Prognosis-Related Communication: Ethical Dilemmas Among the Oncology Nurses in China

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Abstract

Background: Effective communication about prognosis is imperative for enhancing the quality of end-of-life care and improving patient well-being. This practice is sensitive and is heavily influenced by cultural values, beliefs, and norms. This can lead to ethical dilemmas. Despite their significance, ethical challenges in nursing practice relating to prognosis communication are understudied in China.

Objective: This study aimed to examine the ethical dilemmas relating to prognosis communication and their associated factors.

Methods: A cross-sectional design was employed to survey 373 oncology nurses in mainland China via online. Data were collected on ethical dilemmas, attitudes, barriers, prognosis communication experiences, and socio-demographic and practice-related information. Ordinary least squares regression was utilized to identify the factors contributing to ethical dilemmas.

Results: Participants reported a moderate level of ethical dilemmas in prognostic communication (M = 13.5, SD = 3.42, range = 5-20). Significant predictors of these dilemmas included perceived barriers ($p < .001$), prognosis communication experience ($p < .001$), and years of work experience ($p = .002$). Nurses who perceived greater barriers had more negative experiences with prognosis communication, and those with less work experience were more likely to encounter ethical dilemmas in prognosis-related communication

Conclusions: Chinese oncology nurses frequently encounter ethical dilemmas as well as barriers in prognosis communication. This study's findings emphasize the importance of culturally tailored communication training. Collaborative inter-professional training, particularly through physician-nurse partnerships, can perhaps enhance proficiency in prognosis-related communication.

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Key words: Prognosis-Related Communication, Ethical dilemmas, Oncology, Nursing practice

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Introduction

Prognosis-related communication, also known as truth-telling or breaking bad news, is a continuous process that encompasses discussing life expectancy, symptom progression, and functional abilities with patients, their families, and healthcare professionals [1]. Effective discussion about prognosis facilitates informed decisions for patients and enhances patient-reported outcomes [2]. Despite the expectation that prognosis communication should be a standard practice and a universal communication ideal in healthcare, clinicians, including nurses, experience discomfort and concerns in breaking bad news. Clinicians are concerned about providing prognostic information that could contribute to emotional distress in patients and families. This raises questions about their professional roles in alleviating suffering and concerns about the potential impact on relationships [3]. In addition, insufficient training, unclear nursing roles, inadequate information about the patient's prognosis, lack of time, and concerns about diminishing the patient's hope [4-6] can impact prognosis communication. Interpersonal factors such as the patient's and family's lack of support, the family's request to withhold information from their loved one, and/or a physician's lack of communication, can influence this process [4, 7]. Nurses often face ethical dilemmas when there is a disparity between their professional duties and complex circumstances surrounding family beliefs and cultural norms, making it extremely difficult to proceed [7, 8]. Such conflicts can yield negative consequences, including increased burdens, moral distress, emotional burnout, anxiety, and guilt [7, 9].

Practices in prognosis disclosure vary by country and cultural groups, influenced by unique cultural beliefs and values [10, 11]. In Western cultures, informing patients about their diagnosis and prognosis is deemed as vital for promoting patient autonomy and is routinely integrated into palliative care. However, in Eastern cultures like China, individual autonomy is often considered

secondary to family-centered decision making [10]. Cultural values that prioritize family-centeredness lead healthcare practitioners to defer disclosure of prognosis to the family, who then decide whether to inform the patient [12]. It is common for families to withhold prognosis information to protect patients from emotional distress [13]. In addition, death and dying are taboo subjects, making it challenging for healthcare providers to facilitate timely and effective prognosis-related communication due to concerns about potential adverse outcomes such as emotional distress, diminished hope, and acceleration of the dying process [11, 12].

In countries where honest disclosure is not well recognized, clinicians' challenges and conflicts are greater. Chinese nurses often experience a conflict between personal dimensions influenced by traditional cultural norms versus professional dimensions of adhering to nursing values and principles [11]. Withholding end-of –life (EOL) communication from patients and relying solely on family members for EOL decision-making raises concerns, as families may not fully understand the patient's prognosis or their EOL wishes [13, 14]. Recent studies indicate that the majority of cancer patients in China want to be informed of their prognosis [15-17]. For example, a meta-analysis of studies in China revealed that 81.8% of cancer patients, compared to 32.4% of the family, prefer prognosis disclosure, but only 19.9% of patients are actually informed [15]. Although clinciains aim to maintain hope through nondisclosure, they experience conflicts in balancing hope preservation with truth-telling [12]. While it is deemed acceptable to protect patients from being informed of their worsening conditions without family permission, some nurses feel uncomfortable and conflicted about deceiving patients about their prognosis [18].

In China, there were 4,546,400 new cancer cases and 2,992,600 cancer deaths in 2020, accounting for 25.1% and 30.2% of global cases, respectively [19]. Despite the increasing rates of cancer incidence and mortality and significant implications for nursing practice, there is limited knowledge about the ethical dilemmas and other factors related to prognosis-related communication among oncology nurses in China. Although several studies in China have examined the complexities

of prognosis communication within a socio-cultural context, most focus on the nurses' attitudes and preferences for diagnosis or prognosis disclosure [20-22]. Addressing ethical dilemmas in terms of nursing practice is imperative for upholding patient advocacy, promoting patient-centered care, navigating complex moral issues, and maintaining professional integrity and accountability. This study aims to explore the ethical dilemmas in prognosis-related communication among Chinese oncology nurses and identify their influencing factors.

Methods

Study Design and Sample

This study employed a cross-sectional design using an online survey conducted with oncology nurses. Convenience sampling was utilized to recruit participants from four hospitals in Wuhan City, Hubei Province, Mainland China. Inclusion criteria were registered nurses currently working in oncology units and practice with advanced cancer patients. Exclusion criteria included nurses with less than one year of practice in oncology, intern nurses, rotating nurses, and those working in pediatric oncology.

Data Collection and Procedure

Our research team contacted nursing directors at four hospitals with oncology units in Wuhan and explained the purpose and procedures of the study. The nursing directors and the head nurse distributed the online survey to the oncology department's WeChat group, inviting all oncology nurses to participate. Before taking the survey, nurses were informed about the study's purpose, risks and benefits, and their right to withdraw and then provided their consent to participate. The survey was administered from September 17, 2018 to October 24, 2019. A total of 410 eligible nurses enrolled in the study but 37 withdrew, resulting in a final sample of 373 participants.

Ethical Considerations

This study was approved by the Ethics Committee of the University (Blinded for Review), and all procedures followed ethics standards.

Measures

We developed measures by adapting items from the questionnaire used in previous studies [23, 24]. The questionnaire was translated from English to Chinese and back-translated to English by different post-doctoral staff independently to avoid bias. Some wordings and phrases were modified to enhance clarity in translation. Discrepancies were resolved with the help of a bilingual nursing faculty. The translated questionnaire was pilot-tested with 25 oncology nurses to make further improvement. Item responses were summed to calculate three composite (scale) scores: dilemmas, attitudes, and barriers.

Dilemmas in prognosis-related communication: This scale assessed experiences with dilemmas in prognosis-related communication such as discomfort in discussions and social/cultural conflicts (4 items). Responses were on a 5-point Likert scale (1 = Never/almost never to 5 = Always/ almost always). Total score of ethical dilemmas ranges from 4 to 20, with higher scores indicating greater dilemmas. Cronbach's alpha for this scale was .82.

Attitudes toward prognosis-related communication: This scale (6 items) measured attitudes toward engaging in prognosis communication using a 4-point scale (1 = Strongly disagree to 4 = Strongly agree). Sample items were: "Patients can make timely decisions about their treatment if they understand their prognosis" and "Answering questions about prognosis-related information is within the scope of nursing practice." Total scores of attitudes scale ranges from 6 to 24, with higher scores indicated more positive attitudes. Cronbach's alpha for attitudes was .87.

Barriers to prognosis-related communication: This scale (4 items) assessed perceived barriers to engage in prognosis communication, such as role uncertainty, lack of time and fear of diminishing hope. Responses were on a 4-point scale (1= Strongly disagree to 4 = Strongly agree), with higher scores indicating greater barriers. Total score ranges from 4 to 16. Higher scores indicate greater levels of barriers in communicating prognosis. Cronbach's alpha for barriers was .80.

Prognosis-related communication experience was measured using three items: the frequency of experiencing (1) patients do not want their family members to be told of their diagnosis, (2) family/relatives requesting a patient not be told of bad news patients, and (3) nurses not being encouraged to be involved in prognosis-related communication. Responses were on a 5-point scale (1 = Never to 5 = Always/almost always). Total score ranges from 3-15, with higher scores indicating negative experiences in prognosis communication. Cronbach's alpha for this scale was .70.

Lastly, socio-demographic and practice-related questions included age, gender, marital status, education level, years of oncology nursing experience, and formal training on prognosis communication (1 = None/almost none to 4 = A lot).

Data Analysis

Descriptive statistics were utilized to demonstrate the distributions of participants' socio-demographic characteristics and other study variables. For continuous variables, mean and standard deviation were calculated, while for categorical variables, count and frequency were reported. To identify factors associated with increased or decreased dilemmas in engaging in prognosis communication, ordinary least squares (OLS) regression was performed. This analysis controlled for several covariates, including participants' age, gender, marital status, and education level, to ensure an unbiased assessment of each predictor's independent impact on the dependent variable—dilemmas in prognosis communication. All analyses were conducted using SPSS, and statistical significance was determined at .05 alpha level.

Results

Socio-Demographic and Practice-Related Characteristics

Table 1 presents the socio-demographic information about the study sample. The average age of the participants was 30.8 years. The majority were female (94.4%), married (73.5%), and had a bachelor's degree (58.7%). On average, participants had been working as oncology nurses for about

six years, with 65.6% reporting that they had received little or no formal training in prognosis communication.

Table 1. Socio-Demographic and Practice-Related Information (*N* = 373)

Variable	*M* (*SD*) / *n* (%)
Age	30.8 (4.7)
Gender	
Female	352 (94.4%)
Male	21 (5.6%)
Level of Education	
Secondary specialized school of nursing	50 (13.4%)
Junior college nursing degree	97 (26.0%)
Bachelor's degree	219 (58.7%)
Master's degree	6 (1.6%)
Ph.D. degree	1 (0.3%)
Marital Status	
Married	274 (73.5%)
Separated	1 (0.3%)
Divorced	18 (4.8%)
Widowed	4 (1.1%)
Never married	76 (20.4%)
Years Working as an Oncology Nurse	6.2 (4.5)
Formal Training for Prognosis-Related Communication	
None/almost none	77 (21.2%)
Little bit	161 (44.4%)
Moderate	90 (24.8%)
A lot	35 (9.6%)

Regarding prognosis-related communication, about half (51.1%) of the participants believed that physicians should be responsible for delivering prognostic information, compared to 10.2% who believed nurses take on this role (see Table 2). Approximately 87% of the participants engaged in prognosis communication, providing either full or partial disclosure to patients or their families. Only 20.1% of the participants reported providing full disclosure to *patients*, 50.1% provided partial disclosure, and 29.7% avoided disclosure. In contrast, about 44% of the participants reported providing full disclosure to *patients' families*, while 37% providing partial disclosure.

Table 2. Prognosis-Related Communication (*N* = 373)

Variables	*n* (%)

When patients have a poor prognosis, should this be disclosed to the patient? (Yes)	254 (68.1%)
Who should inform about the prognosis?	
Physician in charge	228 (51.1%)
Family member	90 (24.1%)
Nurse in charge	38 (10.2%)
Other	17 (4.6%)
Experiences in prognosis communication to patients, if prognosis is poor	
Fully inform patient	75 (20.1%)
Provide only partial information	187 (50.1%)
Avoid of informing prognosis/never disclosed prognosis to the patient	111 (29.8%)
Experiences in prognosis communication to families, if the prognosis is poor	
Fully inform family	163 (43.7%)
Provide only partial information	139 (37.3%)
Avoid of informing prognosis/never discussed prognosis to the family	71 (19.0%)

Ethical Dilemmas, Barriers, Attitudes and Experiences in prognosis-related communication

Table 3 presents study measures and response distributions. In regard to Ethical dilemmas, the most frequently reported items include participants reporting that they always or often felt pressure not to provide information with a concern of contradicting what doctors said (48.3%) and social custom/cultural barriers prevent from sharing prognostic information (44.8%). Oncology nurses in our study reported that they experienced a relatively moderate level of ethical dilemmas in prognosis communication (M = 13.5, SD = 3.43, range = 5-20).

In terms of attitudes, the majority of participants were positive toward prognosis-related communication. For example, the majority agreed/strongly agreed that oncology nursing were responsible to help patients for preparing their end of life care (88.5%) and that prognosis communication can help patients make a timely decision about their treatments (87.9%). Its mean score was 18.84 (SD = 3.65)

In regard to barriers for prognosis-related communication, the items that the participants

reported agree/strongly agree include worries about taking away patients' hope (85.0%), followed by feeling uncertainty about their roles (82.8%). The overall barrier score was 12.0 (SD= 2.50). In prognosis-related communication, 71% of the participants reported that families always or often requested withholding communication about prognostic information from patients and more than half (53.4%) reported that nurses were always or often not encouraged to be involved in prognosis communication. Its mean score was 10.64 (2.49).

Table 3. Study Measures and Response Distributions (*N* = 373)

Items	Never/ Almost never (n/ %)	Rarely (n/%)	Sometimes (n/%)	Often (n/%)	Always/ Almost always (n/ %)
Dilemmas in prognosis-related communication					
Feel pressure not to provide information about prognosis to patients to avoid contradicting what the doctors have said	16(4.3%)	49(13.1%)	128(34.3%)	110(29.5%)	70(18.8%)
Avoid talking with patients about prognosis-related information due to the discomfort in giving bad news	19(5.1%)	49(13.1%)	149(39.9%)	95(25.5%)	61(16.4%)
Social customs/cultural barriers prevent you from sharing prognosis-related information	17(4.6%)	50(13.4%)	139(37.3%)	105(28.2%)	62(16.6%)
Ethically conflicted when patients or family ask about prognosis-related communication	19(5.1%)	59(15.8%)	148(39.7%)	85(22.8%)	62(16.6%)
Prognosis-related communication Experience	**Never/ Almost never (n/ %)**	**Rarely (n/%)**	**Sometimes (n/%)**	**Often (n/%)**	**Always/ Almost always (n/ %)**
Patients do not want their family members to be told of their prognosis	22(5.9%)	72(19.3%)	118(31.6%)	106(28.4%)	55(14.7%)
Families/Relatives request that the patient is not told bad news	8(2.1%)	26(7.0%)	74(19.8%)	171(45.8%)	94(25.2%)
Nurses are not encouraged to be involved in breaking bad news in my area.	27(7.2%)	57(15.3%)	90(24.1%)	130(34.9%)	69(18.5%)
Attitudes toward prognosis-related communication	**Strongly disagree**	**Disagree (n/%)**	**Agree (n/%)**	**Strongly agree (n/%)**	

	(n/%)			
Patients can make timely decisions about their treatments if they understand their prognosis.	10(2.7%)	35(9.4%)	158(42.4%)	170(45.6%)
Patients can make timely decisions about hospice enrollment if they understand their prognosis.	24(6.4%)	24(6.4%)	159(42.6%)	166(44.5%)
I feel it is my responsibility to initiate a discussion with physicians about a patient's prognosis if the patient has questions about his/her prognosis.	13(3.5%)	43(11.5%)	213(57.1%)	104(27.9%)
I feel that oncology nurses have a responsibility to help patients prepare for their end of life.	21(5.6%)	22(5.9%)	154(41.3%)	176(47.2%)
I am willing to initiate a discussion with patients regarding prognosis-related information.	22(5.9%)	57(15.3%)	193(51.7%)	101(27.1%)
I feel that answering questions about prognosis-related information is within the scope of nursing practice.	25(6.6%)	77(20.6%)	187(50.1%)	84(22.5%)
Barriers to prognosis-related communication	**Strongly disagree (n/%)**	**Disagree (n/%)**	**Agree (n/%)**	**Strongly agree (n/%)**
Uncertainty about my role in communicating about prognosis-related information is a major barrier to helping patients and families understand their prognosis	22(5.9%)	42(11.3%)	219(58.7%)	90(24.1%)
Lack of time is a major barrier to discussing prognosis-related information with patients and families.	17(4.6%)	72(19.3%)	173(46.4%)	111(29.8%)
Fear of taking away patients' hope is a major barrier to discussing prognosis-related information with patients and families.	15(4.0%)	41(11.0%)	199(53.4%)	118(31.6%)
Physician discomfort with giving bad news is a major barrier to helping patients and families understand their prognosis.	18(4.8%)	102(27.3%)	174(46.6%)	79(21.2%)

Factors Impacting Prognosis-Related Communication

Table 4 summarizes the results of the OLS regression analysis. Perceived barriers (β = 0.40, p

< .001), prognosis communication experience (β = 0.46, p <.001), and years of work experience (β = –0.14, p = .002) were significant predictors of experiencing ethical dilemmas in engaging in prognosis-related communication. These findings suggest that participants who perceived more barriers or had more negative experiences in prognosis communication encountered more dilemmas. Participants with fewer years of experience as oncology nurses were more likely to experience a dilemma. All other variables, including attitudes, formal training, and demographic covariates, did not significantly predict dilemmas in prognosis-related communication. This model explained a substantial portion (61.7%, p < .001) of the variance in ethical dilemmas in prognosis communication.

Table 4. Predictors for Dilemmas in Prognosis-Related Communication (*N* = 373)

Predictor	*b*	*SE*	*β*	*p*	*95% CI*
Barriers	0.55	0.07	0.40	< .001	0.41; 0.69
Prognosis communication experiences	0.62	0.06	0.46	< .001	0.50; 0.73
Attitudes	–0.02	0.05	–0.02	.66	–0.12; 0.07
Marital Status	–0.10	0.07	–0.05	.18	–0.25; 0.05
Age	0.04	0.03	0.05	0.23	–0.03; 0.10
Gender	–0.80	0.50	–0.05	.11	–1.80; 0.19
Level of education	–0.27	0.17	–0.06	.10	–0.60; 0.06
Years of working as an oncology nurse	–0.11	0.03	–0.14	.002	–0.18; –0.04
Formal training	–0.20	0.13	–0.05	.13	–0.45; 0.06

Discussion

In this study, about 89% of the participants reported either fully or partially engaging in prognosis communication with patients or their families, which is higher than a previous study in Taiwan where about 71% of nurses reported doing so [25] but it is lower than another study in China that 97.2% of oncology nurses engaged in truth telling [26]. However, consistent with a previous

study [15], our study revealed that full disclosure of prognosis was more frequently given to families (43.7%) rather than to patients (20.1%).

Oncology nurses in our study experienced a relatively moderate level of ethical dilemmas in prognosis-related communication. One significant predictor was the perceived barriers in prognosis communication. Nurses who perceived a greater level of barriers were more likely to experience dilemmas. This finding aligns with previous studies indicating that clinicians' discomfort and bearing burdens on breaking bad news, stemming from their concerns about patients' inability to cope, and relational distress [3]. Our study participants' uncertainty about their role might stem from the hierarchy in the health care system in China, where physicians are traditionally expected to lead discussions about prognosis [27]. Nevertheless, conflicting informed consent laws and regulations in China which emphasize a patient's right to know but discourage healthcare providers from truth telling if it could cause adverse events creates fear of legal lawsuits and conflict with the family [12, 28]. Consequently, the discomfort and lack of engagement among clinicians in prognosis communication may impose additional burdens and challenges on nurses when patients or family members seek information.

Another significant predictor of dilemmas surrounding prognosis-related communication was the nurses' experience with prognosis communication. Negative experiences, such as family requesting that prognosis communication be withheld from patients, were positively associated with experiencing dilemmas. Previous studies also supported that family requests to withhold prognosis information hinder clinicians' disclosure of this information to patients [12, 15]. However, deciding whether to disclose a prognosis is complex, requiring a balance between patients' wishes and family concerns. Ling and colleagues [29] underscore the significance of nurses' assessment of patients' preferences regarding the disclosure of their medical conditions. Family members' preferences might not aligned with the patients', creating conflicts with clinicians. Regardless, the family is the

important source of support and patients value positive relationships with their family members. Hence, integrating family into palliative/EOL care is important [30].

In addition, engaging the entire healthcare team in the communication process and decision-making serves as a collective approach to address ethical dilemmas [29]. Oncologists are primarily tasked with delivering unfavorable news, yet often evade this duty due to personal discomfort, concerns regarding patients' psychological well-being, time constraints, and inadequate communication training [26, 31]. This perhaps compels nurses to be responsible for filling the informational voids. A recent study with oncology nurses in China highlighted the benefits of an interdisciplinary approach, especially collaboration between physicians and nurses, such as sharing patient information. [26]. An inter-professional approach to prognosis communication can effectively empower nurses to communicate truthfully and foster enhanced collaboration with physicians.

The number of years of employment as an oncology nurse was another significant factor in the dilemmas surrounding prognosis-related communication. Previous studies have shown that years of nursing experience has a significant association with communication [32] and confidence in palliative/EOL care [33]. Oncology nurses with limited experience encountered uncertainty in addressing prognosis-related inquiries, which engendered apprehension about inadvertently imparting inaccurate information to the patients [34]. Conversely, oncology nurses with extensive experience are likely to have developed advanced communication skills, attributed to their heightened exposure to patients with advanced cancer. Therefore, involving experienced nurses in communication skills training might be beneficial. Previous studies with Chinese nurses indicated a lack of education in death, dying, and palliative/EOL care [11, 35]. Although formal communication training increases health care practitioners' engagement in disclosing diagnosis and prognosis [36], it was not statistically significant in our study. This may be due to the lack of an established formal curriculum on prognosis communication, particularly culturally tailored and adapted skill training in which the health care professionals, regardless of receiving formal training, may still be unsure about

how to facilitate such challenging communication. Therefore, experienced nurses providing communication skills training can help address dilemmas in such difficult topic.

Nurse communication training is still relatively new, and few training programs provide comprehensive skill training for palliative care. One example is the Communication, Orientation and Options, Mindful communication, Family, Openings, Relating, Team (COMFORT) framework, which outlines communication pathways for palliative care [37, 38]. COMFORT incorporates communication theory into clinical research, providing a solid framework for palliative nursing communication with patients and families. Its 'train-the-trainer' model has been found to improve nurses' attitudes, comfort levels, perceived self-efficacy, and confidence in engaging in challenging communication topics with family caregivers [37]. Despite its promising approach, it is crucial to culturally tailor its components for successful adoption. Healthcare organizations should adapt the curriculum to meet the unique needs and expectations of the oncology nurses while accounting for cultural nuances in the Chinese cultural context.

Limitations and Future Studies

This study has several limitations that need to be acknowledged. This study included only four hospitals in Wuhan, China, which may limit the generalizability of the findings to oncology nurses in other provinces. Different provinces may have varying regulations and protocols regarding prognosis communication. The four hospitals where participants were recruited are tertiary hospitals, which are part of a three-tier system (Primary, secondary, and tertiary hospital). A tertiary hospital has more than 500 beds and offers specialized healthcare services, along with playing a significant role in medical education and research. This may lead to different experiences for nurses compared to those working in primary or secondary hospitals, or smaller regional hospitals. Future studies expanding study sites by including different levels of the hospital can broaden our understanding of this topic. Additionally, the psychometric properties of the measures used in this study were not empirically confirmed. Hence future research is needed to develop a reliable and valid measures.

Conclusion

Prognosis communication is a complex process in that ethical dilemmas that nurses encounter need to be understood within their social and cultural contexts. Strategies to address ethical dilemmas require ongoing training and interdisciplinary collaboration. Communication training tailored to specific cultural contexts is indispensable within healthcare settings. Without uniform or unified policies, gaps and dilemmas in practice inevitably arise, potentially compromising patient care. Given the diverse preferences of patients and their families, communication about prognosis must be individualized and sensitive to their unique needs and backgrounds. Effective communication about prognosis requires a collaborative effort centered around the patient. By harnessing their expertise and utilizing tools that guide understanding of patient preferences, healthcare providers can ensure that discussions are informative, respectful, and supportive. Ultimately, emphasizing teamwork and ethical awareness enhances the quality of prognosis discussions and promotes the well-being of both patients and providers.

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Conflicts of Interest

The authors have no relevant financial or non-financial interests to disclose.

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