

Nurses' attitudes toward caring for terminally ill neonates and their families in Iran: a cross-sectional study

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Abstract

Providing care for terminally ill neonates is an important issue in NICUs. This research aimed to determine nurses' attitudes toward providing care for terminally ill neonates and their families. A total of 138 nurses working in neonatal intensive care units (NICUs) affiliated to Tehran University of Medical Sciences participated in this cross-sectional study via convenience sampling in 2019. The Data collection tool was the Frommelt attitudes toward caring for terminally ill persons and their families scale. The nurses in this study had the most positive attitudes toward the items "nursing care should include the family of the terminally ill patient, too" (4.2 ± 0.6) and "the care provider can prepare the patient or his/her family for death" (4.1 ± 0.7). The nurses had the least positive attitude toward the item "the time spent on caring for terminally ill patients creates a sense of frustration in me" (1.06 ± 1). The mean score of the attitudes of NICU nurses toward caring for terminally ill neonates and their families indicates the necessity of improving this attitude.

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Introduction

The development of neonatal intensive care units (NICUs) has caused new problems for the caring staff working in these wards. One of these problems is related to the provision of advanced care for neonates with poor prognoses (1). Accordingly, one of these advanced care modalities is end-of-life care provided for terminally ill neonates (2). This type of care is considered standard practice in NICUs (3). While providing therapeutic interventions for terminally ill neonates, caregivers suffer from the pain neonates might feel (4). Therefore, some countries like France have regulated rules to avoid performing therapeutic interventions in the late stages of life to respect human dignity and decrease the neonates' discomfort. It seems that these rules help care providers to make therapeutic decisions in the late stages of patients' lives. However, these rules can pose certain ethical challenges; for example, there is a probability of survival of neonates with brain tumors following a period of maintenance therapy (5).

It can be stated that decision-making about life prolonging treatments for neonates hospitalized in NICUs has led to a conflict among care providers, which makes it difficult to decide about neonates' lives (6). In this regard, some studies have emphasized the necessity of paying attention to end-of-life care for terminally ill neonates. According to Iranian nurses working in NICUs, the most important obstacles to providing end-of-life care for neonates are inadequate resources and equipment, inappropriate individual and

social attitudes, and defective organizational culture (7). Jordanian nurses, on the other hand, consider legal constraints as one of the obstacles to making decisions about neonates' end of life (3). The results of a study conducted in Korea suggested that the factors affecting these decisions are related to the clinical conditions of terminally ill neonates (8). The findings of a national survey in Belgium showed that 90-100% of nurses are willing to withdraw from providing end-of-life care for terminally ill neonates (9). In addition, the results of a study performed in the US suggested that while providing end-of-life care for neonates, nurses experience moral distress that threatens their professional progress (10). Furthermore, the results of a study performed in Vietnam suggested that 40% of the nurses respect the children's families' beliefs about continuing maintenance treatments, and 72% of them believe that these treatments should be stopped by families (11). According to a study in Canada, the factors affecting nurses' decision-making about the life of terminally ill neonates include the patients' condition (90%), the families' desire (81%), the disease characteristics (74%), and acceptance of death (36%) (12).

When the applied treatments are not effective on the neonates hospitalized in NICUs, the most important choice will be palliative care (PC) (13). PC has been used for neonates hospitalized in NICUs for more than 30 years (14). In order to provide PC in NICUs, the health care team should be familiar with this type of care, and they

should have the required support to be able to offer professional consultation in difficult conditions (15). However, the results of a study in Brazil showed that only 20% of the neonates hospitalized in NICUs received PC (16). The family members of the neonates hospitalized in NICUs also need spiritual care, because they suffer from emotional and spiritual problems such as depression and anxiety on account of their neonates' hospitalization (17).

Neonatal death is one of the most unpleasant incidents for families (18). The stated facts highlight the necessity of paying attention to the provision of spiritual care for these families. Nevertheless, PC specialists do not usually provide consultation for neonates in life threatening conditions and their families (19). Furthermore, it is possible to provide PC for neonates and their families even before birth, and this type of prenatal care provides the families with support and postpartum consult (20). Provision of PC for terminally ill neonates has not been defined clearly (21). Regarding terminally ill neonates, NICU nurses might face ethical challenges associated with end-of-life decisions including end-of-life care, cardiopulmonary resuscitation, and medical futility. In addition, the important issue that makes ethical decision-making difficult in the case of neonates is that they are not independent individuals. Thus, considerations about neonates' and their families' rights in making decisions lead to moral distress in nurses. Other issues that increase nurses' distress regarding ethical

decision-making about end-of-life-care are uncertainty about treatment results and neonates' poor prognoses (22). With regard to the importance of this issue, the present study aimed to determine the nurses' attitudes toward providing care for terminally ill neonates and their families.

Methods

This descriptive cross-sectional study was performed in the first six months of 2019. The research was performed in Children's Medical Center, Bahrami, and Arash Hospitals affiliated to Tehran University of Medical Sciences (TUMS). The population included all the nurses working in the NICUs of the mentioned centers. With a significance level of 95% and test power of 80%, 145 nurses were selected as the samples by convenience sampling. The inclusion criteria were: at least one year of work experience and full-time employment in the NICUs of the abovementioned centers. It should be added that after the distribution of the questionnaires, they were filled by 138 nurses, all of whom were women (the response rate was 98.7%).

Data were collected using a demographic characteristics questionnaire for measuring the variables of age, marital status, working record, education level, working shifts, economic status, and background of participation in PC courses. Also, the attitudes toward caring for terminally ill persons and their families scale was used as another tool. This scale has been designed by Frommelt (1991) and used for terminally ill patients of any age (23). The scale

consists of 30 items, 15 of which are expressed in a positive manner (1, 2, 4, 10, 12, 16, 17, 19, 20, 21, 22, 23, 24, 26, and 29) and emphasize the nurses' attitudes toward the role of families in caring for terminally ill patients; the remaining 15 items are expressed in a negative manner (3, 5, 6, 7, 8, 9, 11, 13, 14, 15, 18, 25, 27, 28, and 30) and are related to the nurses' fear and stress in caring for terminally ill patients. The items are scored based on the Likert scale (completely disagree, disagree, no idea, agree, and completely agree), and the overall scores range between 30 and 150. The positive items are scored from 1 to 5 and the negative items from 5 to 1, with higher scores indicating a more positive attitude to caring for terminally ill patients and their families. In Iran, the reliability of the scale for use in NICUs was evaluated and reported to be 0.7 using Cronbach's alpha coefficient (24). In this study, validity was evaluated based on content validity. For this purpose, the Persian and English versions of the tool were reviewed by 7 expert nursing professors and their opinions were applied to modify the tool. Total reliability of the tool was obtained as 0.84 based on Cronbach's alpha coefficient.

Data Analysis

Data analysis was done by descriptive statistics (frequency, percentage, mean, and standard deviation) and inferential statistics (independent t-test, and ANOVA) in SPSS 16; p -value < 0.05 was considered as the significance level.

Ethical Considerations

The present study was conducted after receiving permission from the Research Ethics Committee of TUMS (ethics code: IR.TUMS.FNM.REC.1396.3239). Also, it was supported by the Nursing and Midwifery Care Research Center, TUMS; under project No. 96-02-99-34966. The researcher explained the research goals to the nurses, and the nurses were reminded that participation in the study was optional and their information would be kept private. Then, the researcher started data collection by referring to the wards in which the nurses worked in morning and evening shifts. The time required to answer the questionnaire was determined to be 15 minutes and the whole process of data collection lasted for 4 months.

Result

According to Table 1, among the demographic characteristics, age and previous participation in PC courses were significantly related to the nurses' attitudes toward providing care for terminally ill neonates and their families ($P < 0.05$).

The nurses had the most positive attitudes toward the items "nursing care should include the family of the terminally ill patient, too" (4.2 ± 0.6), "the care provider can prepare the patient or his/her family for death" (4.1 ± 0.7), and "the family should be involved in physical caring for the terminally ill patient" (3.9 ± 1.02). The nurses' least positive attitude was related to the item "the time spent on caring for terminally ill patients creates a sense of

frustration in me” (1.06 ± 1). Table 2 presents the mean of the nurses’ answers to each item based on the 1-5 score range. The

total score of the nurses’ attitudes was reported to be 97.07 ± 8.93 .

Table 1- Frequency distribution of the demographic characteristics of the participants

Demographic Data		Number	Percentage	Test Results
Age (years)	Less than 30	41	29.1	$F = 0.322$ $*P = 0.001$
	30 - 40	85	61.6	
	More than 40	12	9.3	
Marital Status	Single	78	56.5	$t = 0.644$ $P = 0.326$
	Married	60	43.5	
Job Experience, (years)	Less than 5	15	10.9	$F = 0.662$ $P = 0.552$
	5 - 10	98	71	
	More than 10	25	18.1	
Education Level	Bachelor’s Degree	129	93.5	$t = 1.122$ $P = 0.342$
	Master’s Degree	9	6.5	
Shift Work	Fixed	28	20.3	$t=1.224$ $P=0.162$
	Rotational	110	79.7	
Previous Participation in PC Courses	Yes	40	29	$t = 0.724$ $*P = .001$
	No	98	71	
Economic Status	Good	32	23.2	$F = 0.128$ $P = 0.426$
	Moderate	64	46.4	
	Weak	42	30.4	

Table 2- Nurses’ attitudes toward caring for terminally ill neonates and their families

No	Item	Mean \pm Standard Deviation
1	Caring for terminally ill patients is a valuable experience.	2.1 ± 0.8
2	Death is not the worst thing that may happen to a patient.	1.7 ± 0.7
3	It is unpleasant for me to talk to the family of a terminally ill patient about death.	2.25 ± 0.8
4	Nursing care for the patient’s family continues until the end of their grief period.	2.4 ± 0.76
5	I don’t want to be assigned the responsibility of caring for terminally ill patients.	2.96 ± 1.8
6	The nurse is not the one to talk to the family of a terminally ill patient about death.	2.32 ± 0.88
7	The time spent on caring for terminally ill patients creates a sense of frustration in me.	1.06 ± 1
8	It is unpleasant for me to see frustration in the family of terminally ill patients.	2.4 ± 1.01
9	It is so difficult to closely communicate with the family of a terminally ill patient.	2.34 ± 0.9
10	Sometimes, the family of a terminally ill patient welcomes the death.	1.91 ± 0.8
11	When the family asks the nurse, “Is our patient about to die?” the best thing to do is talk about a happy subject.	2 ± 0.01
12	The family should be involved in physical caring for the terminally ill patient.	3.9 ± 1.02
13	I hope the patient dies when I am not on my shift.	1.94 ± 0.7

No	Item	Mean ± Standard Deviation
14	I am afraid of having a friendly relationship with the family of a terminally ill patient.	2.11 ± 0.8
15	When the patient dies, I want to leave the place.	2.08 ± 0.8
16	The family needs emotional support to be able to accept the changes in the patient's condition.	2.94 ± 1
17	Families should note that helping the terminally ill patient is the best action in the remaining days of his/her life.	2.87 ± 1.1
18	The family of a terminally ill patient should not be allowed to make decisions about physical care.	2.93 ± 1.1
19	The family should provide normal conditions for the patient as far as possible.	2.25 ± 0.8
20	It is helpful for the family of a terminally ill patient to express their emotions.	2.99 ± 1.1
21	Nursing care should include the family of the terminally ill patient, too.	4.2 ± 0.6
22	The care providers should let the family of a terminally ill patient have flexible visiting times.	3.88 ± 0.77
23	The family of a terminally ill patient should be the ones to make decisions.	3.22 ± 1.88
24	Narcotic addiction should not be the nurse's concern in the case of terminally ill patients.	2.82 ± 1.1
25	It upsets me to enter the room of a terminally ill patient and see him/her crying.	2.94 ± 1
26	The family of a terminally ill patient should receive honest answers about the patient's condition.	3.87 ± 1
27	The care providers are not responsible for training the families about death and dying.	2.48 ± 1
28	The continuous presence of family members of terminally ill patients interferes with care.	1.87 ± 1
29	The care provider can prepare the patient or the family for death.	4.1 ± 0.7
30	Nurses should avoid getting close to terminally ill patients or their families.	2.45 ± 1.06

Discussion

In the present study, the most positive attitude of the nurses to caring for terminally ill neonates and their families was related to the item “nursing care should include the family of the terminally ill patient, too”. A study conducted on Chinese nurses demonstrated that most of the subjects had a positive attitude toward paying attention to the families of these patients (25). According to the results of a qualitative study in Iran about caring for terminally ill patients, it is important to avoid harming them and respect their cultural and religious beliefs, as well as the patients' and their families' dignity (26). The results of a

qualitative study in Saudi Arabia also showed that nurses working in NICUs had the experience of providing end-of-life care while respecting the neonates' families, and that this respect remained the same even after the neonate's death (18). According to the Islamic and cultural doctrine, family institution is considered vulnerable in Iran, and therefore the nurses in this study observed this and considered the families in caring for neonates.

The second priority in the nurses' viewpoint was the item “the care provider can prepare the patient or the family for death”. In this regard, a qualitative study in Iran suggested that the families of neonates hospitalized in

NICUs want the nurses to provide them with information about their neonates' disease, and in this way, they can get prepared for the patients' death (27). The results of a study in Australia suggested that the nurses working in NICUs try to prepare the parents of terminally ill patients for their death (28). In consistence with this finding, the results of a systematic review showed that preparing the Asian parents of neonates hospitalized in NICUs for their death is affected by the families' religious and cultural beliefs (29). Accordingly, it is important for nurses to provide the families with the necessary information to prepare them for their neonates' death while considering their cultural and religious beliefs.

The third priority in the nurses' attitudes toward providing care for neonates and their families was related to the item "the family should be involved in physical caring for the terminally ill patient". According to the findings of a qualitative study in Brazil, NICU nurses consider care provision for neonates a service that should be offered while respecting the family's values, and one in which the families should preferably participate (30). These findings emphasize the necessity of the families' participation in providing physical care for terminally ill neonates. Also, they suggest the importance of family-centered care in NICUs, which should be developed in Iran. In Iran, mothers can stay with their neonates in NICUs and take part in the physical care of the neonates to encourage parental collaboration through family-centered care. However, this

opportunity is not provided for fathers or grandparents (31). As a result, since the mother is the only one participating in the physical care of her neonate, cooperation of other family members might be limited.

In this study, the least positive attitude was related to the item "the time spent on caring for terminally ill patients creates a sense of frustration in me". In this regard, the results of a systematic review showed that while providing care for neonates hospitalized in NICUs, nurses have a feeling of professional incompetence that can lead to their frustration in long term (32). It seems that the nurses participating in this study did not feel that end-of-life care was accompanied by a sense of frustration, so their attitude was not affected. In general, the total score of the nurses' attitudes to providing care for neonates and their families was 97.07 ± 8.93 . With regard to the scores range (30 - 150), it seems that promotion of the scores requires holding PC and end-of-life care training courses. In this regard, the findings of a qualitative study in Brazil showed that nurses working in NICUs claimed they had not received adequate training about PC for neonates and therefore needed support (30). According to Taiwanese nurses, the factors affecting their attitude about caring for terminally ill neonates included lack of relevant training courses and PC guidelines (33).

Moreover, the results of studies performed in Iran show that although clinical care staff members believe in the positive effects of spiritual care on patients, they have not received adequate training in these areas

(34). The most important challenge in providing end-of-life care for children is lack of spiritual and mental support by the caring staff (35). As spiritual care is a part of PC, it is obvious that nurses should receive relevant training to acquire the necessary skills for providing optimal care to neonates and their families.

Among the demographic characteristics, age and the experience of participating in PC courses had a significant relationship with the nurses' attitudes toward providing care for terminally ill neonates and their families. In other words, older nurses and those who had an experience of participating in PC courses had a more positive attitude toward providing care for terminally ill neonates and their families. The results of another study in Iran suggested that the performance of the nurses working in NICUs is affected by their age (35). The results of a study in Taiwan suggested that providing PC for neonates hospitalized in NICUs by clinical specialists is affected by age and relevant training (36). A study in China showed that nurses who had the experience of participating in courses on death-related issues had a more positive attitude toward caring for terminally ill patients (25).

One limitation of this study was that non-random sampling decreased the generalizability of the findings. Moreover, this study only investigated the nurses' attitudes, and it is suggested to investigate the doctors' attitudes about caring for terminally ill neonates and their families in

future studies.

Conclusion

Since the scores obtained through the tool used in this study ranged from 30 to 150, it seems that nurses' attitude toward the investigated issue was at a moderate level. It seems that age has a positive effect on the nurses' attitudes toward the studied issue. Taking PC training courses can promote positive attitudes in nurses by improving their knowledge of the subject. It is suggested to provide the nurses working in NICUs with end-of-life and PC training courses, as they can promote the nurses' attitude about caring for terminally ill neonates and their families. Furthermore, it is recommended to develop a pediatric PC curriculum for nurses, since it will lead to improvement of the nurses' knowledge, attitude and skill in the field of the studied issue. Also, as mentioned previously in the introduction section, nurses working in NICUs experience moral distress regarding making ethical decisions about end-of-life care for terminally ill neonates. Therefore, it is necessary to provide nurses with training programs on ethical decision-making in NICUs in order to decrease their moral distress.

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Conflicts of Interests

None declared.

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