IJN
Iranian Journal of Neonatology
http://ijn.mums.ac.ir

Open Access

Original Article

Ethical Challenges of Saving Extremely Premature Infants Using a Grounded Theory: Iranian Neonatologists' Perception

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ABSTRACT

Background: Extremely premature infants are at greater risks of cognitive, behavioral, growth, and developmental problems, compared to the term infants. In addition to physical problems, these infants also incur a lot of emotional costs, stress, and financial burden to the family. This study aimed to explore ethical challenges and factors affecting decisions about initiation, sustain, and termination of the life of extremely premature infants that neonatologists face every day in the clinics.

Methods: The present qualitative study was conducted based on a grounded theory. The participants were 21 practitioners who were interviewed after giving consent and being briefed about the study. All interviews were recorded, transcribed, and then analyzed in this study. The data were then analyzed using Strauss-Corbin (1998) method in three phases of open, axial, and selective coding.

Results: During analysis, 1420 initial (open) codes, 19 subcategories, and two specific categories were obtained to explain the ethical challenges of decision-making on the sustaining or terminating the life of extremely premature infants. These categories included 1) Independent decision-making of physicians, followed by two subcategories of "professional decision-making based on knowledge and clinical experience" and "uncertainty about the consequences of consulting with parents", and 2) Improper conditions and facilities, followed by three subcategories of "lack of local scientific resources on medical ethics", "inefficient neonatal intensive care units", and "lack of efficient rules and guidelines". According to the obtained results, factors leading to ethical challenges included the lack of ethical and legal guidelines tailored to clinical conditions, lack of local scientific documentation in accordance with clinical conditions and health facilities available in the Neonatal Intensive Care Unit (NICU), conflicts between the current law on life preservation and moral guidelines, and lack of facilities, manpower, and equipment in the NICU.

Conclusion: A physician's decision is based on personal scientific and clinical experiences according to the conditions of the wards.

Keywords: Ethical challenges, Extremely premature infants, Physicians' decision-making

Introduction

Children born before the gestational age of 37 weeks are considered premature (1). Every year, out of 15 million neonates born worldwide, about 1 million newborns die due to premature birth complications. In developed countries, 5%-10% of the extremely premature infants develop cerebral palsy, and those without disabilities are at a greater risk of cognitive, behavioral, growth, and developmental problems, compared to term infants. These infants suffer a higher mortality rate in low-income countries due to the lack of neonatal intensive care units (NICU) and insufficient special care facilities, such as proper temperature, breastfeeding, and primary care, to prevent further infections and respiratory problems (2).

In addition to physical and clinical health problems, extremely premature infants incur a lot of emotional costs, stress, and financial burden to the family (3, 4). Since extremely premature infants are at a greater risk of death and developmental

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Please cite this paper as:
Bazmi S, Forouzandeh M. Ethical Challenges of Saving Extremely Premature Infants Using a Grounded Theory: Iranian Neonatologists' Perception. Iranian Journal of Neonatology. 2021 Apr: 12(2). DOI: 10.22038/ijn.2021.51371.1907

complications, compared to term infants, mothers' depressive symptoms appear as long-term outcomes (5). Moreover, families experience limitations in social life (6), complications of the infant's disease (7), stress, worries, and emotional burden that last for many years (8).

Accordingly, the decision to sustain or terminate the life of such infants is difficult, and in most countries, the decision to accelerate their death or prolong their life are made after discussions with parents (9). If parents disagree, the clinical team's decisions will not be practiced (10,11). Therefore, parents have the desire to participate in the infants' life supportive decisions before and after birth, and even at the end of life (12-14) since they believe that their decisions take precedence over the clinical team's in terms of the best interests of the infant (15).

Most parents are eager to be involved in the decision to resuscitate their infant in the delivery room in which religion, spirituality, and hope are very important (16). On the other hand, the amount and manner of communication between parents and healthcare providers can affect parents' decisions about their infant (2,17,18,14) because they need the healthcare providers to respond to their requests and concerns (7,19,20) and present parents with the information, possibilities, and decisions they have considered for the infant.

Numerous studies have shown that parental involvement is extremely important in the care of extremely premature infants that reduces their stress and anxiety to some extent (21). Results show that the knowledge, counseling, guidance, and basic support provided during the intervention made parents feel less stressed and boosted their self-confidence to feel qualified to provide care for an extremely premature infant, compared to parents who did not enter the study. This qualitative study showed that parental intervention had a positive and important effect on their education and support that reduced their stress (22).

Mark showed that the quality of mother-infant bonding would be effective in the growth and development of extremely premature infants. It is very difficult for parents to accept caring for their infant in the NICU and endure a difficult experience that includes parental anxiety, depression, and stress. These data suggest that physicians and nurses should be available in these departments and play a key role in facilitating the initiation of positive parent-child interactions. The study also shows that it is very important for parents to be provided with information about the infant's health status and how the equipment works, which makes parents feel more comfortable and get closer to their infant (7).

Despite these challenges, physicians and clinical teams have not well understood and recognized parental involvement in making decisions for supporting life before, during, and after childbirth (5). One of the important points in providing parents with information on the potential complications and survival rate of infants to encourage them to participate in decision-making is that the information should be based on epidemiological evidence and national statistics. This is because the outcomes, as well as medical, social, cultural, and economic factors that affect prognosis in these infants, differ from one country to another (23). Given the increasing prevalence of such infants in Iran and the development of technical and scientific advances, the subject of decision-making for sustaining or ending the life of extremely premature infants has attracted researchers' attention, and ethical decision-making is one of the important and controversial issues in pediatrics and pediatric ethics.

Therefore, it is necessary to investigate the pathology of decision-making for sustaining or ending the life of extremely premature infants in the clinical practice of neonatologists who face it every day. To the best of our knowledge, no studies have yet been conducted in this field in Iran, and there have been no presumptions or knowledge about the ethical challenges in deciding about the life of premature infants. Accordingly, a qualitative research approach is regarded as one of the best ways to understand and explain the process of ethical problems in clinical practice in neonatology (24). The mission of a qualitative approach is the attainment of knowledge about the social conditions that are conducive to behaviors, explanation of the effective and hidden social variables in which human behavior is formed, and analysis of the phenomena and concepts with a comprehensive and extended approach (25).

The present study aimed to understand the views and perceptions of neonatologists and some other related physicians in terms of ethical challenges affecting their decisions to save extremely premature infants in the current situation in public teaching hospitals and some private hospitals.

Methods

The present qualitative study was conducted based on a grounded theory using the method of "context-based theory". This method is used to discover and recognize current social processes in human interactions. The purpose of its implementation is beyond the mere description of a specific phenomenon, rather it is to formulate a theory about the dominant social processes that underlie the formation of that phenomenon. Researchers can study social processes and explain the process of formation of a phenomenon using this approach in the real conditions of its occurrence (26). In the present study, due to the multifactorial nature of moral challenges and the impact of various educational, economic, social, and cultural factors in its occurrence, the "context-based theory" approach was selected to explain the process and identify the various dimensions of this phenomenon in pediatrics. This qualitative study was extracted from a Ph.D. thesis using the grounded theory during 2014-17. The sampling was performed from July 2014 to March 2015. The participants included general practitioners (n=2), neonatal specialists (n=4), and neonatal subspecialists (n=15) working in private or public teaching hospitals (a Pediatric Medical Center, Mofid Hospital, Ali Asghar Medical Training Center, as well as Shohadaye Tajrish and Ibn-e-Sina Private Hospitals) in Tehran, Iran. The data were collected via in-depth interviews with semi-structured questions. The sampling method was initially purposive, and interviews began by visiting the offices of general practitioners or physicians working in healthcare centers since they were easier to access and then continued with specialists and subspecialists. Furthermore, the sample selection was initially conducted gradually and purposefully. It was then followed by theoretical sampling. According to this, decisions regarding sample selection were made during the data collection and analysis process. In theoretical sampling, the data collection process was to develop the theory.

Accordingly, the researcher collected, coded, and analyzed the data in an interconnected manner in order to develop the theory that emerged during the process. At each stage of the research, the researcher decided what data to collect and where to obtain it. The individuals were selected according to the status of the developing theory, and the selection criterion was the expected level of new insight that these items provided for the developing theory. At the end of each interview, it was immediately transcribed. Afterward, the data were collected and analyzed, the concepts were extracted, and primary (open) coding was performed in this study. The grounded theory was explained based on the concepts derived from the data and categories.

All interviews were coordinated via contact with the participants checking the proper time and place. At the beginning of each interview, the researcher introduced herself and gave a brief description of the research plan and its objectives. After obtaining consent to record the voice of the interviewees, the personal information form was completed by the participant. Subsequently, the interview was conducted and recorded in a completely comfortable and reliable environment regardless of mentioning the name, place of work, or the specialty considering the social status of the interviewees. Each interview lasted 45-120 min depending on the participant’s interest and the interview process.

Data collection

The questions that were asked at the beginning of each interview included "What problems do you face during a day in the clinic with infants and their parents?", "What are your clinical experiences in this field?", and "What solutions do you think of?". In this type of interview, each answer was further explored during the interview with questions, such as "Why?" and "How?", and the interviewees were asked to elaborate on their answers. Data collection and analysis were performed simultaneously based on the grounded theory. After the first interview, the analysis began and continued throughout all interviews. The sampling was based on the previous data collection and analysis and became more specific over time. The data were analyzed manually using the constant comparative analysis with Strauss-Corbin's (1998) method in three phases of open, axial, and selective coding. Each interview was transcribed immediately and led the researcher(s) to the next interviews.

Analysis

The encoding method was used for data analysis, and each transcript was divided into codes. Some codes were obtained from six participants regarded as neonatologists 1, 2, 3, 4, 5, and 6, as well as pediatric intensive care unit [PICU]). Therefore, some codes were extracted as follows: "Lack of scientific, legal support, and specific instructions in the clinical situation of the physician", "Lack of evidence-based local scientific and ethical guidelines", and "Lack of clear decision reference and interdisciplinary interference". All the codes were inserted in individual tables. In the

Tabe1. Open and selective coding

Participants	Open coding	Selective coding
n1,n2,n5,PICU	Lack of scientific and legal support, as well as specific instructions in the clinical situation of the physician	Adherence to inflexible rules and lack of position-based instructions
n4,n2,picu,n1,n3	Lack of evidence-based local scientific, and ethical guidelines	
n1,n2,n6	Lack of clear decision reference and interdisciplinary interference	

next step, the codes were classified and immerged as primary classes; moreover, the main category was obtained (selective coding) using the integration of the primary category (Table1).

During the open coding process, the researcher read the interview transcripts several times and recorded the main concepts in the form of codes in the margins of the sheets. Following that, the initial codes were categorized based on their similarities and formed categories. During the theoretical sampling process and as new concepts emerged after each interview, it was necessary to collect the observational data in clinics. Even more physicians in a subspecialty were required for data saturation in some categories. Analytical methods, such as questioning and comparison, were used to identify the characteristics of each concept. Interviews and group discussions continued until data saturation when no new data were obtained in the interview.

Rigor

Credibility: In the present study, the researcher's long partnership with physicians (approximately 12 months) allowed her to spend sufficient time to build trust and mutual understanding with participants and devote sufficient time to data collection. In addition to the lead researcher, other members of the research team (at least two people) were actively involved in all stages of data collection, analysis, and interpretation. After coding each interview, a full copy was provided, including the obtained codes and key phrases to assess the compatibility of the codes with the participants' experiences. Discussion by the research team about contradictory findings and reaching a final consensus were other ways to ensure acceptability in the present study.

Confirmability: In the present study, the researcher re-read and coded the transcript of the interviews a few days after the initial coding and compared the results with the first coding. If similar results were achieved, the stability and consistency of the data were confirmed.

Transferability: The researcher collected and recorded all stages of the research; therefore, it was possible to follow the methods and decisions step by step, as well as evaluate the ability to transfer data and results to other situations and groups for other researchers

Dependability: A number of experienced professors in the field of clinical ethics were provided with documents to confirm compliance. More than 50% of the copies and codes were revised during this process.

Results

The participants included physicians (n=21), the majority (47.6%) of whom were female. Out of these participants, 9.5% and 19% of the physicians were General physicians and Pediatricians, respectively. Moreover, 71.4% of the cases were pediatric subspecialists (Neonatologist [40%], Nephrologist [13.3%], PICU [6.6%], Oncologist [13.3%], Neurologist [6.6%], Infectious diseases [6.6%], and Gastroenterologist [13.3%]). It is worth mentioning that 71.4% and 15.2% of the participants were faculty members and state university graduates, respectively.

In total, 1420 initial (open) codes and 19 subcategories were obtained during analysis. More reviews and comparison of subcategories revealed two specific categories to explain the ethical challenges of decision-making about sustaining or ending the life of extremely premature infants for the neonatologists. These categories included 1) Independent decision-making of physicians consisting of two subcategories, namely "professional decision-making based on knowledge and clinical experience" and "uncertainty about the consequences of consulting with parents", as well as 2) Improper conditions and facilities consisting of three subcategories of "lack of local scientific resources on medical ethics", "inefficient neonatal intensive care units", and "lack of efficient rules and guidelines". The axial coding, as well as categories and sub-categories of ethical challenges, are presented in Table 2.

First concept: Independent decision-making of physicians

- ***Professional decision-making based on knowledge and clinical experience***

According to the findings, pediatricians were

Table 2. Categories and subcategories of ethical challenges

Main concepts	Conceptual categories
Independent decision-making of physicians	Professional decision-making based on knowledge and clinical experience
	Uncertainty about the consequences of consulting with parents
Improper conditions and facilities	Lack of local scientific resources on medical ethics
	Inefficient neonatal intensive care units
	Lack of efficient rules and guidelines

involved in a wide range of decisions about saving extremely premature infants. Most physicians have decided to resuscitate infants despite having sufficient clinical experience and knowledge of the not-so-promising prognosis for the resuscitation of extremely premature infants, which was partly due to religious beliefs and medical values.

"*...Most physicians act according to their religious beliefs and almost arbitrarily. Most feel they have to keep the infant alive until the last moment. I myself, for example, resuscitate the infant until the last moment*" (PICU fellowship).

"*...Many physicians say it is our religious, legal, and human duty to save everyone*" (Neonatologist 3).

Participants suggest that they decide based on clinical criteria, neonatal viability, and healthcare system conditions.

"*...From the very beginning, I'd tell parents that I have experienced (these conditions) and I can't save their child, and I wouldn't consult with them in decision-making. However, if based on my previous experience, I knew from the beginning that the infant would survive and be healthy, I'd resuscitate the newborn*" (Neonatologist 2).

"*...Pediatricians currently don't consult with parents, and they tell them from the beginning that the infant won't survive. If the family wants to save the infant, the gynecology fellowship would call the pediatrician"* (Neonatologist 1).

Another problem is that when physicians act upon their clinical experience, there is no consistency between different physicians.

"*...They act arbitrarily. Most professors pity the infant and do not turn the device off. Few physicians say not to resuscitate if the infant has an arrest; however, they don't separate the infant from the device. They only don't resuscitate fatal anomalies*" (Neonatologist 1).

Uncertainty about the consequences of consulting with parents

Some participants considered lack of parental involvement or limited involvement in decision-making due to their inappropriate complaints against the physician and denial of unfavorable conditions of their infants. Additionally, they believed that due to the economic, social, and cultural conditions of most parents, informing and involving them in the treatment process will not have favorable outcomes.

"*...If you want to violate the law of Iran and involve the parents in the end-of-life decision-making, the parents will sue and say that 'we were not aware at the time and wanted our child to survive. At that time, I didn't realize, and I wish the physician hadn't told me and had resuscitated our child', and since the law doesn't support the physician, the physician has no right to ask the parents to declare their opinion and act according to their opinion*" (Neonatologist 3).

In some cases, physicians prefer not disclosing clinical facts to the disclosure of information, establishment of a proper relationship with parents, and their involvement in vital decisions to maintain their professional interests, as well as reduce complaints and conflicts with the hospital.

"*...Experience has shown that if you tell the parents the truth, they won't come back to the hospital. Most of the time, the given addresses and phone numbers aren't answered. We can't trust these addresses. They go and they don't come back. Therefore, we inform the parents of the very bad conditions. However, we don't say there is no hope. Hospital officials don't like us to tell the truth since if the infants die, at least the parents will pay the expenses. This has happened over and over again*" (Neonatologist 1).

"*...Parents eventually say let them die; however, we say life and death are in God's hands and we have to do our duty or they say our infant is in a bad condition and we want to take him/her away so that we don't need to pay the hospital expenses because we don't have the money*" (Neonatologist 3).

On the other hand, most physicians believed that most families had some degree of unawareness about the disease, treatment, and timely visit, and if we do not guide them, they might neglect timely treatment or follow-up of their child. Therefore, the physician knows what is best for the infant in the first place, and the main decisions are made by the physician. If the attending physicians deem it appropriate, they will inform the parents about the child's condition, illness, and treatment, and the parents are only actively involved in giving informed consent, discharging against medical advice, and selecting a public or private hospital. Therefore, most physicians prefer physician-centered decision-making.

Accordingly, in making decisions on sustaining or ending the life of extremely premature infants, most participating physicians acknowledged that the extent of parental involvement and decision-making, as well as the manner of informing them varied based on physician's scientific and clinical experience, environmental conditions, and families' emotional, cultural, and social needs. Moreover, they are the physicians who determine the degree of parents' participation.

Second concept: Improper conditions and facilities

In the present study, one of the ethical challenges in deciding on the survival of extremely premature infants was improper conditions and facilities, presented with three concepts of "lack of local scientific resources on medical ethics", "inefficient neonatal intensive care units", and "lack of efficient rules and guidelines".

- ***Lack of local scientific resources on medical ethics***

"*…We don't have a specific source of medical ethics in the country to refer to and decide accordingly. So, we inevitably turn to western sources that don't fit our circumstances*" (PICU fellowship).

Another challenge that physicians mentioned was the lack of documented information on the development of these infants with the conditions, facilities, and equipment available in Iran so that physicians could make decisions based on local scientific sources.

"*…First, we don't have the right data on the survival of infants and lack of disabilities in them to be able to have a specific guideline. Based on our experiences, we tell parents: 'This is the course your child will go through, now you decide', (These should be based on national scientific documents*)" (Neonatologist 2).

"*…Recently, our research center is conducting a research project to determine the age of the right to life, as well as the minimum viability in Iran and Tehran or at least in our hospital*" (Neonatologist 1).

- ***Lack of efficient rules and guidelines***

Physicians participating in making decisions to resuscitate extremely premature infants expressed that they resuscitate the infant according to the law of our country (i.e., obligation to preserve life), even if they have a physically poor prognosis. Physicians believed that it is not acceptable to spent energy and facility for an infant with a poor prognosis while this energy and facility can be spent on an infant with quite good conditions and excellent prognosis. Therefore, in a situation where it is difficult and very unlikely to save the infant's life, they do not have a special rule or moral instructions to act upon them. If the physicians follow western ethical guidelines, on the one hand, they are not applicable in Iran because of differences in conditions, facilities, and equipment, and on the other hand, in case of the parents' sue, there is no legal ethical support for the physician.

"*…Infants that are legally allowed to be aborted but are not, when they are born, the physicians are not allowed to refrain from resuscitation and have to do all the things that all do for other infants. This is the law and medical ethics of our country*" (Neonatologist 1).

The end-of-life decisions for infants with poor prognosis and in the futile care cycle vary in different hospitals. Most neonatologist participants state that there are no specific instructions and people act arbitrarily; however, most participating physicians express that they act based on the law of the obligation to preserve life.

"*…The legislator has not considered a role for parents to permit to end an infant's life. The legislator has not also allowed us to consult parents on whether they agree to resuscitate their infant. The legislator will not allow me to do so*" (Neonatologist 3).

"…*You have no right to violate the law and ask the parents to express their opinion and act accordingly. We should say 'we hope that your 25-week-old fetus will survive'. Thus, we have both acted according to the law and kept parents in peace*" (Neonatologist 4).

One of the most important challenges for neonatologists, especially in very crowded hospitals, is the lack of practical rules and guidelines for ethical decision-making. The law indeed dictates that life preservation is obligatory; however, more practical guidelines and rules can be applied in situations where there is no hope to save premature infants.

"*…Every day, we face the birth of a large number of 24-week-old and younger infants, and we don't know what to do. We neither have protocols, nor is it settled in the country, nor do forensics have any guidelines for us*" (Neonatologist 5).

"*…In Iran, you have to resuscitate the infant because the law does not protect you. Even for a patient who has many complications, yet you have to. The family would say leave it alone, but when the patient dies, the parents will sue, and there is no law*" (Neonatologist 5).

Some physicians have made a more balanced approach in this absence of rules and regulations:

"*…If parents agree that the infant has a very poor prognosis and agree not to do anything for it, we will not perform aggressive interventions, but we will provide supportive care. However, if the accompaniers want to do all the care for the patient, we will obey. If the family agrees to no code, we won't resuscitate, but if they want resuscitation, we will proceed with the family decision*" (Neonatologist 4).

A small number of participating physicians made the decisions based on the guidelines derived from the neonatal medical ethics chapter along with the jurisprudential and religious topics in Iran compiled by themselves.

"*…I didn't have an ethical challenge in this case because I act based on the written set that I prepared myself and I work within the medical ethics framework that I myself developed. I have solved the challenges according to up-to-date references*" (Neonatologist 2).

The next challenge that most participating physicians face and has become a habit due to its daily repetition and unresolved nature, is the lack of specific clinical decision-making reference when extremely premature infants are born with numerous life-threatening physical problems or severe anomalies. Is the gynecology department responsible for deciding to resuscitate the infant or not? Is it necessary to consult a neonatologist or the family before birth to decide on saving the infant's life?

The participating physicians considered these ethical challenges as routine issues and argued that this was an interdisciplinary interference, for which there were no specific ethical guidelines for the gynecology department.

"*…Currently in this center, if a gynecologist and a perinatologist pity the mother and infant for any reason, they will call us in advance. The neonatal fellowship and attending professors are always willing to save the infant's life in all circumstances. In fact, they begin resuscitation and express that 'we knew it would not survive, but we couldn't just do nothing'. So here, gynecologists make the decision. If it is not important for them and they think that the infant would not survive, they won't call us. They leave the infant for 1-2 h and if it is still breathing, then they will call us*" (Neonatologist 1).

Therefore, one of the factors that make physicians uncertain about deciding for this group of infants is the lack of applicable rules and ethical guidelines in Iran. Therefore, physicians need a comprehensive consensus based on the available scientific data on the mortality rate and the developmental complications of extremely premature infants in Iran, Islamic law, and Iran's local medical ethics.

Inefficient neonatal intensive care units

One of the challenges of deciding on extremely premature infants with a poor prognosis is the presence of adverse conditions in the ward (personnel, improper equipment), which can lead to the death of infants even in appropriate physical conditions.

"*... There was a 25-week-old infant in the ICU who had been taken care of for nine days and had stable conditions. In the morning round, it was realized that the infant had died. Our healthcare system was not advanced. If a 25-week infant was born, we had to use all the facilities to help them survive, but this won't always happen*" (Neonatologist 3).

Discussion

This study was conducted to explain the ethical challenges regarding extremely premature infants in the clinic via a qualitative study as part of a Ph.D. dissertation. Ethical challenges of deciding on sustaining or ending the life of extremely premature infants were explained in two categories of "Independent decision-making of physicians" and "Improper conditions and facilities". The first category consists of two concepts, namely "professional decision-making based on knowledge and clinical experience" and "consequences of consulting with parents".

According to a study, some participants considered a lack of parental involvement or their limited involvement in decision-making due to their inappropriate complaints against the physician with unethical purposes and denying unfavorable conditions of their infants. On the other hand, most participating physicians considered more rights for themselves to decide for the infant, compared to the parents since they believed that parents did not completely understand the conditions of the infant due to their economic, social, and cultural conditions. Therefore, the majority of physicians tended toward physician-centered decision-making. Accordingly, in the decision-making process on sustaining or ending the life of extremely premature infants, the participating neonatologist acknowledged that the extent of parental involvement, decision-making, and way of informing varied based on physician's scientific and clinical experience, environmental conditions, and families' emotional, cultural, and social needs.

Numerous studies were conducted in Japan on physicians and adult patients, and the results have shown that the Japanese have very few opportunities to participate in medical decision-making, which is consistent with the results of the present study. Ishi reported that most Japanese patients believed that the physician should make the final decision (27).

Among the physician-patient interaction models in the clinic, the patriarchal system of medicine prevails in Japan and many other Asian countries, which is very different from western countries and requires the active participation of patients in medical decision-making (28).

Traditional healthcare systems treat patients as inactive recipients of care, while active patient participation turns their confusion, fear, and doubt into peace, transparency, and assurance. Moreover, the positive role of physicians relieves patients of disappointment leading to higher satisfaction, better adherence to instructions, and improved health (29).

In the present study, physicians have accepted the patriarchal model and the passive role of patients to prevent the active participation of parents and challenges, such as taking measures favored by parents and against the current legislation, complaints against physicians, and lack of legal and ethical protection of physicians. However, all physicians considered the necessity of the participation of parents in providing the child's history and cooperation in the examination, obtaining informed consent, and giving consent for discharge against medical advice. Mary argued that the communication should be a two-way or three-way relationship, and the physician-patient relationship should not be a monologue. In other words, it is not a question and answer exercise. Over the past years, the concept of proper communication has included a dialogue between physicians and parents (30).

This argument is inconsistent with the results of the present study. In the present study, physicians considered the parents' lack of awareness and full understanding of the clinical condition of the infant as one of the reasons for not involving them. Additionally, they considered giving medical information to parents in vain which would cause unnecessary anxiety for them. This argument was explained as the right to decision-making for physicians because of their higher ability. In a study in Japan, one of the factors influencing active patient participation was their higher socio-cultural status for understanding medical information; moreover, the patients preferred to play an active participatory role.

In the present study, one of the physicians' challenges in decision-making on sustaining or ending the life of extremely premature infants was the cultural, social, and economic poverty of many families referring to public teaching hospitals. This led to the lack of provision of extremely premature infants' clinical information to the parents because they would leave the hospital as soon as they found out about their child's condition due to economic, cultural, and social poverty; in addition, they leave the costs, infant discharge, and other problems for the treatment team. This issue is somewhat consistent with the findings of the above study. A study stated that multiple perceptions of parents in decision-making before, during, and after the birth of extremely premature infants should be considered, and they should be involved in this process (6).

Meert found that mothers considered alleviating their child's pain and suffering as an important factor in end-of-life decision-making (31), while in the present study, the physician was the final decision-maker. Moreover, there was no place for active parental involvement, and parents were only involved in obtaining information from the clinical team. In line with the findings of a study conducted by Meert, other studies (32-35) also found that mothers were asked to be actively involved in end-of-life decision-making for their infants. According to a study (2), ethical considerations related to decision-making about extremely premature infants included the priority of infants' best interests, parental independence, physicians' duties of beneficence and non-maleficence, and distributive justice. In line with these findings, a study (6) suggested that parents were required to empathically and sympathetically receive the information that was understandable to them. Parents often need the information to be repeated, and the most important challenge for the neonatologists in this study is the answer to these questions: "Who is responsible for deciding on sustaining or ending the life of this group of infants? Are the attending physician and inflexible law the same for all clinical situations or parents?

Another major challenge for neonatologists participating in this study was improper conditions and facilities explained with three concepts of "lack of local scientific resources on medical ethics", "inefficient neonatal intensive care units", "lack of efficient rules and guidelines". One challenge was the lack of local sources of medical ethics and the use of western ethical resources, which in many clinical cases, are not applicable due to the cultural, economic, social, and religious conditions of Iranian society.

Therefore, physicians of extremely premature infants follow a law that cannot be generalized to all clinical conditions due to the lack of situational guidelines. This leads to a conflict of interest in selecting infants who are in need of NICU, loss of golden opportunities to save the lives of infants with better clinical conditions, as well as unnecessary care and increased costs for the hospital and family.

Therefore, some physicians decide to perform dos without informing the parents, which is a solution to many of the problems created in the neonatal ward due to the lack of required laws and instructions. Moreover, due to the lack of legal support for physicians in implementing western guidelines in the neonatal clinic, most participating physicians follow conventional principles and traditional methods governing neonatal wards, which is saving the lives of all premature infants despite clinical conditions with very poor prognosis.

In this study, another challenge faced by neonatologists was the lack of clear decision-making authority and interdisciplinary interference. As a result, the responsibility for deciding whether to sustain or end the life of extremely premature infants with unfavorable conditions at birth is not clear. Are the obstetrics, gynecology and neonatal wards, or the parents responsible for decision-making? According to the present study, the American Nurses Association state that ethical behavior is poor in developing countries (36).

In such countries, there are medical ethics rules; however, they are not applicable for physicians and patients. It described the current situation for physicians in terms of compliance with ethical guidelines since physicians should be monitored and that each country's medical council approves those with good standing as long as there are no trials or charges of misconduct. Most developing countries do not have sufficient medical facilities and face a lack of medical equipment, especially in the emergency department. Physicians in these countries have too much responsibility and work. Meanwhile, they need to make sure that their daily clinical performance is in accordance with the law and ethical principles (37). Therefore, physicians must learn the principles of medical ethics and practice them in the clinic, which is more difficult in developing countries due to poor healthcare systems, shortages of medical staff, as well as poor equipment and supplies.

Findings indicate that adverse conditions, such as inadequate equipment, limited space and facilities, and lack of sufficient expertise in healthcare personnel, lead to the loss of infants with good physical conditions. In line with the findings of the present study, a study conducted in India showed a need for suitable and appropriate space and facilities, finance, equipment and skilled personnel, care protocols, and infection control measures in the neonatal wards in India and other developing countries. The provision of such conditions in the neonatal wards can reduce neonatal mortality (38). The study argued that despite tremendous care improvements in developing countries (39), neonatal mortality is unacceptably high due to some challenges. The main reasons for this gap between developing and developed countries are poor infrastructure, limited resources, and lack of developed systems in neonatal wards in developing countries. Another study suggested that the volume of activities in the NICU and other quantitative and qualitative variables, such as manpower, workload, environment, healthcare organization, and geographical location, may affect infants' clinical prognosis. This result was consistent with the findings of the present study (40).

Conclusion

This study revealed one of the most important ethical challenges in neonatal medicine, followed by factors and concepts that explain the formation of this problem faced by physicians every day in the clinic. According to the present study, the attending physician bears the responsibility to decide to initiate, sustain, and end the life of extremely premature infants with adverse clinical conditions, which confront physicians with challenges and uncertainties. Factors causing these challenges found in the present study include lack of ethical and legal guidelines tailored to clinical conditions and ultimately lack of ethical and legal support for physicians. In the presence of local medical ethics guidelines, the extent and manner of parental participation in decision-making for extremely premature infants will be determined for physicians. The second factor is the lack of local scientific documentation in accordance with clinical conditions and health facilities available in the NICU in Iran. Furthermore, there are conflicts between the current law on life preservation and moral guidelines, in which, it is necessary to preserve life; accordingly, it is practically impossible to involve parents and comply with their requests to make decisions for infants. Finally, one can name the lack of facilities, manpower, and equipment in the NICU. Therefore, the physician’s decision is based on personal scientific and clinical experiences according to the conditions of wards.

It should be noted that this study is based on interviews with some pediatricians and neonatelogists, which certainly does not represent the entire medical community, and further studies are necessary either qualitatively (with people involved, such as patients’ families and hospital healthcare staff), or quantitatively in the form of questionnaires and surveys. Such studies will solve some of the problems and guide authorities in decision-making, developing relevant instructions and regulations, and training the medical team involved in caring for such infants.

Acknowledgments

I would like to thank all the professors and pediatricians who were working in educational, general and private hospitals in Tehran and they had the necessary cooperation in the interviews

Conflicts of interest

There is no conflict of interest in this research and article

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