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Nurses' Perceptions of Diagnosis and Prognosis-Related Communication: An Integrative Review

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Abstract

Background: Disclosure of diagnostic and prognostic information has become the standard in the United States and increasingly around the world. Disclosure is generally identified as the responsibility of the physician. However, nurses are active participants in the process both intentionally and

inadvertently. If not included in initial discussions regarding diagnosis and prognosis, the nurse may find it challenging to openly support the patient and family.

Objective: The aim of this study is to synthesize published literature regarding nurses' perceptions and experiences with diagnosis and prognosis-related communication.

Methods: The Whittemore and Knafl method guided the integrative review process. Electronic databases including Cumulative Index to Nursing and Allied Health Literature, Health Sciences in ProQuest, PubMed, and Web of Science were used to review the literature from 2000 to 2015. Constant comparison methods were used to analyze the data and develop themes.

Results: Thirty articles met all of the inclusion criteria and were included in this review. Several themes emerged from the data, including the nurse's role in the process of diagnosis and prognosis-related communication, barriers and difficulties related to communication, and positive and negative outcomes.

Conclusions: Nurses play an integral role in the process of diagnostic and prognostic disclosure. Further exploration of both physician and patient perceptions of the nurse's role are needed. Interprofessional training regarding diagnosis and prognosis-related communication is essential to promote collaboration and better empower nurses in this process.

Implications for Practice: Nurses should aim to purposefully partner with physician colleagues to plan and participate in diagnostic and prognostic discussions. Nurses should identify opportunities to improve their knowledge, understanding, and comfort with challenging conversations.

In the 1950s and 1960s, physicians were often hesitant to discuss with patients diagnoses associated with poor prognoses.[1] Increasingly, patients are routinely informed of their diagnoses even when life-threatening[2] and are encouraged to be active participants in decision making related to their care.[3] An accurate understanding of one's prognosis is a critical aspect of participating in one's healthcare.[4] The definition of prognosis generally includes aspects of life expectancy, how the illness may progress, future symptoms, and effects on the patient's ability to function.[3] For patients with cancer and other life-threatening illnesses, disclosure of diagnosis and disclosure of prognosis are processes that may occur concurrently or sequentially. In either case, these disclosures initiate a cascade of decision making. How such information is conveyed is crucial as it impacts the patient's acknowledgement and acceptance of the diagnosis, ability to cope with illness, and capacity to make necessary treatment-related decisions.[2]

The initial disclosure of diagnostic and prognostic information is generally considered the responsibility of the physician.[5] Although critical, this initial discussion is just the starting point, as disclosure is a process that involves numerous conversations among patients, families, physicians, and other healthcare providers.[3,6-8] Such exchanges occur before, during, and after prognosis is initially discussed.[9] Patients are often in a state of shock when prognosis about a life-threatening condition is conveyed, and therefore, recall of the initial conversation may be limited. As patients and family members start to process the information presented, they often identify the nurse as a source of information.[10] A nurse may or may not have been present for the initial discussion. Lack of

participation in these discussions and clarity as to what was presented may put the nurse in a position of vulnerability as he/she attempts to be truthful with the patient about the diagnosis and prognosis but not convey information that is different from what was said by the physician.[11]

Nurses play an integral role in the care of patients. Nurses are responsible for direct patient care, patient and family satisfaction, care coordination, policy development, safety, and communication.[12] For patients with life-threatening illnesses, the nurse becomes even more essential as he/she helps to translate information provided by the physician and assists the patient and family to make sense of the illness, its treatment, and the required actions. If the nurse is not present for key discussions regarding the patient's diagnosis and prognosis, the nurse is in a position of disadvantage, not knowing how to assist the patient and family in moving forward with their journey. The aim of this integrative review, therefore, is to summarize and synthesize published research regarding nurses' perceptions of and experiences with diagnosis and prognosis-related communication.

Methods

The method of Whittemore and Knafl[13] was used to guide the integrative review process. The method includes 5 steps: problem identification, literature search, data evaluation, data analysis, and presentation. Constant comparison methods were used to identify themes that were evident across the papers.

Research studies were identified through electronic searches of the literature using the databases Cumulative Index to Nursing and Allied Health Literature, Health Sciences in ProQuest, PubMed, and Web of Science from 2000 until March 2015. For an article to be considered for review, the following inclusion criteria were established: English language, research report, published in peer-reviewed journal, and description of the nurse's perceptions or experiences with diagnosis and prognosis-related communication. As the review aimed to generate a broad understanding of nurses' perceptions and experiences with diagnosis and prognosis-related communication, articles were not limited to a specific diagnosis or condition. The following search terms were used in combinations: *nursing*, *communication*, *prognosis*, *truth disclosure*, and *prognostic disclosure*. The search method identified 4428 research articles (Figure). Titles and abstracts were reviewed to determine whether they were relevant, and duplicates were removed. Abstracts from conference proceedings and unpublished dissertations were also excluded. This screening of sources resulted in the identification of 79 records eligible for further review. Articles reviewing or describing error disclosure were excluded. Articles that described interventions related to skills training or end-of-life discussions were eliminated. Reports that focused on the ethics or ethical dilemmas inherent in truth-telling were eliminated unless they specifically included nurses' perceptions related to the process. Subsequently, 26 papers remained for detailed review. Reference lists of selected papers were also reviewed, yielding another 4 papers. Ultimately, 30 publications were identified as the source material for this integrative review (Table).

Findings

Both qualitative and quantitative studies were represented. Sixteen (53%) of the papers used qualitative methods, and 11 (37%) used quantitative methods. Three papers (10%) reported mixed methodologies. Sixteen (53%) of the studies used surveys for data collection. Most of the surveys (69%, n = 11) used closed answer or Likert-scale questions. Two (13%) included open-ended questions, and 3

(19%) used both open- and closed-answer questions. In addition to the evaluation of open-ended survey questions (n = 5), other qualitative studies used interview (n = 8; semi-structured, n = 7; unstructured, n = 1) or focus group (6%, n = 6) techniques. One study included a written exercise, which instructed nurses to write a narrative/clinical exemplar. One report included findings from both focus groups and interviews.

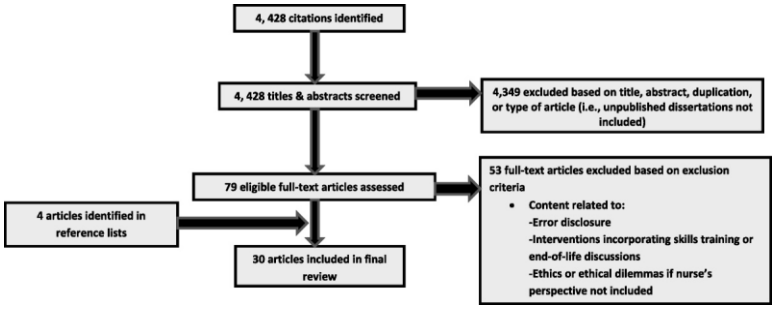

Figure: Flowchart for articles included in the review

The sample sizes ranged from 6 to 7360, with 50% (n = 15) of the studies having more than 100 participants. Most (60%, n = 18) of the papers focused solely on nurses' perceptions or experiences with disclosure of diagnostic or prognostic information. Six papers (20%) also included physician perspectives, and 3 (10%) included patients in addition to both physicians and nurses. One paper (6%) explored the perceptions of nurses and patients. Two papers examined the views of multiple members of the interprofessional team, that is, nurses, physicians, dieticians, physical therapy, and play therapists. The predominant patient population referenced was cancer patients (47%, n = 14) followed by the general population (17%, n = 5) and terminally ill patients (17%, n = 5). Three (10%) of the reports focused on patients with life-limiting illnesses. Single papers dealt with patients enrolling in palliative care, patients with heart failure, and patients with spinal cord injuries. Ten (33%) of the papers explored the process of ''breaking bad news.'' This concept of breaking bad news is used throughout the literature and has been defined by Buckman[14] as ''any news that drastically and negatively alters the patient's view of his or her future.''(p15) Nine papers (30%) focused on prognostic disclosure, and 8 papers (27%) investigated truth-telling related to diagnosis. Three articles (10%) discussed communication and communication difficulties. Sixteen different countries were represented in this review: 7 papers from the United States; 4 papers from the United Kingdom; 3 papers from Ireland; 2 papers each from China, Israel, and Turkey; and single papers each from 10 countries (Canada, Greece, Hong Kong, Iran, Japan, Mexico, Nigeria, Spain, Sweden, and Taiwan).

Data analysis techniques varied based on the study design. Survey data were generally reported as descriptive statistics, frequencies, and correlations. Several papers (13%, n = 4) included more advanced statistical techniques including logistical or multivariate regression. One paper used factor analysis. Content analysis was one of the most common approaches to qualitative data analysis (23%, n = 7). A phenomenological approach was followed in 3 (10%) studies. A grounded theory approach was cited in 2 (7%) papers. Two papers used constant comparative methods, and 2 used thematic analysis.

One qualitative study described using supra-analysis to perform secondary analysis of a data set, and 1 paper reported using Wolcott's framework[15] to analyze data.

Communication of Diagnostic and Prognostic Information

Similar to the views of physicians, most nurses believe that patients have a right to know both their diagnosis and prognosis.[16-21] Beliefs about the extent of disclosure were often determined by the nurse's country of origin. Sullivan et al[20] reported that 99% of nurses in the United States believe that patients have the right to be fully informed of their diagnosis and prognosis, and that physicians are obligated to do so. In China,[18,22] patients are often not told of their diagnoses, and rather family members are trusted with such information. Nurses are challenged both personally and professionally by this nondisclosure directly to the patient. Nurses reported believing that their patients had a right to know their diagnoses but did not think that they had the authority or confidence to provide such information against the wishes of the family or the orders of the physician. Similarly, nurses from Mexico[23] reported that the minority of their patients (4.5%) were given explicit information regarding their cancer diagnoses. In Greece and Iran, nurses believe that disclosure of such information is potentially harmful and may lead to distress and feelings of despair, disappointment, and isolation.[24,25] Global consensus regarding the disclosure of diagnostic and prognostic information is lacking, which reinforces the notion that nurses, physicians, and other healthcare providers need to be sensitive to the cultural preferences of patients and explore with them and their families their desired levels of disclosure.[18]

Table & Summary of Research Reports

Source/Country of Origin	Design	Sample	Key Findings
Adebayo et al (2013)/Nigeria	Cross-sectional, descriptive survey	113 healthcare providers (doctors and nurses) from 2 major government-owned healthcare facilities	Only 22% of respondents had formal training or education in breaking bad news (BBN). High perceived competence rating among respondents in response to scenarios requiring BBN. Those who had formal training had significantly higher perceived confidence ratings on all of the scenarios except for the diagnosis of sickle cell disease. Of the ~50% who reported recently witnessing BBN, only 13% indicated that it went well. Only 7% of respondents were aware of any guidelines for BBN that existed within their hospitals.
Angeles-Llerenas et al (2003)/Mexico	Cross-sectional, descriptive survey	741 nurses from 12 hospitals	Nurses reported rarely witnessing explicit communication in cancer patients.
Ben Natan et al (2009)/Israel	Cross-sectional, descriptive correlational survey	100 physicians and 200 nurses	Caregivers find it difficult to disclose terminal status information to all types of patients. Behavioral beliefs, subjective attitudes, and previous clinical experience with disclosure were the main factors influencing disclosure.
Citak, Toruner, & Gunes (2013)/Turkey	Focus groups	21 pediatric hematology/oncology nurses	Three main themes emerged: 1) Communication difficulties, 2) effects of communication difficulties, and 3) suggestions for communication difficulties. Nurses found communication with patients and families challenging, which left them feeling incompetent, exhausted, and avoidant of communication with children and their families. Nurses provided suggestions for addressing communication challenges including more nurses to help care for patients, rotating through different clinical areas to provide breaks, regular team meetings to debrief, and more training on difficult communication and how to cope with difficult or intensely emotional cases.

Demirsoy et al (2008)/Turkey	Cross-sectional, descriptive survey	166 hospital-based nurses	90% of nurses indicated that they believed that patients should be accurately informed regarding their diagnosis and prognosis.
		435 medical or surgical patients	Two-thirds of patients wanted to be correctly informed of their diagnosis as well as how the diagnosis would impact their lives. Patients described wanting family to be present during such discussions.
Dewar (2000)/Canada	Focus group interviews	22 nurses working on acute spinal cord injury unit	Nurses are placed in a position of being the bearers of bad news. To maintain the patients' hope and preserve their own integrity, nurses must develop strategies to address the patients' needs.
Dunniece and Slevin (2000)/Ireland	Semistructured interviews	6 nurses from a large teaching hospital with more than 18 months of experience	Seven core themes were established: (1) ''What if it was me?'' (2) divergent feelings, (3) being there, (4) becoming closer, (5) method of disclosure, (6) time as an influence, and (7) learning by reflection.
Georgaki et al (2002)/Greece	Cross-sectional, descriptive survey	148 staff nurses from oncologic hospitals and oncologic departments of general hospitals	Nurses believe that patients should be informed of their condition. Nurses find it difficult to engage in open conversations about the disease and the prospect of dying because of lack of training.
Griffiths et al (2015)/United Kingdom	Focus groups	40 district nurses	BBN about the transition to dying was often the role of the district nurse because they spent a lot of time with patients and families, knew them well, and would be caring for them at the end of life.
Helft et al (2011)/United States	Cross-sectional, descriptive survey	394 Oncology Nursing Society members	Uncertainty exists regarding the scope of oncology nurses' role in prognosis-related communication. Opportunities exist to improve prognosis-related communication through the inclusion of nurses in the process.
Hjelmfors et al (2014)/Sweden	Cross-sectional, descriptive survey	111 heart failure (HF) nurses, who worked in primary healthcare centers and hospitals	96% of HF nurses reported having discussed prognosis at some point. Nurses seemed to feel confident in their ability to discuss prognosis and end-of-life care. Nurses were often hesitant to have such discussions because they believe it is the physician's responsibility or other barriers present themselves. 92% of nurses indicated never having education about such discussions, and 91% reported a need for further training.

Huang et al (2014)/Taiwan	Cross-sectional, exploratory survey	68 oncology nurses, who worked in oncology units, hospice care units, and treatment day units	70.6% of nurses had performed truth-telling, although 77.9% believed that doctors should be the ones to reveal the truth. Nurses with more experience in oncology, nurses with more perceived truth-telling authorization, and nurses who reported less difficulty talking about do-not-resuscitate status with terminal patients were more likely to perform truth-telling to patients with terminal illness. Most nurses agreed with the importance of truth-telling as the basis of a treatment relationship and that concealing the truth would increase patient's anxiety. Many nurses stated that they follow families' requests for confidentiality.
Kendall (2006)/Hong Kong	Written exercise, including narrative/clinical exemplar of nurse-patient interactions in clinical practice	335 registered nurses	Nurses experienced considerable difficulties when caring for patients who were not informed of their diagnoses. Nurses reported having learned from these experiences and hoped they had found a resolve to act in the future.
Li et al (2008)/China	Cross-sectional, descriptive survey	199 oncology nurses	Oncology nurses differed in their attitudes towards truth-telling based on different stages of cancer. Nurses were less likely to support truth-telling in patients with terminal illnesses. Common reasons reported for withholding information included avoiding psychological distress and the maintenance of hope.
McLennon, Lasiter, et al (2013)/United States	One-on-one structured interviews	27 oncology nurses	Six themes were identified: (1) being in the middle, (2) assessing the situation, (3) barriers to prognosis communication, (4) nurse actions, (5) benefits of prognosis understanding, and (6) negative outcomes. Nurses often perceived readiness for communication regarding prognosis, but faced barriers to providing such information. Nurses acted collaboratively or independently to overcome barriers, which was met with both positive and negative consequences.
McLennon, Uhrich, et al	Cross-sectional, descriptive survey	137 Oncology Nursing Society members	Oncology nurses routinely experienced ethical dilemmas related to prognosis-related communication.

(2013)/United States			Healthcare providers would benefit from interdisciplinary education about prognosis-related communication.
Millar et al (2013)/Ireland	2-staged process of focus group interviews followed by semistructured interviews	25 participants (nurses, dieticians, specialist nurses, and medical staff) from the cancer center of a large teaching hospital	Custom and established practices within the organization dictated that the telling of bad news is the responsibility of the medical practitioner. Nurses and other healthcare professionals indicated that it was not their role to tell patients of a terminal diagnosis. Nurses were reluctant to engage in discussions about the irreversible trajectory of cachexia, and were guarded in their discussions. This limited their ability to provide appropriate information and support.
Miyashita et al (2006)/Japan	Cross-sectional, descriptive survey	2422 people from the general population, 1577 physicians, 3361 nurses	Most participants from the general population reported they wanted full disclosure of diagnosis and prognosis, even if incurable. Physicians and nurses reported more frequently providing family members [vs patient] with diagnostic and prognostic information. Highlighted the need for physicians to dialogue with patients regarding their preferences for disclosure.
Noble et al (2014)/United Kingdom	Secondary analysis of data obtained from previous focus groups	35 pediatric palliative care staff members (24 nurses, 3 doctors, 3 play specialists, 3 healthcare assistants, 1 teacher, and 1 physiotherapist), 24 adult renal palliative care staff members (14 nurses, 8 doctors, and 2 counselors)	Truth-telling was identified as a central concern for professionals. Three major themes emerged from both groups: (1) ‘‘hiding the truth,’’ (2) ‘‘practical consequences of not dealing with the truth,’’ and (3) ‘‘professionals’ response when unable to be truthful.’’
Pontin and Jordan (2011)/United Kingdom	Focus groups	16 hospital specialist palliative care team members (9 clinical nurse specialists and 7 doctors)	Two major themes were identified: (1) difficulties of prognostication and (2) benefits of prognostication. Nurses and healthcare assistants working on the wards were considered the most accurate prognosticators owing to the time they spent with the patient and their close involvement in essential care delivery.
Rassin et al (2006)/Israel	Cross-sectional, descriptive survey	51 patients with cancer, 51 nurses, 50 doctors from internal	Patient preferences for methods of disclosure were described. Patients indicated a desire to have other family members present when discussions occurred.

		medicine and surgical wards	
Reinke et al (2010)/United States	One-on-one semistructured interviews	22 nurses caring for patients with advanced chronic obstructive pulmonary disease or cancer	Nurses identified both independent and interdependent actions that support hope. Nurses emphasized dependence on physicians when providing and supporting patient information needs. Findings support development of interdisciplinary interventions targeting communication around end-of-life care.
Schmidt Rio-Valle et al (2009)/Spain	Semistructured interviews	21 doctors and 21 nurses who work with terminally ill patients and their families in hospitals and health centers	A conspiracy of silence exists. The patient does not ask questions, the health professional does not want to be interrogated, and family members don't talk about the disease and want health professionals to follow their example. Nurses reported feeling bad when communicating such information, believed it was the responsibility of the physician, and generally avoided discussions.
Schulman-Green et al (2005)/United States	Cross-sectional, exploratory survey	174 hospital-based nurses from 6 different hospitals, who work full-time in hospital practice areas where terminally ill patients routinely receive care	Five major obstacles to communication of prognosis and referral to hospice were identified, including (1) unwillingness of a patient or the patient's family to accept a prognosis and/or hospice care, (2) sudden death of the patient or a sudden change in patient's status that prevented communication, (3) belief of physicians' hesitance, (4) nurses' discomfort, and (5) nurses' desire to maintain hope among patients and patients' families.
Sullivan et al (2001)/United States	Cross-sectional, descriptive correlational survey	337 patients, 72 physicians, and 60 nurses from an acute care hospital	Patients reported wanting to know condition even if life-threatening. Physicians and nurses both underestimated the number of patients who wanted full disclosure. Nurses indicated an interest in more formal training in ethical discussions.
Tieying et al (2011)/China	Cross-sectional, descriptive survey	294 doctors and 340 nurses who worked in a premier hospital	Both doctors and nurses identified that most patients are not fully informed of their conditions and prognoses, although 68% indicated that patients had the priority to know the severity first (before family), and the real conditions should be told the patients themselves (50%). Nurses differed from physicians in that they were more apt to agree that patients hoped to learn their real conditions, but nurses reported less

			difficulty when caring for patients when they were prohibited by the family from sharing the truth about the patient's condition. Nurses were more neutral in regards to telling the patient the truth if he/she insisted.
Tobin (2012)/Ireland	Unstructured interviews	20 nurses who worked in adult acute medical or surgical settings	Nursing perspectives highlighted the importance of professional companionship and provided insights into the nurse-patient challenges that arise as a result of lack of information.
Valizadeh et al (2014)/Iran	Semistructured interviews	18 nurses from the main hematopoietic stem cell transplant center	Two main categories were identified: (1) not talking about disease and potentially negative outcomes and (2) not disclosing the sad truth. Nurses devised ways to not talk about the patient's condition or other upsetting information. Nurses would speak in very indirect ways and gradually present bad news. Nurses believed that hiding information from patients would minimize psychological distress.
Warnock et al (2010)/United Kingdom	Cross-sectional, descriptive survey	236 staff nurses from 59 different inpatient areas	Nurses described involvement in a variety of activities related to the breaking of bad news. Barriers to communication as well as difficult experiences were identified. Nurses reported a lack of formal training in BBN.
Wittenberg-Lyles et al (2013)/United States	Focus group	7 oncology clinical care supervisors and managers within a comprehensive cancer center	Nurse managers identified 2 key barriers: (1) lack of consistency from healthcare staff created communication difficulties for patients and family members and (2) expectations and assumptions that physicians hold regarding nurses. Managers identified that nurses are often caught in the middle between the patient, family, and physician, and they struggle to determine the most appropriate communication strategies.

Both positive and negative consequences can occur as a result of disclosure.Warnock et al,[9] in a paper from the United Kingdom, described several potential advantages of disclosure including increased patient participation and the opportunity for patients to prepare for the future. Additional benefits of prognostication include informed decision making and prioritizing.[26] Clear discussions regarding prognosis can improve access to funding and services and ensure that patient preferences are incorporated into the patient's plan of care.[26,27] Finally, the process of disclosure can serve to strengthen the relationship between the patient and the nurse, which can provide mutual satisfaction.[9]

Conversely, discussions regarding diagnosis and prognosis can have a negative impact on nurse-patient relationships.[28,29] If conversations are not well timed, the relationship between the patient and the nurse can be damaged, limiting an ongoing relationship with the patient.[30] Furthermore, if patients or family members are not open to discussions regarding prognosis, tension can develop, leading to anger and frustration on the part of the patient and family, causing additional stress to the nurse and other staff.[30,31] Challenges in communication can leave the nurse feeling incompetent, exhausted, and avoidant of future conversations surrounding prognosis.[32]

The Nurse's Role in Diagnosis and Prognosis-Related Communication

Nurses report numerous different roles in the process of diagnostic and prognostic disclosure. Key roles include that of educator,[5,11,33] care coordinator,[11] supporter,[5,23,34] facilitator,[18,27,34] and advocate.[11,18,27,34,35] As an educator, the nurse stands poised to answer questions that the patient and/or family may have regarding a patient's diagnosis and prognosis. As part of the education process, the nurse often first performs an assessment to determine what the patient already knows about his/her condition and then follows the patient's lead in further discussions.[33] These discussions generally occur after the patient has met with the physician, who has relayed some level of information regarding the patient's diagnosis and prognosis. Nurses continue these discussions, often clarifying or adding to what was relayed by the physician.[11,23,28,33] Unfortunately, in response to these questions, nurses may inadvertently reveal a patient's poor prognosis if full disclosure did not occur with the physician.[5,36] If patients have not received clear information from their physicians, they may press the nursing staff for more information, asking different nurses the same question and then comparing answers or asking the same nurse the same question multiple times.[5]

As a care coordinator, the nurse assists the patient and family to plan for the future as it relates to the patient's diagnosis and prognosis.[11] At times, this may include a transition to hospice or end-of-life care. As a supporter, the nurse provides the patient and possibly family with the emotional support necessary to bear the burden of prognostic information. Warnock et al[9] queried nurses from the United Kingdom who worked in an acute care hospital. They aimed to explore the role of the nurse in the process of breaking bad news. Through surveys, they determined that nurses participate in a number of different activities related to the breaking of bad news. More than 50% of nurses reported frequently providing support to the patient or relative after the breaking of bad news and providing the patient or relative with opportunities to talk about the information given to them. These activities highlight the caring practices of nursing and reinforce the importance of simply being present.[28]

As a facilitator, the nurse works to ensure that communication occurs between the patient and the physician.[34] Nurses will explore with patients and families whether prognosis has been discussed and

what additional questions they may have. The nurse can then partner with the patient and family to talk with the physician.[27] McLennon et al[27] reported that nurses often instruct patients on what questions to ask and offer to set up meetings with the physician to ensure that questions get answered. Conflict can arise if the nurse believes that the patient has been provided with incomplete, inaccurate, or misleading information. Nurses feel compelled to provide patients with accurate information but at times find themselves confused and unsure as to their role within the team when full disclosure has not occurred.[34] Nurses from Hong Kong[18] also identified the need to facilitate such communication, making a commitment to improve systems to ensure that such communication occurred.

Finally, nurses see themselves as advocates. Nurses advocate for prognostic communication to ensure that patients receive care that is consistent with their preferences and goals.[27] Often, such advocacy involves the nurse going to the physician and reflecting on the patient's current situation and the need for better communication with the patient.[34] In addition, the nurse aims to empower the patient and/or the family to talk with the physician about their concerns and questions.[27]

Although nurses are quite clearly involved in discussions regarding prognosis, universally, most nurses indicate that such communication is not within their scope of practice, nor is it their role.[5,11,19,21,24,37-39] In this situation, nurses are speaking to the initial discussion that occurs when the physician tells the patient or family member the diagnosis and related prognosis. Nurses report apprehension with such discussions as they do not feel qualified to be the ones conveying diagnostic and prognostic information.[30,36,38] Oncology and palliative care nurses have increased comfort initiating these discussions,[33,34] and advanced practice nurses (APNs) in oncology report routinely discussing prognosis with patients.[33] In these situations, APNs report framing the discussion differently, in that they focus on quality of life versus statistics related to life expectancy.

Difficulties in Diagnosis and Prognosis-Related Communication

Nurses described numerous barriers that limited their ability to participate fully in the process of disclosure. Many of the nurses also readily identified difficulties encountered through these interactions. Difficulties can be identified as stemming from nurse factors, nurse-patient factors, or nurse-physician factors. Nurse factors include lack of experience or training,10,11,24,27,28,37Y39 discomfort,27,30Y32,39 lack of role definition,11,21,27,28,33,38,40 fears of taking way hope,5,11,19,34,38,39 and lack of time.11,32,38,39 Nurse-patient factors include patient and/or family unwillingness to accept the diagnosis and prognosis18,30,39 and cultural or familial wishes.11,21,27,28,33,38,40 Nurse-physician factors include exclusion11,29,34 and how information is conveyed.11,28,34,38

NURSE FACTORS

Nurses routinely report that the provision of diagnostic and prognostic information is not within their scope of practice. Nurses report feeling inadequately trained to answer questions related to prognosis and at times have great fear in their ability to communicate.[28] In fact, most nurses have not had such skills training and report this as a professional development need.[16,23,30,34,35,39] Sixty-six percent of oncology nurses working in Greece cited lack of training as the reason behind their difficulty engaging patients in open conversations about the disease or the prospect of dying. Warnock et al[9] reported

that more than 50% of the nurses surveyed indicated that they had never received formal training in prognosis-related communication. Hjelmfors et al[39] explored heart failure nurses' experiences with prognostic and end-of-life conversations. Thirty percent of the nurses reported not knowing how to discuss prognosis or end-of-life care. Although most of the respondents (97%) perceived they had the requisite knowledge to discuss prognosis, 55% of heart failure nurses answered that they often or sometimes hesitated in discussing prognosis because they did not know how to answer these difficult patient questions.

Nurses report feeling uncomfortable giving estimates of life expectancy[11] and exploring the concepts of death and dying with their patients.[38] Prognosticating life expectancy and disease trajectory can be challenging.[31,39] Nurses describe struggling to find the right time to discuss prognosis. If presented too early in the patient's disease trajectory when patients and family members are not ready, prognostic discussions can jeopardize the nurse's relationship with the patient and family.[26,30,31] The discomfort associated with these conversations is more prevalent among nurses who have limited experience caring for patients with life-threatening illnesses or those who do not regularly participate in such discussions. In an Israeli study[10] exploring the experience of general medical or surgical nurses, less experience in breaking bad news correlated with increased levels of helplessness. Similarly, nurses from Spain,[37] mostly from primary care clinics, identified that the less experience they had in breaking bad news, the more discomfort they felt when having to communicate such information.

Seventy-five percent of oncology nurses agreed that answering questions regarding a patient's prognosis is part of their role.[11] Unfortunately, 43% of the same group of nurses were unclear of their role in the process of disclosure, and believed this to be a barrier to better helping patients to understand their prognosis. The time point at which the nurse is allowed to participate in prognosis-related discussions is somewhat unclear and leaves nurses feeling uncertain as to their role.[40] This lack of clarity can be driven by the perceived power differential between physicians and nurses.[21,27] Nurses perceive a risk of negative consequences from the physician if they share prognostic information that the physician did not want disclosed to the patient or family member.

One of the main reasons nurses posit for not broaching discussions regarding prognosis is the fear of taking away a patient's hope. Helft et al[11] reported that 67% of oncology nurses cited taking away hope as a major barrier to prognosis-related communication. In a survey of hospital-based staff nurses who routinely work with terminally ill patients, 16% of nurses reported not discussing prognosis or referral to hospice care in an effort to maintain hope among patients and their families.[38] Similarly, nurses working on a unit with patients who had experienced spinal cord injuries had major concerns about answering patient questions for fear of destroying hope and upsetting the patients.[5] In this population, nurses responded by preparing a ''standard line.''5(p326) The standard line generally included both good and bad news, allowing the patient to acknowledge current limitations but also maintain hope. Finally, nurses in China[19] indicated that in some cases, they would not disclose diagnostic information to both early- and late-stage cancer patients for fear that the information would cause them to give up hope and stop therapy or make them feel helpless and hopeless.

Finally, nurses report that lack of time limits their ability to participate in diagnosis and prognosis-related discussions with patients.[32,39] In busy acute care environments and outpatient clinics, nurses are required to care for a complex patient load. Sixty percent of oncology nurses[11] reported lack of

time as a barrier to participation in prognosis-related communication. In a survey of hospital nurses who routinely work with terminally ill patients, Schulman-Green et al[38] described that some nurses indicated that they were simply too busy or it was too much work to discuss prognosis or the possibility of hospice care with patients.

NURSE-PATIENT FACTORS

Several nurse-patient factors can limit the nurse's ability to participate in the process of disclosure. First, patients and/or their family members may be unwilling to accept a patient's diagnosis and its associated prognosis.[9] Schulman-Green et al[38] listed this as one of the major obstacles to communication of prognosis and referral to hospice care. Lack of acceptance was thought to be due to fear of the patient's death or need for hospice care, the desire to maintain the patient's hope, and also the desire to continue with aggressive treatment. Unwillingness to accept the patient's diagnosis and prognosis influences readiness to learn, thus potentially limiting the nurse's ability to openly communicate with the patient and family and provide necessary education and support. Heart failure nurses described not discussing prognosis or end-of-life care because they believed that patients did not want to discuss the topic or were not informed enough about their condition to have such discussions.[39] Nurses felt that if they presented these topics they would upset patients and therefore avoided the discussions.

The second nurse-patient factor is cultural and/or familial wishes. Oftentimes, family members will request that patients not be informed of their diagnoses and/or prognoses. This phenomenon is not as common in the United States but is regularly reported in Asian,[18,21,22] Hispanic,[37] and Middle-Eastern[25] cultures. Family members often demand disclosure of diagnostic and prognostic information to them first. Schmidt Rio-Valle et al[37] described the ''conspiracy of silence''(p193) that permeates the Spanish culture in Granada. This silence is imposed by the family, perpetuated by the patient, and limits any communication with the patient regarding his/her diagnosis and prognosis. Both physicians and nurses report resigning themselves to this conspiracy. Because of culturally established, familial hierarchical structures, physicians in these countries are often more comfortable and follow expected communication patterns in presenting diagnostic and prognostic information to family members. Iranian hematopoietic stem cell transplant nurses[25] were careful not to talk with their patients about their disease or any potentially negative outcomes in an effort to protect patients from upsetting information.

When asked to write about experiences caring for patients with cancer, nurses in Hong Kong[18] frequently reported situations when relatives had requested or demanded that the patient not be told specifics regarding his/her diagnosis or prognosis. Nurses struggled with this lack of disclosure and often remembered certain patients because of the conflict they experienced. Nurses from Taiwan echoed these sentiments, indicating that they generally followed families' requests for confidentiality.[21] One third of these nurses reported telling a white lie to patients. In Canada, nurses caring for patients with spinal cord injuries[5] often found that families did not want patients informed of their prognoses but demanded the information for themselves. McLennon et al[34] reported similar concerns elicited by oncology nurses in the United States, who encounter families who do not want patients to know their prognoses. These demands place the nurse in a position of conflict between the obligation to the patient and the wishes of the family.

Noble et al[31] highlighted the challenges that palliative care nurses and other providers face when parents are unwilling to disclose the truth to their children with life-threatening conditions. Parents may either refuse to admit their child is dying or want to protect their child from information they believe will prompt further suffering. Parents then limit what information is shared with the pediatric patient. Nurses feel conflicted as they believe they should be open and honest with the child but are prohibited from doing so. This conflict results in an underlying tension between the parents and staff. Nurses are then afraid to be left alone with the child, fearing prognosis-related questions may be asked. Nurses described feeling powerless in these situations, which impairs their ability to provide the best care to the child. Nurses from Turkey[32] reported similar sentiments with pediatric oncology patients and the challenges imposed by demands for limited prognostic communication with the child.

NURSE-PHYSICIAN FACTORS

The first nurse-physician factor is exclusion. Nurses may or may not be included in the initial discussion that occurs between the physician and the patient regarding diagnosis and prognosis. Lack of participation often leaves nurses feeling as though they are working in the dark.[34] Eighty percent of surveyed American oncology nurses indicated that they could not advocate for patients as well when they did not have a clear understanding of the patient's prognosis or what was conveyed to the patient.[11]

Tobin[29] interviewed 20 nurses from Ireland in an effort to understand their experiences of caring for patients when the diagnosis of cancer was given. Strong messages arose from these interviews indicating that nurses form bonds with patients as they are awaiting and then receive the diagnosis of cancer. This bond is cultivated by nurses' caring for and journeying with their patients. The nurses truly came to know their patients, and this knowing allowed the nurses to function as patient advocates. Unfortunately, when nurses were not involved in the process of disclosure or were not fully informed, this relationship was strained. Nurses felt unable to fully care for their patients as they were uncertain of what had been said. Dialogue was curtailed, and silence ensued. Nurses reported significant frustration and felt challenged in their efforts to maintain integrity and loyalty to both their patients and the interprofessional team. This scenario puts the nurse in a compromised position.

The second nurse-physician factor is how information is conveyed. As the healthcare providers most frequently approached by patients and family members, Millar et al[36] described the challenges that nurses faced when previous discussions between patients and physicians did not include prognostic information. In this setting, lack of communication rendered nurses unable to provide information and support to patients who were experiencing refractory cachexia associated with a terminal diagnosis. In addition, adult oncology nurse managers asserted that when communication does not occur between the physician and the nurse, nurses exert an incredible amount of energy gathering and clarifying information for patients and families rather than addressing patient care and other psychosocial needs.[40]

Nurses also perceive that, at times, physicians themselves are uncomfortable with prognosis-related communication.[11] In such situations, the physician may not be as forthright with information, which can result in conflict for the nurse as the patient presses for more details regarding the prognosis.[27] Nurses perceive that physicians are sometimes hesitant to discuss prognosis and hospice care for several reasons, including lack of precision in prognostication, lack of a sense of responsibility, and a

desire to continue aggressive treatment.[38] Alternatively, physicians may paint an overly optimistic picture, which further complicates nurse-patient communication.[34] Nurses describe being stuck in the middle as they aim to advocate for their patients but also support the medical team.[27] If unclear as to what has been communicated, the nurse will often limit communication with the patient, which can have negative implications. Irish nurses[29] described how they believe that this impaired communication damaged the trust bonds they had established with patients, which further challenged their sense of professionalism.

Nurses also reported anger and frustration when such delicate information was presented poorly.[28] In addition to the incomplete or inaccurate provision of information, nurses struggled when the message was delivered without compassion or in a location that did not allow for privacy.[30] Nurses also cited that key people, including family members, primary physicians, or the nurse, are often missing from such discussions. Adebayo et al[41] described healthcare professionals' experiences with breaking bad news. In recalling recent experiences, only 35.8% of participants remembered a nurse or other family member being part of the conversation. In exploring patient perspectives of the process of breaking bad news,[10] patients preferred that in addition to the physician and the patient, another family member be present.

Impact of Nurse Participation in Diagnosis and Prognosis-Related Communication

Nurses frequently reported increased personal reflection when involved in diagnosis and prognosis-related discussions. Nurses were forced to reflect on their own lives and priorities[9,28] and questioned, ''What if this were me?''[28](p613) These reflections were generally considered positive and were seen as a method for self-improvement. Such contacts may prove to lay the groundwork for future interactions with patients in similar situations. Tobin[29] referred to this as the ''ubiquitous past,''(pE25) the ever-present self that is intrinsic to the nurse, and is integrated into interactions with future patients.

There is a cost to the nurse in participating in such communication. [29] Working with patients in such stressful situations can have an emotional toll on the nurse, particularly if conflicting messages are sent by different members of the healthcare team. The nurse is caught in the middle, which can increase personal conflict.[27] Oncology nurses reported experiencing moral distress when they perceived they could not advocate appropriately for their patients due to a lack of honest communication regarding prognosis and therapeutic options.[27] Nurses described witnessing inappropriate interventions and nonbeneficial treatment due to lack of full disclosure regarding prognosis and an inability to provide timely referrals to palliative or hospice care.[27,31]

Discussion

Although physicians hold the responsibility and authority for diagnostic and prognostic disclosure, nurses are active participants in the ongoing process of diagnosis and prognosis-related communication with patients and families. The initial discussion with the physician and healthcare team is just the beginning. Nurses play a prominent role in the ongoing education and enlightenment of their patients regarding their diagnoses and prognoses. Because of the intimacy of the relationship

that develops between the patient and the nurse, the nurse is in a prime position to introduce and reinforce such powerful information.[33] Nurses play a critical role in this process as nurses are perceived as having the training and time to reinforce information, answer questions, educate, and provide emotional support.[42] Nurses also function as skilled facilitators by assessing and preparing both family members and physicians for prognostic discussions. The challenge remains that the role of the nurse is not always recognized and acknowledged. Where the nurse's role starts and stops has not been clearly delineated.

A major barrier to nurse participation in the disclosure of diagnostic and prognostic information is the lack of collaboration between the physician and the nurse. Nurses frequently reported ''working in the dark,''[34](p119) which resulted in a lack of clarity about what information was conveyed to patients. This lack of information challenges the nurse who aims to meet the complex communication needs of the patient but also provide a consistent message from the medical team. Improved communication among team members is required. Explicit communication among team members will help clarify and delineate the different roles that team members play in diagnosis and prognosis-related communication.[38] Interprofessional planning with a patient-focused orientation should occur before diagnostic and prognostic discussions, determining the optimal timing, who should be present, and the content of such discussions.[28]

Unfortunately, because of the many hierarchical structures within healthcare, the role of the nurse in this process often goes unnoticed. Warnock et al[9] warned that the role of the nurse risks being overlooked if not better elucidated. Dewar[5] noted that because the nurse's role is often played out in an ad hoc manner, it risks being invisible and therefore not valued. This invisibility places the nurse in a vulnerable position, one in which he/she is often subservient to the actions and decisions of the physician. Without better clarification and illumination of the nurse's role in this process and what the nurse can contribute to positive patient outcomes, the role of nursing remains marginalized. Nurses must aim to purposefully partner with their physician colleagues to ensure such communication occurs in a meaningful way.

One way to augment improved professional relationships and collaboration is through education regarding difficult communication with patients. A limited number of nurses have had education and training in discussing diagnosis, prognosis, or end-of-life care. Nurses describe learning most of what they know through informal methods such as observation or experience with other patients.[30] Education has the potential to provide nurses with the knowledge and skills they need to feel more confident in participating in these discussions. Education should also aim to assist the nurse in learning how to manage the intermediary role that nurses often play among the patient, the family, and the physician.[40] Finally, as collaboration between nurses and physicians is integral to improving this process, such skills training should be done in an interprofessional setting.[5,33] Short skills-building retreats have been found to improve medical residents' abilities to deliver bad news and confidence in having end-of-life conversations.[43] Similar methods can be implemented to educate nurses and other interprofessional team members.

The nurse's role in the delivery of diagnostic and prognostic information is quite complex and is fraught with ethical dilemmas. Ethical dilemmas become particularly prominent when tension exists between the nurse's perception of what is right for the patient and competing beliefs by other members of the

healthcare team.[34] This tension surfaces when nurses believe that patients have not been provided with accurate or complete information, or if information has been hidden from patients at the request of family members. Ethical dilemmas present themselves in everyday nursing practice when honesty, sensitivity, and respect for professional standards conflict.[17] Nurses do not always feel empowered to address such conflicts, which can result in internal tension and strained nurse-patient relations. These ethical challenges highlight further the need for improved communication and training among members of the interprofessional healthcare team.

Limitations

Most of the studies presented were descriptive, survey designs. No intervention studies were included. Sixteen different countries were represented in these papers. Although this presents a global perspective on the topic, generalizability is limited as the idea and extent of diagnostic and prognostic disclosure is not universally accepted. One of the areas of interest for this researcher is the pediatric population. Only 2 papers were found that explicitly explored the nurse's perspective of diagnostic and prognosis-related communication in the pediatric population.

Conclusion

Although not always acknowledged, nurses play a critical role in the process of diagnostic and prognostic disclosure. As nurses provide day-to-day care to patients, they function as educators, care coordinators, supporters, facilitators, and advocates. As nurses fulfill their many roles, they develop strong relationships with the patients who are the recipients of their care. These relationships are often built on trust. Once patients and families have been given diagnostic and prognostic information, they look to the nurse to help better understand and explain information provided to them. This situation can place the nurse in a compromising position as, oftentimes, the nurse may be unaware of the details of such discussions. The nurse then struggles to support the patient and family while aiming to not contradict what was shared by the physician. This challenge creates an ethical dilemma for the nurse, which may impair his/her ability to best care for the patient and family. To improve the process of diagnostic and prognostic disclosure for the patient, the family, the nurse, and the physician, more collaborative communication must occur. For such collaboration to occur, the established hierarchies within the healthcare team must be addressed, and nurses must be viewed and willing to participate as the physician's partner. Through interprofessional communication skills training, nurses and physicians can partner to improve and enrich this process for all involved. Future research efforts should include exploration of both the physician's and the patient's perspectives of the nurse's role in this process. Also, further explication of the unique role that the APN may play in this process is essential. Based on these findings, future work can explore possible nursing interventions to assist patients, families, and physicians in diagnostic and prognostic disclosure and ongoing communication processes.

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