2018; Organization, 2010) and is considered as an important undergraduate nursing curriculum component (Nursing, 2008).

Educators and health administrators should critically evaluate the need for educational programs to

improve nurses' communication skills and develop new opportunities for nurses to receive additional training in PRC to ensure they are ready to be engaged in this process. Therefore, more funding is needed at local and national levels to ensure that nurses receive adequate communication education and training and to educate physicians about the role of nurses in PRC. Future studies are needed to discover the most effective methods to improve nurses' communication skills.

Limitations

Only 10% of survey respondents answered the open-ended questions, representing a small number of nurses from Jordan. Notably, no nurses from outside Jordan participated in either the online survey or focus groups. Cultural values and norms certainly play an important role in health care communication; therefore, the results of this study cannot be generalized as nurses' experiences with PRC. In addition, clarification of responses was not possible due to the nature of the survey.

In conclusion, the nurses participated in this study felt that their role in the PRC was limited and they were not involved in this process though, as health care providers, they were most closely in relation with the patient and family. Therefore, nurses should be encouraged and empowered to do so. Education at both undergraduate and professional levels must apply more time and resources in preparing nurses for communicating with patients, families, and other members of the health care team, ideally in an interprofessional environment.. In addition, physicians should be better educated about the integral role that nurses can play in this process. Critical conversations must occur among nursing and medical administrators in education and academia to support the enhanced role and leadership opportunities for the nurse in developing innovative communication models. Increased interprofessional collaboration and communication can enrich the patient and family experience to proceed along the trajectory of the disease.

Author Contribution Statement

The author confirms sole responsibility for the following: study conception and design, data collection, analysis and interpretation of results, and manuscript preparation

Acknowledgments

This publication was supported by the Deanship of Scientific Research at Prince Sattam bin Abdulaziz University, Alkharj, Saudi Arabia. I would like to thank the Deanship of Scientific Research at Prince Sattam Bin Abdulaziz University.

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