

The differences in nurses' willingness to discuss palliative care with patients and their family members

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Abstract

Background: This study aimed to evaluate the differences in nurses' willingness to discuss palliative care with terminally ill patients and their family members.

Methods: The participants were randomly recruited from registered staff nurses ≥ 20 years of age who were responsible for clinical inpatient care in a tertiary hospital in northern Taiwan. A semi-structured questionnaire was administered to evaluate nurses' experiences of discussing do-not-resuscitate (DNR) decisions and their willingness to discuss palliative care with terminal patients and their family members. The differences in nurses' experiences regarding DNR and willingness to discuss palliative care with terminally ill patients and their family members were compared using the Chi-square test. Logistic regressions were used to analyze factors associated with nurses' willingness to discuss palliative care with patients and their families.

Results: More participants had experienced initiating discussions about DNR with patients' families than with patients (72.2% vs 61.9%, $p < 0.001$). Unadjusted logistic regression analysis showed that the experiences of actively initiating DNR discussions with patients were a significant factor associated with palliative care discussion with patients (odds ratio [OR] = 2.91, 95% confidence interval [CI]: 1.09–7.79). On the other hand, the experiences of actively initiating DNR discussions with patients and with patients' families were significant factors associated with palliative care discussion with patients' families (OR = 3.84, 95% CI: 1.22–12.06 and OR = 3.60, 95% CI: 1.19–10.90, respectively). After adjusting for covariates, no significant factors were found to be independently associated with nurses' willingness to discuss palliative care with patients and their family members.

Conclusion: There are significant differences in nurses' willingness to discuss palliative care with patients and their family members. Further research is needed to evaluate factors associated with nurses' willingness to discuss palliative care with patients and their families to facilitate these discussions and protect patients' autonomy.

Keywords: Decision making; Hospice and palliative care nursing; Palliative care; Terminally ill

1. INTRODUCTION

Health professionals such as physicians and nurses play important roles in decision-making discussions about do-not-resuscitate (DNR) with patients and their families. However, some studies have reported that physicians, not nurses, are usually expected to initiate DNR discussions.¹ Although nurses have

confidence in their ability to participate in DNR decisions and wish to be involved in such decision making, only about one-fifth of nurses do participate in DNR decisions.^{2–4} Nurses' initiation of discussions about DNR decisions enables them to talk openly about DNR and to provide adequate support and care to the patients and their relatives, and this may help the family to understand the condition of these patients and prepare the patient for a peaceful death.^{5–7} However, some nurses feel unsure of their role in the DNR designation process, which may make them hesitant to initiate or be involved in these discussions.³

Palliative care discussion is another goal of care discussion for patients suffering from incurable diseases. Some nurses consider that physicians have the authority to make end-of-life decisions,⁸ and some report uncertainty about having to administer treatment dictated by physicians, regardless of the nurses' own beliefs.⁹ Some nurses even express reluctance to provide patients with end-of-life information for fear of being reprimanded by physicians. Previous studies showed that nurses experienced serious challenges and frustrations in communicating with family

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members and physicians about end-of-life care.⁸ However, it is desirable that nurses should be involved in such discussions, as different aspects of the situation must be considered to determine the wishes of patients and their families,¹⁰ and their roles involved in patient care and relationships with patients and their families.¹¹ Intensive care unit nurses deemed their involvement in palliative care discussion as a key component of quality patient care which should be facilitated.¹² According to the Taiwanese Nursing Personnel Act, nursing instruction and counseling are the function and responsibility of nursing personnel.¹³ In addition, providing patients with adequate information is important in improving the nurse–patient relationship.¹⁴ Because of the nature of their role in patient care, nurses understand patients' needs; thus, they play an important role in end-of-life decisions.⁹

However, only a few studies have focused on nurses' communication with terminally ill patients or their families regarding palliative care and DNR in Asian countries. Some previous studies explored nurses' experiences with end-of-life care in Taiwan, focusing on nurses' emotional issues and only those nurses enrolled in the field of oncology and hospice care.^{15–17} No study has explored the differences in nurses' willingness to discuss palliative care with patients and their families. Therefore, the aim of this study was to evaluate this issue in a tertiary hospital in Taiwan. We hoped that the study would help nurses to initiate such discussions with patients and their families (especially with patients) to protect their autonomy.

2. METHODS

2.1. Ethical statements

This study was approved by the institutional review board of Taipei Veterans General Hospital, Taipei, Taiwan (2017-01-004AC). Informed consent was obtained from all individuals before participation in the study.

2.2. Setting and participants

This was a cross-sectional survey conducted in a tertiary hospital in northern Taiwan. Registered staff nurses taking care of terminally ill patients who were consulted to the hospice care team were invited to participate by a research assistant. The inclusion criteria were that participants should be registered nurses ≥ 20 years of age, be responsible for inpatient care, and agree to provide written informed consent. Thus, registered staff nurses < 20 years of age and those who were mainly in charge of administrative affairs were excluded.

2.3. Measurements

A semi-structured questionnaire was developed to evaluate nurses' experiences of discussing DNR and their willingness to discuss palliative care with terminally ill patients and their families. In our questionnaire, we defined the initiation of palliative care discussion as discussing issues associated with the terminal condition of the patients, issues about withdrawal of life-sustaining treatments, or providing patients and their families with end-of-life information. The validity of the questionnaire was examined by two medical doctors and five palliative care nurses who had at least 10 years of experience in clinical care. We then conducted a pilot test of the questionnaire with 20 medical professionals comprising nurses, attending physicians, and residents, and then revised the questionnaire according to the results of the pilot testing. The final questionnaire used in the survey contained both open-ended and closed-ended questions and was administered by the participants themselves. As shown in Table 1, the questionnaire comprised four components that assessed the following: experiences of discussing DNR; willingness to discuss palliative care when caring for terminally

Table 1

Questionnaire to assess nurses' experiences of DNR discussion and willingness to discuss palliative care

Experiences in discussing DNR and palliative care
Have you ever actively initiated discussions about DNR with patients?
Have you ever actively initiated discussions about DNR with patients' families?
Willingness to discuss palliative care
Will you discuss palliative care decisions with patients when caring for terminally ill patients in the future?
Will you discuss palliative care with patients' families when caring for terminally ill patients in the future?
Open questions for the reasons for whether or not to discuss palliative care
The reasons for whether or not to discuss palliative care with patients
The reasons for whether or not to discuss palliative care with patients' families
Demographic information
Sex, age, educational level, religious beliefs, and marital status

DNR = do-not-resuscitate.

ill patients in the future; open questions about the reasons for deciding whether or not to discuss palliative care with patients and the reasons for deciding whether or not to discuss palliative care with patients' families; and demographic characteristics (age, sex, educational attainment, religious affiliation, and marital status).

2.4. Statistical analyses

Statistical analyses were performed using IBM SPSS version 20.0 (IBM Corp., Armonk, NY). For descriptive statistics, age was presented as mean \pm SD. Demographic characteristics including age, sex, educational attainment, religious affiliation, and marital status were presented as number (n) and percentage (%). The differences in the nurses' experiences of discussing DNR with patients and their families and the nurses' willingness to discuss palliative care with patients and their families were analyzed using the Chi-squared test. Unadjusted and adjusted logistic regressions were used to analyze factors associated with nurses' willingness to discuss palliative care with patients and their families. A two-tailed p -value < 0.05 was considered statistically significant.

3. RESULTS

One hundred twenty-eight nurses participated in this study. Their mean age was 37.2 ± 8.5 years, 112 (87.5%) were female, 109 (85.2%) were university graduates, 71 (55.5%) were single, 46 (35.9%) had no religious affiliation, and 39 (30.5%) were Buddhists (Table 2).

With regard to the nurses' experiences of discussing DNR, 78 (61.9%) had actively initiated DNR discussions with patients and 91 (72.2%) had actively initiated DNR discussions with patients' families ($p < 0.001$) in the past. Seventy (54.7%) of them had actively initiated DNR discussions with both patients and their families in the past. When asked about their willingness to discuss palliative care in future care of terminally ill patients, 102 (83.6%) respondents said that they would discuss palliative care decisions with patients and 107 (87.7%) said they would discuss palliative care decisions with patients' families ($p < 0.001$) (Table 3 and Fig. 1). Some respondents said that they would consider initiating discussions after other professionals' recommendations due to lack of experience in end-of-life care discussions and respect for other professionals' recommendations.

Unadjusted logistic regression analysis showed that the experiences of actively initiating DNR discussions with patients were a significant factor associated with palliative care discussion with

Table 2
Participant demographics

Characteristics	n	%
Sex		
Female	112	87.5
Education level		
University	109	85.2
Above university	19	14.8
Marital status		
Single	71	55.5
Married	57	44.5
Religious affiliation		
None	46	35.9
Buddhism	39	30.5
Taoism	21	16.4
General folk beliefs	19	14.8
Christian	2	1.6
Others	1	0.8

patients (OR = 2.91, 95% confidence interval [CI]: 1.09–7.79). In addition, experiences of actively initiating DNR discussions with patients and with patients’ families were significant factors associated with palliative care discussion with patients’ families (OR = 3.84, 95% CI: 1.22–12.06 and OR = 3.60, 95% CI: 1.19–10.90, respectively) (Table 4). After adjusting for covariates, no significant factors were found to be independently associated with nurses’ willingness to discuss palliative care with patients and their family members. Seventy-eight (60.9%) respondents expressed that they would discuss palliative care with patients or their families to lessen their suffering, maintain their quality of life, and lead them to a peaceful death.

4. DISCUSSION

For patients who are in the terminal stage of incurable diseases, DNR and palliative care may alleviate their suffering and allow them to have a peaceful death. There were four major findings in the present study. First, more participants had experiences of initiating discussions about DNR with patients’ families than with patients. Second, more participants reported willingness to discuss palliative care decisions with patients’ families rather than with patients. Third, unadjusted logistic regression analysis showed that active initiation of DNR discussions with patients was a significant factor associated with palliative care discussion with patients. Fourth, experiences of actively initiating DNR discussions with patients and with patients’ families were significant factors associated with palliative care discussion with patients’ families.

Nurses have the necessary professionalism and ability to initiate discussions about DNR and palliative care with patients and their families. Previous studies have shown that nurses have confidence in their ability to take part in DNR decisions and that

they should be able to initiate such discussions.^{1,2,4} Nurses play an important role in assisting patients and families with DNR decisions because they spend the most time with patients and are familiar with patients’ beliefs, values, and wishes. However, as DNR discussions usually involve complex ethical and legal issues, physicians are usually expected to take the main responsibility for initiating such discussions.¹ End-of-life decisions may be influenced by the status quo bias¹⁸ and responsibility aversion (ie, the feeling of responsibility for negative outcomes is greater when one’s decisions have the potential to harm others rather than oneself).^{18,19}

This study showed that more nurses discussed decisions with patients’ families than with patients, which is in line with the findings of some previous studies. Data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment showed that 75% of seriously ill elderly patients in the United States never discussed cardiopulmonary resuscitation with health professionals.²⁰ Pettersson et al found that almost half of the nurses and physicians in Sweden reported that patients were not likely to be involved in DNR decisions.⁷ A South Korean study conducted by Oh et al²¹ showed that discussions about DNR orders took place between physicians and patients in only one out of 143 cases. This may reflect the ethical concerns of health professionals, who may worry that suggesting DNR discussions could do more harm than good to patients. Sudore et al²² demonstrated that family involvement in medical decision-making at the end of life is associated with higher quality end-of-life care and a higher prevalence of DNR orders. Conversely, some studies have concluded that patients tend to discuss DNR decisions with doctors, preferably while they are still healthy.²³

The consciousness levels of terminally ill patients are usually suboptimal for DNR or palliative care decision-making because of poor health status and advanced disease. In addition, older adults may have an impaired ability to comprehend information about end-of-life choices because of sensory and cognitive deficits. Some families tend to avoid discussing death with patients due to cultural taboos.²⁴ Traditional Chinese culture does not encourage nurses to discuss issues associated with death; instead, nurses are expected to give hope to patients.^{15,25} There is a similar trend in Eastern countries such as Japan, South Korea, and Taiwan, where proxy decision-making by family members is frequent in DNR decisions.²¹ A previous study in Taiwan found that while DNR orders were established for 99.8% of patients with terminal cancer, 22.6% of the orders were personally signed by patients.²⁶ Another study suggested that less emphasis is placed on the autonomy of terminally ill patients in East Asia; only 5.1% of Chinese physicians and 5.9% of Korean physicians would discuss DNR orders with capable patients.²⁷ In Western countries, patient involvement in end-of-life care is more frequent. A Finnish study by Hildén et al²⁸ found that 72% of physicians always or often discussed DNR decisions with patients who were able to communicate. In our study, about 90% of the nurses who had discussed DNR decisions with patients also had

Table 3
Nurses’ experiences of DNR discussion and willingness to discuss palliative care

Items	No		Yes		p
	n	%	n	%	
Had you ever actively initiated DNR discussions with patients?	48	38.1	78	61.9	<0.0001
Had you ever actively initiated DNR discussions with patients’ families?	35	27.8	91	72.2	
Will you discuss palliative care with patients when caring for terminally ill patients in the future?	20	16.4	102	83.6	<0.0001
Will you discuss palliative care with patients’ families when caring for terminally ill patients in the future?	15	12.3	107	87.7	

DNR = do-not-resuscitate.

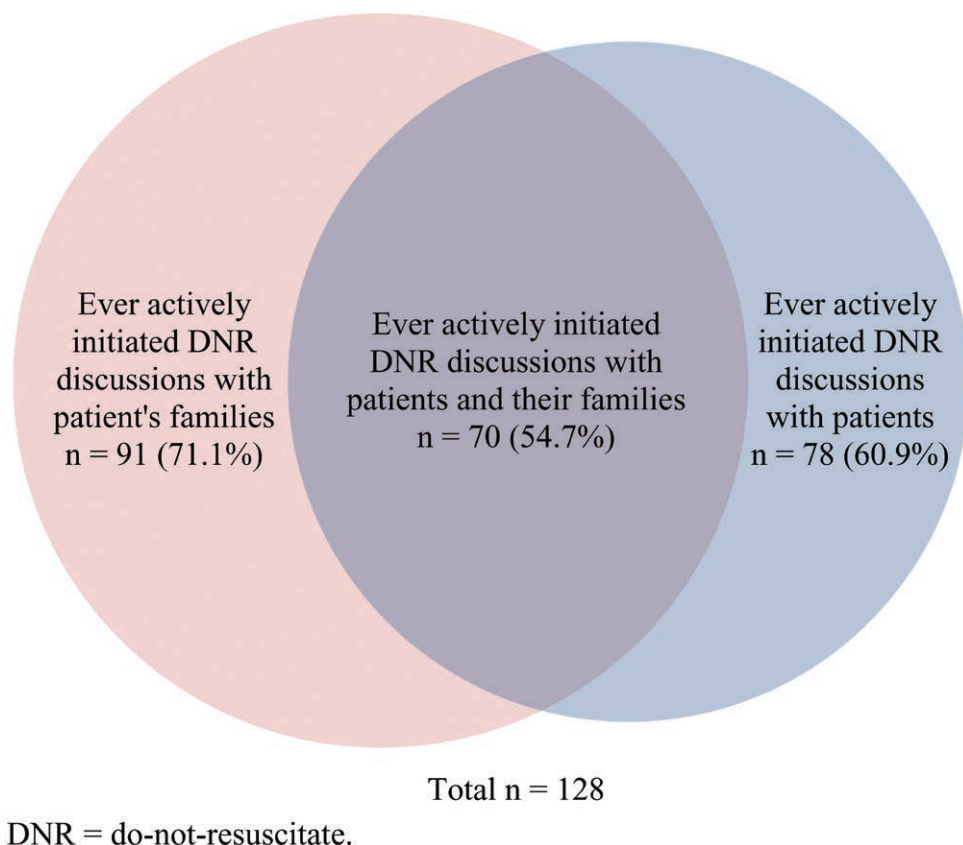


Fig. 1 Nurses' experiences of DNR discussion. DNR = do-not-resuscitate.

Table 4
Factors related to nurses' willingness regarding palliative care discussions with patients and patients' families

Variable	Discuss with patients			Discuss with patients' families		
	OR	95% CI	p	OR	95% CI	p
Experiences of actively initiating DNR discussions with patients						
No	Reference			Reference		
Yes	2.91	1.09–7.79	0.033	3.84	1.22–12.06	0.021
Experiences of actively initiating DNR discussions with patients' families						
No	Reference			Reference		
Yes	1.39	0.51–3.81	0.523	3.60	1.19–10.90	0.023
Age	0.97	0.91–1.02	0.202	1.0	0.94–1.06	0.932
Sex						
Female	Reference			Reference		
Male	1.37	0.29–6.59	0.693	0.88	0.18–4.35	0.876
Marital status						
Married	Reference			Reference		
Single	0.71	0.27–1.85	0.477	1.11	0.38–3.28	0.848
Education level						
University	Reference			—		
Above university	3.68	0.46–29.38	0.219	—		

CI = confidence interval; DNR = do-not-resuscitate; OR = odds ratio.

experiences of discussing DNR decisions with patients' families. Some respondents reported that both patients' and their families' opinions were important in the process of decision-making and that sometimes their decisions were influenced by each other. If a consensus was reached among the team members, the

nurses expressed that they would have more willingness to initiate palliative care discussions with patients and their families.

This study had some limitations. First, this was a single-center study; therefore, our results may only apply to tertiary hospitals with similar facilities. Second, the respondents were drawn only

from one tertiary hospital; therefore, the results reflect only the medical facilities in similar-level hospitals rather than the general status of medical facilities in Taiwan. Third, the results of the adjusted logistic regression did not show a significant factor that was associated with nurses' willingness to discuss with patients and their family members about DNR and palliative care and it requires further research. Additional factors, such as nurses' seniority and the duration of the discussion, could be considered in further studies.

In conclusion, the results of this study revealed that more nurses had experiences of discussing DNR decisions with patients' families than with patients. There are significant differences regarding nurses' willingness to discuss with patients and their family members about palliative care. Unadjusted logistic regression analysis showed that the nurses' experiences of actively initiating DNR discussions with patients were a significant factor associated with palliative care discussion with patients, and their experiences of actively initiating DNR discussions with patients and with patients' families were significant factors associated with palliative care discussion with patients' families. However, after adjusting for covariates, no significant factors were found to be independently associated with nurses' willingness to discuss palliative care with patients and their family members. Further research is needed to evaluate factors associated with nurses' willingness to discuss palliative care to facilitate these discussions and to protect patients' autonomy.

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