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End-of-life Decisions at Neonatal Intensive Care Units: Jordanian Nurses Attitudes and Viewpoints of Who, When, and How

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ABSTRACT

Purpose: To explore factors predicting neonatal nurses' attitude towards end-of-life decisions in neonates, and to describe the nurses' viewpoints on end-of-life decisions; barriers to end-of-life decision making; parents', nurses', and ethical committees' involvement in the process of end-of-life decision making; and who should regulate end-of-life decisions regarding neonates.
Design and Methods: A cross-sectional descriptive correlational design was applied. Sample included 279 neonatal nurses working in 24 neonatal intensive care units across Jordan. Data were collected using internationally-accepted questionnaires. Descriptive and inferential statistics were applied in data analysis.
Results: Most nurses perceived that everything possible should be done to ensure a neonate's survival, even when they suffer severe prognosis (80%) and irrespective of the burden of the child's disability on the family (75%). Almost all nurses (96%) were against administering drugs with the purpose of ending the neonate's life and 63% were against continuing current treatment without adding others. The nurses' perceived effect of end-of-life decisions on their everyday life, and the importance of religious values to the nurses' personal lives, significantly predicted pro-life attitude scores. According to 80% of the nurses, legal constraints were the most significant barriers to end-of-life decision making. The majority of nurses (84%) indicated that non-religious bodies should establish end-of-life regulations for neonates.
Conclusion: Generally, nurses' attitude was supportive of life saving decisions at end-of-life, regardless of the survival odds and the probable health outcomes of the neonates.
Practice Implications: Neonates' end-of-life care, and parents' bereavement care, should be standard practices in every NICU, worldwide.

Introduction

When a neonate is at high risk of death or disability, and has a poor prognosis despite treatment, end-of-life decisions are often considered. The ethical debate focusing on how and when to stop treatment during the intensive care of neonates is both complex and controversial. End-of-life care constantly presents ethical challenges to healthcare professionals, including neonatal nurses. End-of-life care is one aspect of palliative care in which neonatal and palliative care nurses play an essential role to support and ensure a peaceful, dignified death for the infant (Catlin, Brandon, Wool, & Mendes, 2015).

Neonatal and palliative nurses share, with other healthcare professionals, the moral and professional obligation of caring and reducing the suffering for dying neonates. Nurses are more likely to be at the bedside during the end-of-life time of neonates than any other healthcare professionals. The nurses' roles overlap with those of the professionals from other disciplines in sharing the responsibility, and being obliged to make end-of-life decisions. The path of achieving that goal is quite unique to the scope of professional nursing practices (Epstein, 2010).

The published literature has presented an extensive exploration of the standpoints, attitudes, and practices of the healthcare professionals, medical personnel in particular, regarding neonatal end-of-life. The extensive exploration of the topic across diverse countries and cultures has moved the ethical debate about neonatal end-of-life to the forefront of the international stage (Abdallah, Radaeda, Gaghama, & Salameh, 2016; Arzuaga, Adam, Ahmad, & Padela, 2016; Eventov-Friedman, Kanevsky, & Bar-Oz, 2013; Fajardo et al., 2012; Fallahi et al., 2016; Hellmann, Knighton, Lee, & Shah, 2016; Nayeri et al., 2017; Peng, Liu, Chen, & Bachman, 2012). Despite the plethora of literature on the topic, evidence relating to the nurses' standpoints and attitudes on end-of-life decisions in the neonatal intensive care units (NICU) is limited. In previous studies on the topic, the neonatal nurses' perspectives were perhaps studied but not reported (Cuttini, Casotto, & Orzalesi, 2006; Cuttini et al., 2000; Rebagliato et al., 2000), or their attitudes were studied jointly with other healthcare professionals, mainly physicians, and reported as findings from one combined sample (Bilgen, Topuzoğlu, Kuşçu, Altuncu, & Ozek, 2009; Shivananda, Lee, Marc-

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Aurele, Hellmann, & Braid, 2013). These research approaches provided little understanding of nurses' attitudes across cultures, or about their contribution to the ongoing international ethical debate over neonatal end-of-life practices. In order for neonatal and palliative care nurses to take an active role in the complex ethical debate of how and when to stop a neonate's treatment in the NICU, it is a priority that those nurses' opinions regarding end-of-life decisions in neonates be evaluated and documented.

Pioneer studies found that the end-of-life decisions in the NICU were implemented diversely within and between countries (De Leeuw et al., 2001; Rebagliato et al., 2000; Verhagen et al., 2010), suggesting that, beyond the professional factors, there is an influence of cultural and social factors informing the healthcare providers on end-of-life decision making regarding neonates (Rebagliato et al., 2000). It is worth noting that the majority of the studies on the topic documented Western points of views and practices of neonatal end-of-life situations. However, studies on the topic in cultures from the Middle East and non-European Mediterranean countries are surprisingly few.

Jordan is a country in the Middle East with an annual neonatal mortality rate of 11 per 1000 live births in 2015 (World Bank, 2018). A recent national study showed that 79% of all neonatal deaths in Jordan occurred in the first week after birth, with over 42% occurring in the first 24 h after birth. The study also showed that congenital anomalies, immaturity, and asphyxia were among the most important causes of neonatal deaths in Jordan (Batieha et al., 2016).

The vast majority of the population in Jordan is Sunni Muslim, with the Jordanian culture often being described as moderate in its adoption of Islamic values. Religion has been a common reference informing individuals and communities in many bio-ethical controversial debates such as abortion, organ donation, and assisted death. The standpoint of Islam is clear in its opposition to euthanasia, i.e., the purposeful interruption of life (Naga & Mrayyan, 2013). However, the Islamic regulations are less specific for its use on guiding decision making on issues of withdrawing and withholding life sustaining interventions, especially regarding neonates.

In addition to that, currently there are no standardized guidelines or laws to regulate clearly and unambiguously the practices of neonatal end-of-life decision making and palliative care in Jordan. This situation may indicate that end-of-life practice in Jordan, as it may be in other countries, is largely affected by the attitudes and values of the healthcare team. However, the standpoint of the healthcare providers in general, and neonatal nurses in particular, regarding the matter of end-of-life in neonates is unclear and under-documented in Jordan. The literature describing pediatrics and neonatal palliative and end-of life care practices in Jordan are extremely limited in number and quest. The viewpoints of the Jordanian neonatal nurse as part of the healthcare team caring for neonate at end-of-life have never been documented.

The purpose of this study is to explore neonatal nurses' attitudes and viewpoints on end-of-life decisions made by health professionals for neonates with life-limiting and disabling medical conditions. Exploring the neonatal nurses' attitudes and expressed opinions on the topic could provide a base for understanding and anticipating the practices of end-of-life decision making in the NICUs of Jordan. The documented information from this study provides a reference for nurses and the healthcare professionals who are interested in improving care of neonates at their end-of-life. Additionally, the information documented in this study about the perspectives of NICU nurses in Jordan, if added to comparable evidence from other cultures of the world: i) offers additional evidence for further understanding of nurses' attitudes across cultures, ii) facilitates the nurses' contribution to improved neonatal intensive caring practices, and iii) increases the nurses participation in the ongoing international ethical debate over neonatal end-of-life practices. The objectives of this study were: a) to determine neonatal nurses' attitude towards life support and end-of-life decisions in neonates, b) to explore factors predicting nurses attitude towards life support in neonates, c) to describe nurses viewpoints on aspects related to end-of-life practice in neonates including the acceptability of common end-of-life decisions in NICU, barriers to end-of-life decision making, the supposed level involvement of parents, nurses, and ethical committees in the process of end-of-life decision making, and who should regulate end-of-life decisions regarding neonates.

Methodology

Study Design

A cross-sectional descriptive correlation design was employed. The findings presented in this paper are part of a larger study, which explored aspects of end-of-life care among neonatal nurses and physicians; only the results regarding the nurses' attitudes are included here.

Setting

Data were collected from high turnover and large NICUs located in 24 major hospitals in Jordan. The hospitals represented the public, private, and educational health sectors. The hospitals' selection process reflected the population distributed across the three geographical divisions of the country. Sixteen hospitals were located in the middle cities of Jordan, five main hospitals were located in three cities in the north, and three hospitals were major public hospitals in three cities in the south. Two of the private hospitals were faith-based hospitals. A wide socio-demographic range of the population is served by the selected hospitals and their scope of services cover both rural and urban areas in the country.

Participants

All registered nurses and nurse mangers working fulltime in the NICUs of the selected hospitals were eligible to participate. There were no exclusion criteria regarding participants' demographic or religious backgrounds and professional characteristics due to the exploratory and descriptive nature of the study.

The target sample size was calculated using G*Power (version 3) program (Faul, Erdfelder, Lang, & Buchner, 2007). A sample of 118 subjects were required to provide 80% power for detecting 0.15 effect size on a linear multiple regression analysis, adjusting for 10 independent categorical variables. An alpha level of 0.5 or less was considered significant.

A convenient sampling method was used to recruit the participants from the selected hospitals. Three research assistants collaborated with the unit managers, or facilitators (assigned from the hospitals), to invite the neonatal nurses to participate in the study and to provide any interested nurses with the research questionnaires. Free-will participation was emphasized to the units' managers, as well as the hospital facilitators, and was stressed on the study information sheet at the front page of the questionnaires. No incentives for participation were provided.

Variables and Measurements

Data for the study were collected using a internationally-accepted questionnaire. The questionnaire was an instrument originally developed for the EURONIC Project: "*Parents' information and ethical decision making in neonatal intensive care units: staff attitudes and opinions*" (Cuttini, Kaminski, Saracci, & De Vonderweid, 1997). The project was developed and adapted for implementation in several languages and cultures across the European Union (EU Contract n. BMH1-CT93-1242). The principal investigator of the project was Dr. Marina Cuttini has granted permission for the use of the instrument in this current study. The results from the neonatal nurses' version of the instrument are reported in this paper.

For this study, the original instrument was transculturally adapted following guidelines from Beaton, Bombardier, Guillemin, and Ferraz (2000) for cross-cultural adaptation of self-report instruments. The guidelines involved translation and back-translation of the questionnaire's items by bilingual experts, as well as several content revisions for clarity and cultural terminology. The tool was pilot tested on 10 nurses to explore its overall clarity and performance, before presenting the questionnaire in its final form. Data from the pilot test of the questionnaire was excluded from the main research population's data.

The survey questionnaire consisted of three sections. Results from the first two sections are reported in this paper. The first section was designed to collect socio-demographic and professional information regarding the NICUs' nurses. Variables included: a) age, b) having children, c) religion, d) perceived importance of religious values in the respondent's personal life, e) perceived effect of end-of-life decisions on the respondent's everyday life, f) involvement in caring for healthy neonates, g) taking a role in neonatal follow-up post-NICU discharge, h) participation in research activities, i) overall number of years in the nursing profession, and j) length of neonatal nursing experience.

The questionnaire's second section employed multiple choice and Likert-type questions to explore nurses' attitudes, standpoints, and opinions regarding end-of-life decisions and practices. In this section of the questionnaire, the first question included 12 attitude statements to assess nurses' attitudes towards end-of-life decision making. Responses were measured using a 5-point Likert scale ranging from: 5 = *strongly disagree* to: 1 = *strongly agree*.

A *pro-life attitude subscale* was generated from a set of 6 out of the 12 attitude statements that were, by using factor analysis, shown to be highly inter-correlated. The nurses' pro-life attitude scores represented the sum of the answers to the 6 selected statements, weighted by their factor loadings (M. Cuttini, personal communication, September 12, 2017). The nurses' pro-life attitude scores ranged from 0 to 10, with the lower scores reflecting agreement with the idea of an absolute value of life, i.e., higher pro-life attitudes. As used in this study, the internal consistency and reliability scores for the pro-life attitude scores were adequate, with Cronbach's $\alpha = 0.74$.

Further questions in the second section of the questionnaire included inquiries about nurses' opinions and standpoints regarding:

1) situations where it is acceptable to withhold active resuscitation and/or ventilation;
2) acceptability of a set of decisions, strategies, and doctor orders that are commonly made at end-of-life;
3) importance of barriers affecting end-of-life decision making;
4) parents' involvement in end-of-life decision making;
5) supposed nurses' role in end-of-life decision making;
6) ethical committees' roles in end-of-life decision making, and
7) entities that should be responsible for regulating end-of-life in neonates.

The third section of the questionnaire explored nurses' and physicians' self-reported practices regarding end-of-life decision making in the work place. Results from this section are not within the scope of this paper, and will be reported elsewhere.

Data Sources and Data Collection

Data were collected between August (2015) and February (2016). Three trained research assistants managed the data collection in collaboration with the NICU managers or assigned facilitators from the selected hospitals. The questionnaires were given to the nurses in self-sealed envelopes; the completed questionnaires were subsequently collected from the nurses through the unit managers or the facilitators. Nurses were asked to return the completed questionnaires in sealed envelopes and not to include any self-identifiers, such as names, to ensure anonymity.

The Scientific Research Committee at the School of Nursing, The University of Jordan, reviewed and approved the ethical and scientific merits of the study. Further Institutional Review Boards' (IRB) approvals were obtained from three private hospitals, one educational hospital, and the Ministry of Health (MoH) in Jordan. The IRB at the MoH permitted the data collection in all of the public hospitals in Jordan. No IRB reviews were required by the remaining hospitals; instead, managerial and departmental approvals were obtained through the hospitals' official channels.

Statistical Methods

Those questionnaires with 95% or more completed responses were included in the analysis. Descriptive statistics were applied to describe the sample's professional and demographic characteristics, as well as nurses' responses to the survey questions. Ordinal responses were grouped when necessary. A stepwise multiple regression, at 95% confidence level, was conducted to evaluate whether the nurses' demographic and professional variables predicted the pro-life attitude score. Regression analysis assumptions were verified prior to analysis. Statistical significance was taken as alpha ≤ 0.05. The statistical package for social sciences for Windows (version 21) was used for data analysis (IBM® SPSS®, Armonk, New York, USA).

Results

Sample Description

Of the 310 neonatal nurses who were invited to enroll in the study, 289 agreed and were given questionnaires, a response rate of 93%. Ten questionnaires were removed from the analysis due to missing data, reducing the final sample response rate to 279/310 = 90%. Several strategies used in this study are believed to have contributed to the increased response rate by the neonatal nurses. First of all, the research questionnaire was carefully designed by the author to be simple, comprehensible, colorful, and user-friendly. The research questionnaire was printed in the form of an attractive booklet in which colorful papers were used. Additionally, the relevance of the study topic to neonatal nursing care was highlighted in the covering letter, which formed the front page of the questionnaire, addressing and inviting the nurses to participate.

Another factor that is believed to have strongly contributed to heightening the response rate in this study is distributing the questionnaires through collaboration with a particular staff who was assigned from the nurses' working places, rather than via the researcher or research assistants. As compared to researchers and research assistants, the assigned staff from the nurses' working places were more familiar with the processes, structures, and nurses' work dynamics of the selected institutions. In addition, the collaboration with an assigned staff member from each unit allowed frequent announcements about the study for potential nurse-participants, greater tracking of participating nurses' responses, and regular reminders for participating nurses to return the completed questionnaires. Finally, several measures were taken in this study to emphasize participants' voluntary contribution, anonymity, and confidentiality. Examples include returning completed questionnaires in self-sealed envelopes and explaining research participants' rights of anonymity, confidentiality, etc., in the covering letter of the questionnaire. These measures are believed to have encouraged the nurses to participate in the study and to express their opinions freely.

The characteristics of the sample are detailed in Table 1. Over half of the respondents were between 20 and 29 years of age (56%); 48% had <5 years of experience in neonatal nursing. Some nurses reported active involvement in scientific research activities; however, 65% were not involved. Almost all (99.6%) of the respondents followed the Islamic faith; 87% perceived religious values as very important in their everyday lives.

Table 1
Sample characteristics and perceptions (N = 279).

Characteristics	F (%)	Median (interquartile range)
Nurses per hospital type		
Public	158 (56.6)	
Private	100 (35.8)	
Educational	21 (7.5)	
Nurses per geographic division		
North	65 (23.3)	
Middle	172 (61.6)	
South	42 (15.1)	
Age (years)		
20–29	152 (54.5)	
30–39	91 (32.6)	
≥40	36 (12.9)	
Having children		
Yes	145 (52)	
No	134 (48)	
Religion		
Islam	278 (99.6)	
Other	1 (0.4)	
Perceived importance of religious values in personal life		
Very important	242 (86.7)	
Important to some extent	29 (10.4)	
Not so important	3 (1.1)	
Not important	5 (1.8)	
Perceived effect of end of life decisions on everyday life		
Often	138 (49.5)	
Occasionally	122 (43.7)	
Rarely	15 (5.4)	
Never	4 (1.4)	
Involvement in caring for healthy newborns		
No	99 (35.5)	
Yes at the present	137 (49.1)	
Yes in the past	28 (10)	
Yes, both now and in the past	15 (5.4)	
Involvement in neonatal follow-up post-NICU discharge		
No	167 (59.9)	
Yes at the present	91 (32.6)	
Yes in the past	7 (2.5)	
Yes, both now and in the past	14 (5)	
Involvement in scientific research		
Yes regular	14 (5)	
Yes occasionally	84 (30.1)	
Rarely/never	181 (64.9)	
Total nursing experience (years)		6 (10)
Neonatal nursing experience (years)		4 (8)

The majority of the respondents (93%) also perceived end-of-life decisions in their workplace as affecting their everyday lives.

Nurses' General Attitudes Towards Life Support and End-of-life Decisions in NICUs

The general attitude of the nurses was positive towards life sustaining interventions, whatever the survival odds and health outcomes of the neonates. The mean pro-life attitude score was relatively low 2.84 out of 10 (SD = 1.960); a result indicating a high pro-life attitude. Examining the specific attitude items revealed that most nurses perceived that everything possible should be done to ensure a baby's survival, even when the neonate suffers: i) a severe-worst prognosis (80%), ii) would have physical (67%) and iii) mental (62%) disabilities, and iv) regardless of the disability burden on the family (75%). However, nurses' attitudes changed slightly when health care costs were considered, with fewer nurses (44%) supporting life-sustaining measures without considering the cost of treatment.

Nurses' responses varied when asked whether those common end-of-life strategies in a NICU would make a difference in relation to life ending of dying newborns. The attitude of 46% of the nurses pointed towards no difference between withholding and withdrawing intensive care, as well as between withdrawal of intensive care and administration of drugs for ending life. Nurses' responses to the attitude statements are detailed in Table 2.

A stepwise multiple regression was conducted to evaluate whether the nurses' demographic and professional variables were necessary to predict nurses' attitude scores. At step 1 of the analysis '*perceived effect of end-of-life decisions on everyday life*' entered into the regression equation and was significantly related to the attitude score $F(1,277) = 12.985$, $p < .001$. At step 2 of the analysis, '*perceived importance of religious values in personal life*' entered into the regression equation and was significantly related to the attitude score $F(2,276) = 8.943$, $p < .001$. The multiple correlation coefficient was 0.25, indicating that approximately 6% of the variance of the pro-life attitude score could be accounted for by the nurses' perceptions of the effect of end-of-life decisions on their everyday lives; together with the importance of the nurses' religious values to their personal lives. The remaining demographic and professional variables did not enter into the equation at step 3 of the analysis ($p > .05$).

Nurses' Standpoints on End-of-life Decisions for Neonates With Specific Medical Conditions

Nurses were asked their opinions regarding the acceptability of withholding emergency cardio-pulmonary support in specific medical conditions, as detailed in Table 3. Irrespective of the medical condition, the general attitude of the nurses was against allowing natural death of neonates to take its course without hospital interventions. Fifty nine percent of the nurses opposed deliberately setting limits to intensive interventions in neonates with fatal conditions, and 65% were against it in neonates with a poor neurologic prognosis. Few nurses excluded setting limits to intensive interventions for some neonates with congenital anomalies, and indicated the justification of an end-of-life decision in the narrative questions. One nurse wrote "*justifiable in some cases of neonates with multiple congenital abnormalities with poor neurologic prognosis*".

Similarly, most of the nurses (65%–79%) opposed the withholding of emergency cardio-pulmonary support in neonates with the life-limiting and disabling medical conditions detailed in Table 3, except for anencephaly and prematurity. Slightly more nurses (54.1%) supported the withdrawal of cardio-respiratory resuscitation and/or mechanical ventilation for neonates with anencephaly than those who opposed it. However, the nurses' views conflicted regarding withdrawing cardio-pulmonary support for severely premature and extremely low birth weight premature neonates.

Nurses' Opinions of the Acceptability of End-of-life Strategies

As shown in Table 4, the majority of the nurses considered all types of end-of-life strategies, which are usually taken to limit neonatal intensive care, as unacceptable. Responses ranged from 96% of the nurses being against administering drugs with the purpose of ending the neonate's life, to 63% of the nurses being against continuing current treatment without adding or trying other options.

Nurses' Views on Barriers Affecting End-of-life Decisions Making in NICU

Nurses were asked to rate the importance of barriers commonly encountered by health professionals during the process of end-of-life decision making in the NICU (Table 5). Consensus was obvious among the nurses that all of the barriers were 'important' to 'very important' when making a decision to limit the intensive care offered to neonates. Legal constraints related to end-of-life decision making posed particularly significant problems during the process of setting life-limits in the NICUs, according to 80% of the nurses. The nurses were split equally

Table 2
Nurses' attitudes towards end-of-life decisions in NICU.

End-of-life attitude statement	Nurses' responses F (%)		
	Disagree/strongly disagree	Undecided	Strongly agree/agree
Even with severe physical disability, some life is always better than no life at all	58 (20.8%)	33 (11.8%)	188 (67.4%)
From an ethical point of view, there is no difference between withdrawal of intensive care and administration of drugs with the purpose of ending life	117 (24%)	34 (12.2%)	128 (45.8%)
Because humane life is sacred, everything possible should be done to ensure a baby's survival, however severe the prognosis	28 (10%)	28 (10%)	223 (79.9%)
The burden that a disabled child will represent for the family is not so relevant when making ethical decisions for that baby	38 (13.7%)	33 (11.8%)	208 (74.6%)
Even with severe mental disability, some life is always better than no life at all	61 (21.9%)	44 (15.8%)	174 (62.3%)
The increasing costs of health care for preterm newborns and disabled children do not allow us to treat each patient regardless of outcome	123(44.1%)	51(18.3%)	105(37.7%)
Limiting intensive care, even if only in extremely selected situations, is a "slippery slope" which will lead to abuses	64 (22.9%)	54 (19.4%)	161 (57.7%)
From an ethical point of view, there is no difference between withholding and withdrawing of intensive care	98 (35.1%)	49 (17.6%)	132 (46.3%)
Withholding intensive care without simultaneously taking active measures to end the baby's life is dangerous because it makes it more likely for the baby to be severely disabled if he/she survives	74 (26.5%)	59 (21.1%)	146 (52.4%)
Intensive care is a "slippery slope" likely to lead to therapeutic aggressiveness	110 (30.1%)	54 (19.4%)	115 (41.2%)
There is no room for ethical decisions when the law does not allow any limitation of treatment	49 (17.6%)	50 (17.9%)	180 (64.5%)
Every baby should be given the maximum amount of intensive care irrespective of outcome, because the clinical experience acquired will benefit patients in the future	31 (11.1%)	26 (9.3%)	222 (79.6%)

in their opinions regarding the importance of the hypothetical notion of considering the neonates' own views, if such were possible, during the process of making the end-of-life decisions. The impossibility of obtaining the neonates' own views was considered an important barrier by 50% of the nurses, indicating that half of the nurses regarded the neonates' own perspectives, could they be known, as important to consider in such an important decision.

Nurses' Views on the Involvement of Parents, Nurses, and Ethical Committees in End-of-life Decision Making

Nurses' responses towards parents', nurses' and ethical committees' involvement in the decision of limiting intensive care are detailed in Table 6.

Parents' Involvement in End-of-life Decision Making

Nurses' attitudes towards parents' involvement in the decision of limiting intensive care varied: 71% of the nurses indicated that parents should be actively involved in the end-of-life decisions regarding their neonate(s). Out of the total sample, only 127 (46%) nurses stated their views on the reasons not to involve the parents in end-of-life decisions (Table 7). Parents' inability to understand fully the possible options and consequences of the healthcare was the most commonly reported reason (85%) of why parents should not be involved.

When parents request a limitation of intensive care against a medical opinion of continuing treatment, 72% of the nurses' considered the medical staff should be the decision-makers, and only 17% reported that the decisions should be for the parents. When the situation was reversed, (i.e., when parents request continuation of intensive care, while the medical staff think that treatment should be suspended), more nurses (45%) perceived that the decision should be for the parents and 48% of the nurses indicated that the decision should be made by the medical staff.

Nurses' Involvement in End-of-life Decision Making

More than half of the nurses (53%) believed that they should be involved in discussions about limiting intensive care for neonates, but that they should not take part in the ultimate decision making. In comparison, only a minority of nurses (16%) believed that they should be involved in both the end-of-life discussions and in making the final decision; a limited few (8%) believed they should not be involved at all.

Ethical Committees' Involvement in End-of-life Decision Making

Only 21% of the nurses indicated that the ethics committee should be responsible for ultimate decisions regarding individual cases. However, 41% of the nurses indicated that the ethics committees should not intervene in decisions regarding individual cases; rather, such committees should contribute in setting general guidelines for end-of-life decisions. Interestingly, a considerable number of nurses (31%) reported not knowing what an ethics committee is or does.

Nurses' Views on Who Should Establish End-of-life Regulations in the NICU

Nurses' opinions varied when nurses were asked about who should establish regulations for ethical decision making in neonatal intensive care in Jordan. Generally, the nurses were divided almost equally in their opinion between ethical committees (26.5%) and that each hospital should decide its own policy (26.5%). Slightly more nurses (30.8%) indicated that the professional bodies, such as the country's 'Higher Council of Medicine', should establish the end-of-life regulations. A small number of nurses (16.1%) indicated that religious committees should establish such regulations.

Table 3
Nurses' attitudes of withholding emergency cardiopulmonary support in neonates with specific medical conditions.

Medical condition	Nurses' responses F (%)			
	Always	Usually	Sometimes	Never
Thoracolumbar myelomeningocele	30 (10.8)	49 (17.6)	74 (26.5)	126 (45.2)
Fatal chromosomal abnormality (such as trisomy 13)	41 (14.7)	58 (20.8)	64 (22.9)	116 (41.6)
Severe congenital hydrocephalus	34 (12.2)	54 (19.4)	78 (28.0)	113 (40.5)
Down's syndrome with severe congenital heart malformation	16 (5.7)	42 (15.1)	57 (20.4)	164 (58.8)
Severe asphyxia in full-term baby	29 (10.4)	30 (10.8)	40 (14.3)	180 (64.5)
Anencephaly	82 (29.4)	69 (24.7)	40 (14.3)	88 (31.5)
Gestational age below 24 complete week	74 (26.5)	46 (16.5)	64 (22.9)	95 (34.1)
Birth weight below 500 g in premature baby	56 (20.1)	91 (21.9)	59 (21.1)	1.3 (36.9)

Table 4
Nurses' responses to the acceptability of end-of-life strategies in NICU.

End-of-life strategies	Nurses' responses F (%)	
	Acceptable	Not acceptable
Withholding intensive care (e.g. resuscitation at birth, mechanical ventilation)	34 (12.2)	245 (87.8)
Withholding emergency treatment/maneuvers (e.g. resuscitation for cardiac arrest)	19 (6.8)	260 (93.2)
Withholding surgery	38 (13.6)	241 (86.4)
Continuing current treatment, but without adding others	102 (36.6)	177 (63.4)
Refraining from increasing the respirator parameters	68 (24.4)	211 (75.6)
Withholding antibiotics	46 (16.5)	233 (83.5)
Withholding full parental nutrition	34 (12.2)	245 (87.8)
Withholding tube feeding	50 (17.9)	229 (82.1)
Withdrawing mechanical ventilation	51 (18.3)	228 (81.7)
Withdrawing life-saving drugs (e.g. cardiotonics)	43 (15.4)	236 (84.6)
Administering sedatives and/or analgesics to suppress pain, even if this might cause respiratory depression and death	38 (13.6)	241 (86.4)
Administering drugs with the purpose of ending the patient's life	12 (4.3)	267 (95.7)

Discussion

The moral and professional obligation of caring and reducing the suffering for the dying neonate is vital to the clinical nursing practice in the NICUs. Neonatal nurses' opinions and views on end-of-life decision making are worth being explored and could indirectly reflect the actual practice of end-of-life care in the NICUs. This study has explored neonatal nurses' attitudes and opinions on end-of-life decision making in Jordan.

The general attitude of the neonatal nurses was supportive of life saving decisions at end-of-life, irrespective of the neonates' medical condition, survival odds, and health outcomes. Almost all of the end-of-life strategies were unacceptable to most of the nurses in this study. Additionally, end-of-life decisions were seen as unjustifiable in almost all of the medical conditions that are commonly associated with end-of-life decisions in the NICUs.

Studies that have exclusively explored nurses' perspectives and standpoints on end-of-life decisions in NICUs are extremely limited; a paucity of research that allows only a limited base for comparisons to be made internationally and between studies. This difficulty, in turn, leads to a limited generalizability of findings on nurses' end-of-life attitudes across cultures. However, a few similarities were found between the conservative nurses' attitudes on end-of-life in Jordan and those of nurses in Korea (Lee, Cho, Kwon, & Kim, 2017), Taiwan (Huang et al., 2013), and the nurses' and physicians' opinions in Turkey (Bilgen et al., 2009). In comparison to these studies, the findings in this current research indicate that nurses' views in Jordan are relatively more conservative and supportive of life-sustaining interventions than those of the nurses and physicians reported in the previously mentioned studies.

End-of life decisions in the NICU were often made on the basis of the neonates' low possibility of survival (Aladangady, Shaw, Gallagher, Stokoe, & Marlow, 2017; Fajardo et al., 2012; Hellmann et al., 2016; Lam, Kain, Joynt, & van Manen, 2016; Snoep, Jansen, & Groenendaal, 2018), poor cognitive and neurologic outcomes (Cuttini et al., 2000; Hellmann, Williams, Ives-Baine, & Shah, 2013; Lam et al., 2016; Shivananda et al., 2013), and poor quality of life if they do survive (Aladangady et al., 2017; Hellmann et al., 2016; Lam et al., 2016; Snoep et al., 2018). However, the current findings indicate that such reasons for end-of-life decisions were not considered justifiable among most of the nurses in this study, for making such decisions in the NICUs. Rather, the nurses' life-saving attitudes in Jordan were mainly motivated by the belief that human life is sacred and that irrespective of the outcomes, the maximum amount of intensive care should be given to every neonate, regardless of his or her condition.

Demographic and professional characteristics of the nurses, such as age, religion, having children, and years of experience, did not explain the nurses' pro-life attitudes. Rather the attribute of the importance of both religious traditions and end-of-life decisions to the nurses' personal lives were what predicted the nurses' pro-life attitudes. Demographic and professional characteristics of nurses were not found to be significant in determining the nurses' attitudes in other comparable studies in Korea (Lee et al., 2017) and Taiwan (Huang et al., 2013). This study's findings indicate the importance of personal values in determining the nurses' attitudes towards end-of-life decisions. The nurses' attitudes and personal values could possibly reflect the practice of end-of-life decision making in Jordan's NICUs; especially that standardized policies and regulations to inform and direct the end-of-life practice involving neonates are limited in Jordan.

The nurses' attitudes were supportive to maximum intensive care, even when disagreements could possibly emerge between neonates' parents and the healthcare team. Consistent with the nurses' pro-life attitudes, the nurses supported the medical authority over the parents' autonomy when the parents were against life sustaining treatment at the end of the neonate's life. Parents' inability to understand the complexity of the healthcare provided to neonates was perceived as a top reason in this study for not involving parents in end-of-life decisions. However, recent research suggests that the capacity of parents to understand complex healthcare issues should not be underestimated by the healthcare team. Despite the parents' intense emotions of anxiety, grief, and distress, parents were able to participate actively with the healthcare team in making end-of-life decisions (de Vos et al., 2015). Making an end-of-life decision is particularly challenging to the healthcare professionals, who should not only consider the best interests of the neonates but also should account for the interests of the child's parents.

Table 5
Nurses' perceived importance of barriers related to end-of-life decisions in NICU.

Barriers to end-of-life decisions	Nurses' responses F (%)			
	Very important	Important	Not very important	Irrelevant
Difficulty of making an accurate long term prognosis	88 (31.5)	119 (42.7)	41 (14.7)	31(11.1)
Legal constraints	91 (31.6)	135 (48.4)	34 (12.2)	19 (6.8)
Lack of consistent unit policy to guide you	95 (34.1)	103 (36.9)	42 (15.1)	39 (14)
Conflict between your own principles and Unit policy	87 (31.2)	115 (41.2)	37 (13.3)	40 (14.3)
Difficulty of interpreting parents' attitudes precisely	96 (34.4)	120 (43)	40 (14.3%)	23 (8.2)
Society's lack of solidarity for disabled	101 (36.2%)	97 (34.8%)	36 (12.9%)	45 (16.1)
Insufficient time for decision making	60 (21.5)	128 (45.9)	39 (14)	52 (18.6)
Impossibility of obtaining the newborn's own views	69 (24.7)	72 (25.8)	39 (14)	99 (35.5)
Difficulty of foreseeing future developments in medicine which may help babies who now appear hopeless cases	72 (25.8)	127 (45.5)	53 (19)	27 (9.7)
Shortage of services for the disabled	100 (35.8)	112 (40.1)	36 (12.9)	31 (11.1)
Difficulty in foreseeing patient's future quality of life	77 (27.6)	107 (38.4)	54 (19.4)	41 (14.7)

Table 6
Nurses' responses towards parents, nurses, and ethics committee's involvement in the end-of-life decisions.

	F (%)
If a decision about whether or not to limit intensive care for a baby is under consideration, should the parents be involved as a rule?	
Yes, they should have the opportunity to choose the course of action for their baby	69 (24.7)
Yes, they should have the opportunity to take part in the decision	128 (45.9)
No, but their attitudes and wishes should be indirectly sounded out and taken into account	30 (10.8)
No, but they should be informed about the decision taken	43 (15.4)
No, they should neither be involved nor informed about decision	9 (3.2)
If parents request a limitation of intensive care, while the medical staff think that treatment should be continued, who should be the ultimate decision-maker?	
Parents	46 (16.5)
Medical staff	200 (71.7)
Others	33 (11.8)
If parents request continuation of intensive care, while the medical staff think that treatment should be suspended, who should be the ultimate decision-maker	
Parents	126 (45.2)
Medical staff	133 (47.7)
Others	20 (7.2)
What do you think the nurses' role should be in making decision about whether or not to limit intensive care?	
They should not be involved	21 (7.5)
They should be involved in the discussion but not take part in the ultimate decision making	149 (53.4)
They should be involved in the discussion and in the ultimate decision making	44 (15.8)
They should take part in the ultimate decision making share ethical-legal responsibility for it with the doctor	61 (21.9)
Other	4 (1.4)
What do you think the ethics committee's role should be in making a decision about whether or not to limit intensive care?	
It should have no role	17 (6.1)
Its only role should be the be setting general guidelines, but not intervening in decisions regarding individual cases	115 (41.2)
It should have the role of giving advice on decisions regarding individual cases	58 (20.8)
It should be responsible for ultimate decisions regarding individual cases	86 (30.8)
Other	3 (1.1)

Previous studies indicate that involving parents in end-of-life decisions in neonates varied widely among and between countries (Bilgen et al., 2009; Cuttini et al., 1999; McAdams, McPherson, Batra, & Gerelmaa, 2014). However, in general retrospective evaluation of NICU records shows that the degree of parental involvement in the end-of-life decision process for neonatal infants has increased, and those parents have become more active over the years (Eventov-Friedman et al., 2013; Weiner, Sharma, Lantos, & Kilbride, 2011). No doubt, the neonates' parents and the healthcare team should make end-of-life decisions jointly. However, there are few descriptions in the literature of how end-of-life decisions are actually negotiated between the healthcare team and the parents. There is also minimal evidence of the degree of nurses and parents' involvement in the decision. However, some studies have indicated that nurses are the least likely, out of all the healthcare team members, to be involved in the actual discussion with the parents on end-of-life decisions regarding children (de Vos et al., 2015; McAdams et al., 2014). In this current study, nurses preferred a limited role and responsibility in making the end-of-life decisions; however, quite substantial proportion of nurses preferred to be involved at least in the end-of-life discussion.

End-of-life decisions relating to neonates provoke a wide range of often overwhelming emotions among the neonatal nurses (Bloomer, O'Connor, Copnell, & Endacott, 2015; Diel, Gomes, Xavier, Salvador, & Oliveira, 2013; Lewis, 2017). This could explain why nurses in this study prefer a limited role in end-of-life decision making. Delicate issues and emotional factors such as responsibility, grief, anger, guilt, powerlessness and helplessness, alongside unhealthy coping strategies, were documented among neonatal nurses in relation to neonates' end-of-life events (Lewis, 2017). Education on end-of-life care has been reported to improve nurses' comfort levels in providing such a demanding service (Corcoran, 2016; Zhang & Lane, 2013). Therefore, it has been recommended that psychological support and counseling should be available for those nurses caring for neonates at end-of-life, whenever such help is needed (Kenner, Press, & Ryan, 2015).

The finding about nurses' opinions of wanting only a limited role in end-of-life decision making could be further explained by those nurses' perceived professional roles. Epstein (2010) suggested that nurses see their roles in providing care for dying neonates and their parents as more critical than participating in making the decision itself. Nurses perceived professional obligations related to preparing parents and providing them with comfort around the end-of-life time of neonates. In comparison, physicians' stated obligations related to decision making processes, such as talking to parents about the decision and timing regarding the withdrawal of treatment; a time of great importance for the medical role (Epstein, 2010).

Palliative care, including neonates' end-of-life and parents' bereavement care, are important nursing roles in all NICUs. Palliative care must be considered as standard care and treated as an expectation, not as an optional additional service (Kenner et al., 2015). Creating the best possible experience for parents and infants is a continuous caring goal

Table 7
Nurses' views on reasons for not directly involving parents in end-of-life decisions (N = 127).

Reasons	Nurses responses F (%)	
	Yes	No
Discussing options of limiting care may jeopardize the trust parents have in the care providers	65 (51.2)	62 (48.8)
Parents might change their mind later and sue the care providers	83 (65.4)	44 (34.6)
Once involved, parents may become intrusive and put inappropriate pressure on the staff	91 (71.7)	36 (28.3)
The responsibility for such decisions belongs solely to the care providers	64 (50.4)	63 (49.6)
Parents might change their minds later and feel guilty	98 (77.2)	29 (22.8)
Parents cannot fully understand the possible options and consequences	108 (85)	19 (15)
Parents should be spared the burden of such decisions	86 (67.7)	41(32.3)
Parents are not in the right state of mind to take such decisions	97 (76.4)	30 (23.6)

during the end-of-life phase in the NICU (Epstein, 2010; Kymre & Bondas, 2013). Guidelines and evidence-based recommendations for palliative and end-of-life care of the neonate are published, and readily available, serving to direct healthcare professionals' practices in the NICU (Catlin et al., 2015; De Lisle-Porter & Podruchny, 2009; Kenner et al., 2015).

The nurses' varied responses regarding who should establish end-of-life regulations in Jordan, could be a reflection of the novelty of the of end-of-life care as a concept, and as a structured regulated practice, in the minds of the neonatal nurses in Jordan. Irrespective of the entity establishing these regulations, end-of-life standards should be integrated into clinical practice in the form of specific end-of-life policies and palliative care services at each NICU worldwide. End-of-life policies should be available in writing for all neonatal healthcare providers at all times. Additionally, the end-of-life policies should be sufficiently flexible in order to adapt to, and take account of, the cultural and personal values of both the healthcare providers and the neonates' families.

The establishment of end-of-life regulations in Jordan will require comprehensive education and training of the healthcare professionals and others; both those individuals who are directly and indirectly involved in making the end-of-life decisions. This cohort will include, but is not limited to, parents, physicians, nurses, administrators, and stakeholders in the Jordanian health care system.

Limitations

This study is a descriptive correlational study that used a non-probability sampling approach to collect self-reported data. Such a method is known to have limited control over a research sample's characteristics, return rate of self-reported questionnaires, and confounding data (Polit & Beck, 2014). Nevertheless, the study method was appropriate to investigate a topic with limited previous evidence among a geographically widespread sample. In addition, the issue of end-of-life decisions might be perceived by some Jordanian as a sensitive subject which, if that supposition is true, has limitations regarding the validity of responses obtained via the use of self-report questionnaires. The methods used to ensure anonymity in this study could have an advantage in minimizing this limitation.

Conclusion

The findings of this study provide a base for understanding and anticipating the practices of end-of-life decision making in the NICU, as well as adding more evidence to the international ethical debate associated with neonatal end-of-life decision making and practice. Quality neonates' end-of-life care, and parents' bereavement care, should be standard practices in every NICU, worldwide. Multidisciplinary approaches to decision making should be the bases for providing high-quality, dignified neonatal end-of-life care in the clinical practice. The roles of parents and the clinical ethical committees in end-of-life decisions should be activated and supported to facilitate the process of making dignified and culturally sensitive end-of-life decisions for dying neonates as well as their families. Nurses should have an active role in the ethical debate of 'when and how' to limit intensive care provision for neonates. Therefore, nurses and healthcare providers in general, need to be aware of the processes of making effective multidisciplinary end-of-life decisions; the same personnel also need to be aware of the importance of their own, the parents, and the ethical committees' involvement in shaping controversial clinical decisions.

Therefore, the nursing body of knowledge needs to be supported with further research designed to explore nurses' standpoints and views on neonatal end-of-life care practices, as well as examining associated decision making, on both national and multinational levels. Further research is also recommended to: a) describe current neonate-related end-of-life practices and b) to evaluate the quality of neonatal end-of-life caring practices. More studies are needed to describe the decisions making processes informed by "how?" and "on what?" basis such decisions are determined in clinical practice. Finally, the nursing body of knowledge will benefit from further research evaluating the degree of as well as ways to improve parental and nurses' involvement in the end-of-life decision making process for dying neonates in intensive care units.

CRediT Authorship Contribution Statement

Nadin M. Abdel Razeq: Conceptualization; Methodology; Funding acquisition; Validation; Project administration; Data curation; Formal analysis; Writing – original draft; Writing – review & editing.

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N. Abdel Razeq designed and carried out the full study and exclusively wrote the final version of the study report.

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