

Original Article

Views and Decisions of Physicians in Encountering Neonates with Poor Prognosis

Fatemeh Nayeri MD¹, Fariba Asghari MD², Ali Baser MD³, Leila Janani MD⁴, Mamak Shariat MD¹, Bita Eabrhim MD⁵

Abstract

Background: With the development of neonatal intensive care units (NICUs), new issues have emerged for physicians working in this area, including the ethical aspects of providing invasive and advanced care to neonates with extremely poor prognosis. This research was undertaken with the aim of investigating the factors affecting physicians' practice in management of newborns in such complicated circumstances.

Methods: A cross-sectional study was carried out over a period of 5 months (Jan 2012 to Jun 2012) in 9 different tertiary levels and academic NICUs affiliated to Tehran University of Medical Sciences in Tehran, Iran. Checklists related to management of 3 hypothetical cases with very poor prognosis and factors affecting pertinent decisions were administered to 88 neonatologists and pediatricians.

Results: Totally, 81.4% of participants approved the use of advanced invasive methods of treatment in the premature neonate. Concerning the neonate with genetic malformations, 51.3% recommended advanced methods. In severe asphyxia, 42.1% disagreed with use of advanced invasive procedures. Overall, 34.2% of the target physicians approved the use of aggressive procedures in all 3 cases. Age, gender, marital status, parental status, and work experience were identified as influencing factors.

Conclusions: With the prediction of acceptable levels of survivability in very premature infants, physicians are more inclined to treat this group. However, they do not favor aggressive measures in infants with severe asphyxia and advanced anomalies.

Keywords: Invasive procedure, neonatal intensive care units, newborns, prognosis, resuscitation, viability

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Introduction

With the ever-increasing expansion of neonatal intensive care and the possibility of survival of critically ill infants, neonatologists are faced with new issues including invasive and highly advanced care for infants with very poor prognoses or infants who will have very low quality of life (QOL) in case of survival. Severe prematurity, advanced asphyxia, congenital malformation incompatible with life, and advanced metabolic disorders are instances of such cases. In this regard, 2 theories have been proposed; sanctity of life and quality of life. Sanctity of life reflects beliefs on the inviolability of life regardless of illnesses and outcomes of infants and, therefore, necessitates that any and all measures be taken for every infant. The second theory allows the withholding and withdrawing of advanced care in cases involving poor QOL.¹ Each of these theories has supporters.

In industrialized countries, some physicians prefer to take all measures to save the lives of newborns with very poor

prognosis, while others merely recommend supportive care for such newborns.^{2,3} For example, in 2007, policies were established whereby physicians could, with the support of families, make decisions about continuation or withdrawal of advanced care.⁴ The major issues that medical personnel and responsible physicians are faced with include religious beliefs, as well as ethical and legal aspects of the problem. Is continuation of expensive and advanced treatments incumbent upon medical personnel for saving the lives of newborns in cases where there is little hope for survival or a desirable degree of QOL, or should measures only include supportive care and pain relief? In highly developed countries, the second policy has many supporters. Protocols have even been written for making decisions about end of life.^{2,3} In Iran, perhaps due to the religious view, physicians decide on advanced measures for treatment. However, as there are a limited number of studies on the views of neonatal intensive care unit (NICU) personnel, including physicians and nurses, and parents of such babies, this question cannot be answered in all certainty. Hence, the necessity of this research is manifest. As a result, the present research was designed and implemented with the aim of examining the practice of neonatologists and pediatricians working in the NICUs of hospitals affiliated to Tehran University of Medical Sciences, Tehran, Iran.

Materials and Methods

A cross-sectional, descriptive, and analytic study was performed over a period of 5 months (January 5, 2012 to June 4, 2012) in all 9 teaching NICUs affiliated with Tehran University of Medical Sciences. These ICUs had between 6 and 30 active

Authors' affiliations: ¹Family Health Institute, Maternal-Fetal and Neonatal Research Center, Tehran University of Medical Sciences, Tehran, Iran, ²Medical ethics and History of Medicine Research Center, Tehran University of Medical Sciences, Tehran, Iran, ³Pediatric Department, Arak University of Medical Sciences, Arak, Iran, ⁴Department of Biostatistics, School of Public Health, Iran University of Medical Sciences, Tehran, Iran, ⁵Family Health Institute, Breastfeeding Research Center, Tehran University of Medical Sciences, Tehran, Iran.

Corresponding author and reprints: Bita Ebrahim MD, Family Health Institute, Breast Feeding Research Center, Tehran University of Medical Sciences, Vali-e-Asr Hospital at Imam Khomeini Complex, Keshavarz Blv, Tehran, Iran. Tel: +98-21-61192357, Fax: +98-21-66591315, E-mail: BitaEbrahim@yahoo.com.

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beds and between 26 and 50 admissions per month. The NICUs allowed for the possibility of prolonged use of ventilators. Physicians were present in the NICUs in all shifts throughout the 24-hour period. All physicians working in the NICUs, including neonatologists, pediatricians, and neonatology and pediatric residents, were included in the study. First, interviewers administered a questionnaire to participants in order to gather necessary information including their age, gender, marital status, number of children, health status of children, level of education, and work experience. Next, participants were presented with 3 questionnaires based on measurement instruments in clinical ethics⁵ as follows:

I. You are present in the delivery room as an infant is born with a gestational age of 26 weeks. After birth, the infant starts crying by itself and the cry sounds weak. The infant has a heart rate of 120 beats per minute. The infant is limp, its eyes are closed, and its skin is thin and transparent. Its weight is approximately 550 to 600 grams.

II. After a natural birth, a 35-week neonate is transferred to your unit. It has clear manifestations of trisomy 18, including low-set and malformed ears, prominent occiput, micrognathia, short sternum, overlapping flexed fingers, and cleft palate. This diagnosis is confirmed by chromosomal analysis.

III. Due to long-term umbilical cord prolapse, a neonate is born at a gestational age of 37 weeks with a weight of 2900 grams. The infant's shape was normal at birth. However, the infant is limp, has low muscle tone with cyanosis. The infant could not breathe by himself. Resuscitation was performed and the infant was transferred to the NICU. The infant is now 35 days old. Its pupils are fixed and dilated. All 4 limbs are characterized by spastic paralysis. The infant is dependent on gastric feeding tubes and cardiopulmonary support. The neurologist believes that all the infant's movements are spinal reflexes. According to the neurologist, there is little chance of long-term survival and no chance of functional development.

The questionnaires, which were based on measurement instruments in clinical ethics,⁵ were translated, and then, approved by 5 experienced neonatologists. Next, the participants were asked to complete a questionnaire based on a 5-point Likert scale (ranging from strongly agree to strongly disagree) concerning what measures they would approve of with respect to these three cases including aggressive care, conservative care, or palliative care. The measures and services were as follows:

Aggressive Care

This includes all necessary, practical measures that must be taken to preserve the life of the infant. These measures may involve initiation or continuation of mechanical ventilation, medication in order to preserve and protect vital organ functions, and other invasive measures such as intubation and surgery.

Conservative Care

This type of care covers initiation and continuation of a limited number of treatments for the neonate such as administration of oxygen through noninvasive methods, suction, and feeding. It does not include invasive measures such as intubation, mechanical ventilation, or surgery.

Palliative Care

No interventions are initiated or continued except those aimed at warming the infant and making it as comfortable as possible.

It must be noted that the questionnaires were anonymous, no accountability was involved, and no fee was imposed. Moreover, the study did not involve the treatment of any actual infants. The study was approved by the research ethics committee of Tehran University of Medical Sciences.

Statistical Analysis

Mean \pm standard deviation and frequency were utilized for the presentation of quantitative and qualitative variables, respectively. Intergroup qualitative variables were compared using the Chi-square test or Fisher's exact test and intergroup quantitative variables were compared using the independent *t*-test. SPSS software (version 20, SPSS Inc., Chicago, IL, USA) was employed for data analysis and a *P*-value of less than 0.05 was considered statistically significant.

Results

The participants included 88 medical doctors from several different medical centers. The participants' characteristics are presented in Table 1.

The participants' views, based on a 5-point Likert scale (ranging from strongly agree to strongly disagree), concerning what measures they would approve of with respect to these 3 cases, including aggressive care, conservative care, or palliative care, are presented in Table 2.

Overall, 70 responding physicians (81.4%) supported the use of aggressive measures in premature infants. Concerning infants with genetic malformations, 41 respondents (51.3%) agreed with aggressive measures. In the case of infants with severe asphyxia, 38 physicians (42.1%) were in favor of aggressive measures. Overall, 34.2% of the target physicians approved of using aggressive procedures in all 3 cases.

It should be noted that even though the 5-point Likert scale was implemented in the questionnaires, for the purposes of simplifying calculations and arriving at tangible results, "strongly agree" and "agree" were grouped as one category. All the rest were considered as another group. Thus, in the final analysis, there were only 2 groups; those who agreed with the measures and those who disagreed. The results of downscaling are presented in Table 3.

A significant number of women agreed with palliative care in infants suffering from genetic disorders ($P = 0.030$) or asphyxia ($P = 0.026$). Unlike married participants, overall, single respondents agreed with palliative measures in premature infants ($P = 0.009$). Married participants were significantly in favor of aggressive measures in neonates with genetic disorders ($P = 0.042$). The average age of physicians who approved of aggressive measures in premature infants and infants with genetic disorders was significantly higher than those who disagreed ($P = 0.018$ and $P = 0.017$, respectively). The average age of participants who disagreed with palliative measures in premature infants was significantly higher than the advocates ($P = 0.001$). The work experience of supporters of palliative measures in premature infants was significantly lower ($P = 0.014$).

Discussion

The participants of this study included neonatologists, pediatricians and pediatric residents working in the NICUs of 9 hospitals affiliated with Tehran University of Medical Sciences.

Table 1. Characteristics of participants

| | Frequency | Valid Percent |
|---|-----------|---------------|
| Sex | | |
| Male | 61 | 69.3 |
| Female | 27 | 30.7 |
| Age | | |
| < 35 | 36 | 40.9 |
| > 35 | 52 | 59.1 |
| Marital Status | | |
| Married | 70 | 79.5 |
| Single | 18 | 20.5 |
| Children (was reported for married subjects) | | |
| Yes | 50 | 71.4 |
| No | 20 | 28.6 |
| Profession | | |
| Pediatric resident | 45 | 51.1 |
| Pediatrician | 23 | 26.1 |
| Fellow of neonatology | 10 | 11.4 |
| Neonatologist | 10 | 11.4 |
| Work experience (years) | | |
| < 5 | 42 | 47.8 |
| > 5 | 46 | 52.2 |
| Disabled child/children | | |
| Yes | 1 | 2.0 |

Table 2. Summary of views of participants

| | Premature infants | | | Infants with genetic abnormalities | | | Infants with severe asphyxia | | |
|-------------------|---------------------------|--------------------|--------------------|------------------------------------|--------------------|--------------------|------------------------------|--------------------|--------------------|
| | Frequency (valid percent) | | | Frequency (valid percent) | | | Frequency (valid percent) | | |
| | Aggressive Care | Conservative Care | Palliative Care | Aggressive Care | Conservative Care | Palliative Care | Aggressive Care | Conservative Care | Palliative Care |
| Strongly disagree | 3 (3.5%) | 23 (31.5%) | 37 (51.4%) | 13 (16.3%) | 13 (16.3%) | 17 (23.3%) | 24 (31.6%) | 12 (15.6%) | 18 (23.1%) |
| Disagree | 7 (8.1%) | 16 (21.9%) | 12 (16.7%) | 19 (23.8%) | 12 (15.0%) | 12 (16.4%) | 14 (18.4%) | 14 (18.2%) | 16 (20.5%) |
| No comment | 6 (7.0%) | 8 (11.0%) | 6 (8.3%) | 7 (8.8%) | 11 (13.8%) | 10 (13.7%) | 6 (7.9%) | 9 (11.7%) | 5 (6.4%) |
| Agree | 15 (17.4%) | 14 (19.2%) | 6 (8.3%) | 17 (21.3%) | 24 (30.0%) | 12 (16.4%) | 13 (17.1%) | 21 (27.3%) | 17 (21.8%) |
| Strongly agree | 55 (64.0%) | 12 (16.4%) | 11 (15.3%) | 24 (30.0%) | 20 (25.0%) | 22 (30.0%) | 19 (25.0%) | 21 (27.3%) | 22 (28.2%) |
| Total | 86 (100.0%) | 73 (100.0%) | 72 (100.0%) | 80 (100.0%) | 80 (100.0%) | 73 (100.0%) | 76 (100.0%) | 77 (100.0%) | 78 (100.0%) |
| Missing | 2 | 15 | 16 | 8 | 8 | 15 | 12 | 11 | 10 |

The aim of the study was to investigate the behavior of the participants when encountering critically ill infants or infants with very poor prognoses. Considering the increasing development of NICUs throughout Iran and the percentage of beds in neonatal units occupied by such cases, ethical issues concerning this matter are becoming more challenging. Pertaining to the lack of a precise law or national guideline considering the end-of-life decision, the decision of continuation or withdrawal of treatment in incurable cases depends solely on the physician. In the long run, this decision may have an important effect on the future of families and the society as a whole. There is also the possibility that physicians decide on advanced treatment measures for such neonates under the influence of the great importance placed upon human life by religion.

In a paper published by Larijani, it was reported that from a religious point of view, the physician is responsible to do everything possible to preserve the patient's life and health.⁶ Thus, in cases where use of advanced technology is possible, it is not permissible to withhold or withdraw such care unless the doctor knows for sure that the patient will die.⁶ In one study, Kachooi and Ahmadi found that 63% of physicians were against euthanasia due to religious grounds, 24% due to the right of every person to live, and 12% due to human dignity.⁷ Lashani concluded that the right to choose life or death is illegitimate, not just concerning infants, but for any person.⁸ No one has the right to even discuss killing or permitting the death of any infant, sick person, or invalid under various pretexts including strengthening the society, eugenics, faster advancement, or financial and competition-

Table 3. Summary of views of participants in terms of whether they agreed or disagreed with the measures proposed in each case

| | Aggressive | | | Conservative | | | Palliative | | | |
|---|---------------------------------|--------------|--------------|---------------------------|--------------|--------------|---------------------------|--------------|--------------|-------|
| | Frequency (valid percent) | | | Frequency (valid percent) | | | Frequency (valid percent) | | | |
| | Agree | Disagree | P-value | Agree | Disagree | P-value | Agree | Disagree | P-value | |
| General measures taken by physicians when encountering premature infants | Sex | | 0.232 | | | 0.432 | | | 0.383 | |
| | Male | 51 (85.0%) | 9 (15.0%) | 16 (32.0%) | 43 (68.0%) | 10 (20.4%) | 39 (79.8%) | | | |
| | Female | 19 (73.1%) | 7 (26.9%) | 10 (43.5%) | 13 (56.5%) | 7 (30.4%) | 16 (69.6%) | | | |
| | Marital status | | 0.735 | | | 0.261 | | | 0.009 | |
| | Married | 56 (82.4%) | 12 (17.6%) | 18 (32.1%) | 38 (67.9%) | 9 (16.1%) | 47 (83.9%) | | | |
| | Single | 14 (77.8%) | 4 (22.2%) | 8 (47.1%) | 9 (52.9%) | 8 (50.0%) | 8 (50.0%) | | | |
| | Average age (year%) | 39.18 ± 7.48 | 34.31 ± 6.05 | 0.017 | 37.84 ± 8.27 | 38.08 ± 7.69 | 0.902 | 33.41 ± 5.31 | 39.49 ± 8.01 | 0.001 |
| | Work experience (year%) | 7.51 ± 7.34 | 6.09 ± 5.62 | 0.399 | 7.94 ± 8.38 | 7.00 ± 6.75 | 0.625 | 4.55 ± 4.20 | 8.43 ± 8.07 | 0.014 |
| | Has child/children | | | 0.739 | | | 0.574 | | | 0.023 |
| | - | 17 (77.3%) | 5 (22.7%) | | 5 (27.8%) | 13 (72.2%) | | 6 (33.3%) | 12 (66.7%) | |
| + | 42 (84%) | 8 (16.0%) | | 15 (35.7%) | 27 (64.3%) | | 5 (12.2%) | 36 (87.8%) | | |
| General measures taken by physicians when encountering infants with genetic abnormalities | Sex | | 0.810 | | | 0.415 | | | 0.030 | |
| | Male | 29 (52.7%) | 26 (47.3%) | 28 (51.9%) | 26 (48.1%) | 19 (38.0%) | 31 (62.0%) | | | |
| | Female | 12 (48.0%) | 13 (52.0%) | 16 (61.5%) | 10 (38.5%) | 15 (65.2%) | 8 (34.8%) | | | |
| | Marital status | | | 0.042 | | | 0.307 | | 0.410 | |
| | Married | 36 (57.1%) | 39 (42.9%) | 36 (58.1%) | 26 (41.9%) | 25 (43.9%) | 32 (56.1%) | | | |
| | Single | 27 (29.4%) | 12 (70.6%) | 8 (44.4%) | 10 (55.6%) | 9 (56.2%) | 7 (43.8%) | | | |
| | Average age (year%) | 39.75 ± 8.78 | 35.76 ± 5.68 | 0.018 | 38.88 ± 7.12 | 37.52 ± 8.27 | 0.440 | 37.91 ± 7.29 | 38.88 ± 8.33 | 0.818 |
| | Work experience (year%) | 8.15 ± 8.15 | 6.41 ± 5.49 | 0.278 | 8.21 ± 7.17 | 6.08 ± 7.20 | 0.191 | 8.22 ± 7.42 | 7.02 ± 7.50 | 0.498 |
| | Has child/children | | | 0.145 | | | 0.611 | | 0.743 | |
| | - | 10 (45.4%) | 12 (54.4%) | | 9 (47.4%) | 10 (52.6%) | | 9 (50.0%) | 9 (50.0%) | |
| + | 27 (60.0%) | 18 (40.0%) | | 28 (59.6%) | 18 (40.4%) | | 18 (42.9%) | 24 (57.1%) | | |
| General measures taken by physicians when encountering infants with severe asphyxia | Sex | | 0.212 | | | 0.228 | | | 0.026 | |
| | Male | 25 (47.2%) | 28 (52.8%) | 25 (49.0%) | 26 (51.0%) | 22 (40.7%) | 32 (59.3%) | | | |
| | Female | 7 (30.4%) | 16 (69.9%) | 17 (65.4%) | 9 (34.6%) | 17 (70.8%) | 7 (29.9%) | | | |
| | Marital status | | | 0.782 | | | 0.569 | | 0.784 | |
| | Married | 24 (40.7%) | 59.3% | 31 (52.5%) | 28 (47.5%) | 30 (49.2%) | 31 (50.8%) | | | |
| | Single | 47.1% | 35 (52.9%) | 11 (61.1%) | 7 (38.9%) | 9 (52.9%) | 8 (47.1%) | | | |
| | Average age (year%) | 39.25 ± 8.49 | 37.09 ± 6.88 | 0.242 | 38.14 ± 6.79 | 38.20 ± 8.83 | 0.975 | 37.71 ± 7.44 | 38.25 ± 8.10 | 0.761 |
| | Work experience (years%) | 7.15 ± 7.87 | 7.62 ± 7.05 | 0.786 | 8.14 ± 8.68 | 7.45 ± 8.14 | 0.892 | 7.65 ± 7.19 | 7.02 ± 7.43 | 0.706 |
| | Has child/children | | | 0.749 | | | 0.404 | | 0.788 | |
| | - | 7 (35.0%) | 13 (65.0%) | | 8 (42.1%) | 11 (57.9%) | | 11 (55.0%) | 9 (45.0%) | |
| + | 19 (44.2%) | 24 (55.8%) | | 25 (56.8%) | 19 (43.2%) | | 21 (46.7%) | 24 (53.3%) | | |

centered motives.⁸

In the present study, only about one-third of the participants advocated aggressive measures in all cases. The others were opposed to the use of such measures in 1, 2, or 3 of the cases. Significantly more women than men approved of palliative measures in newborns with genetic disorders and asphyxia and were disinclined to take aggressive measures. Married parents were in support of aggressive measures in premature infants and infants with genetic disorders. In contrast, single participants favored palliative measures in premature infants. The average age of those supporting aggressive measures in premature infants and infants with genetic disorders and that of opponents of palliative measures in premature infants was higher than other groups. With increasing work experience, the tendency to opt for aggressive measures in premature infants also increased.

Characteristics such as age, sex, work experience, and marital and parental statuses affected performance. Differences exist between the results of this study and a study performed in Sari, Iran.⁹ In the study performed by Ghaffari Saravi, et al. most doctors were opposed to withdrawal or non-initiation of resuscitation measures for ill infants.⁹ One difference in the study by Ghaffari Saravi, et al.⁹ is that gynecologists and obstetricians were also included in the study. These differences may be related to the differences in lifestyle and workplace conditions in the two cities of Sari and Tehran. In a study, the views of doctors differed by country.¹ In Estonia and Lithuania, doctors were in support of any measure to save the patient at any price, whereas in Sweden and the United Kingdom, physicians also entered QOL into the equation.¹ Important considerations are the social and economic conditions of the society. For example, doctors living in countries with better social and economic situations (i.e. Sweden and the United Kingdom) were more inclined towards higher QOL. However, in countries with more adverse social and economic conditions such as Lithuania, the theory of the sanctity of life enjoyed greater support.¹ It seems that this observation also holds true in Iran. Doctors in Tehran, where individuals have higher social and economic levels, compared to economically lower regions, are less likely to utilize aggressive measures when faced with infants with very poor prognosis and support the theory of QOL. In a study by Wall and Partridge, the reason for limited treatment by neonatologists in 65% of cases was the importance of QOL.¹⁰

In a study performed in Taiwan, 86.5% of partakers agreed with signifying a do not resuscitate (DNR) order to parents for poor prognosis neonates.¹¹ Meanwhile, 76.9% agreed that talking to patients about DNR orders is challenging. Additionally, 94.23% agreed that the clinical ethics committee should evaluate the issue (DNR order) and confirm DNR order before the recommendation of 'DNR' to parents.¹¹

The infant's disease has been an influential factor in the performance of doctors. In a separate comparison of physician performances in each of the 3 cases, almost all doctors opted for all necessary aggressive measures in the case of premature infants. However, in cases of genetic anomalies and asphyxia, most doctors preferred not to utilize aggressive measures. This difference in performance may involve important considerations. It seems that the greater tendency in doctors to apply aggressive care to premature infants indicates that clinicians foresee a better future for such infants. Many physicians consider these infants to possess an acceptable level of viability and, therefore,

endorse all possible methods of care in such cases. Considering that most equipment and planning in neonate units are focused on care for premature infants and that such measures have met with significant success, physicians have more positive prognoses for premature infants. They do not, however, have favorable views about aggressive measures in infants with severe asphyxia and advanced abnormalities. This attitude is justified in view of the low QOL in infants with advanced asphyxia and genetic abnormalities. At present, new methods of treatment, such as therapeutic hypothermia, have led to improved prognosis in these infants. With new treatments and improved prognosis, perhaps the attitudes and performances of neonatologists and pediatricians will change in the future with regard to such cases.

A study by the Royal Dutch Medical Association suggested that end-of-life decisions in newborns should generally be seen as conditional.¹² Upon failure of treatment, palliative care should be directed at both infant and parental suffering. Furthermore, in certain cases, interventions which hasten death may be permitted.¹²

This study demonstrated that female doctors and doctors without children were more in favor of the theory of QOL. Nevertheless, in the study by Ghaffari Saravi, et al. in Sari, no difference was observed in the motives of male and female physicians.⁹

Dupont-Thibod, et al. believed that it should be explicitly stated and justified, according to the established ethical guidelines, whether the guidelines of intervention for the newborn are based on "qualitative futility" of survival.¹³ Furthermore, it should be discussed whether infants are morally different from older individuals, and the reasons behind the recommended intervention thresholds must be explained accordingly. Lastly, the interventions should change from acting on labels derived from gestational age categories alone to establishing individualized goals of care with families.¹³

In conclusion, age, sex, marital status, parental status, and work experience are influential factors in the practice of physicians. With the prediction of acceptable levels of survivability in very premature infants, physicians are more inclined to treat this group. However, they do not favor aggressive measures in infants with severe asphyxia and advanced anomalies. When a reasonable threshold of viability was foreseen for very premature infants, practitioners had greater tendency to apply remedial measures in this group. They did not, however, have a favorable view regarding invasive measures for infants with severe asphyxia and advanced anomalies.

It seems that further comparative studies are necessary on teaching and non-teaching NICU staff, working in large and small cities, religious background and religiousness, and the effect of Muslim physicians' religious beliefs on their practices compared to those with other religions.

Limitations of the study

The present study had some limitations. The questionnaires were completed based on self-report; so we did not have any supervision on their practice. This study was performed only in teaching NICUs affiliated with Tehran University of Medical Sciences. Moreover, all study participants were Muslims.

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