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Website: www.jehp.net
DOI: 10.4103/jehp.jehp_991_23

# Parental factors affecting their participation in decision-making for neonates with life-threatening conditions: A qualitative study

## Parents' participation in decision-making

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### Abstract:

**BACKGROUND:** Parents and healthcare professionals make decisions for neonates with life-threatening conditions (LTCs). Parents may be inadequately included. Limited studies have evaluated influential factors. We aimed to explore parental factors affecting parents' participation in decision-making (DM) for neonates with LTCs.

**MATERIALS AND METHODS:** A qualitative study was conducted in four level III neonatal intensive care units (NICUs) in Tehran, and twenty-two in-depth, semi-structured, face-to-face interviews were conducted in 2019. Interviews were transcribed and analyzed using a conventional content analysis approach. During the coding process, participants' words were condensed into meaning units, and 297 open-coded were extracted and then grouped into thirteen subcategories based on similarities and differences. This process was repeated until four main categories were identified.

**RESULTS:** Main categories and subcategories include “parental capabilities” (level of health literacy, emotional state, paradoxical feelings, and perception of the situation), “a sense of parental self-efficacy” (perception of parental role, awareness of self-abilities, and willingness to accept the parental role), “convictions” (religious beliefs and cultural values), and “living conditions” (job balance, household management and caring for siblings, and commuting) were found.

**CONCLUSION:** Although factors were parental, professionals who care for neonates with LTCs should be trained in family-centered care (FCC) principles to involve parents in DM. Nurses should be aware of parents' abilities and inform them of their rights. Parents' presentation at the bedside prevents their marginalization, reduces feelings of guilt, and helps them understand their baby's behavior and surrounding reality. A formal neonatal palliative care (NPC) program can encourage open communication between professionals and parents. A multidisciplinary team should consider parents' needs and values.

### Keywords:

Decision-making, life-threatening conditions, neonates, parental factors, parents' participation, qualitative study

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Received: 08-07-2023  
Accepted: 28-08-2023  
Published: 29-08-2024

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**How to cite this article:** Banazadeh M, Khanjari S, Behmaneshpour F, Oskouie F. Parental factors affecting their participation in decision-making for neonates with life-threatening conditions: A qualitative study Parents' participation in decision-making. J Edu Health Promot 2024;13:316.

## Introduction

The survival of neonates with life-threatening conditions (LTCs) has extended.<sup>[1]</sup> Parents of these neonates and professionals face the responsibility of making critical decisions<sup>[2]</sup> that have an impact on the outcome for the child and family.<sup>[1]</sup> Family-centered care (FCC), one of the most dynamic philosophies in pediatrics, includes family participation in care and decision-making (DM), meeting family needs, collaboration, respect and dignity, and information exchange between professionals and families.<sup>[3]</sup>

The approach to DM in health care has moved away from a model where healthcare professionals make the final decision, known as paternalistic, to a shared model<sup>[4]</sup> where both parents and healthcare professionals share information and work together to come to a consensus.<sup>[5]</sup>

Parents deserve to participate in DM about their child's health care.<sup>[6]</sup> Their preferences for participation differ from being informed of the decisions being made to making the final decision collaboratively with the physicians or independently.<sup>[5]</sup>

In clinical settings, parents' participation in DM is not adequately implemented.<sup>[7]</sup> In the Iranian context, the role of parents in the child's healthcare decisions is not highlighted, and families face challenges during DM for neonates with LTC.<sup>[8]</sup>

Various factors affect parents' participation in DM for neonates with LTCs. These factors include the neonate's future quality of life and the predicted lifespan,<sup>[9]</sup> the severity of the illness, resulting disabilities and impairments, the type and amount of information provided, access to treatment options, religion, and spirituality, and the level of support provided to parents.<sup>[10]</sup>

Limited studies addressed factors influencing parents' participation in DM in the neonatal intensive care unit (NICU). Parental competence, understanding, and perceived influence and control over their child's health care affected how they manage parental role in DM.<sup>[11]</sup> Parental level of education, age, income, marital status, life circumstances, and attitudes,<sup>[4]</sup> religiosity and spirituality, and past experiences<sup>[10]</sup> affected their participation in DM.

Most studies have examined factors in pediatric general settings. Qualitative studies specifically exploring parental factors in the context of neonates with LTC are lacking. There is a need to gain a deeper understanding of parents' preferences and factors influencing their participation in DM and the challenges they may

face. Qualitative research studies are appropriate for examining the healthcare DM process, the context in which participants view DM, and the perspectives of those involved.<sup>[12]</sup> This qualitative study aimed to explore parental factors affecting parents' participation in DM for neonates with LTC.

## Materials and Methods

### Study design and setting

This qualitative study was conducted using a content analysis approach in 2019. Qualitative content analysis is used to examine and interpret the content of qualitative data, uncover the underlying meanings and experiences of participants, and provide rich insights into complex phenomena.<sup>[13]</sup>

Since DM is an interactive process involving multiple individuals, the study population included twenty-five participants who were directly or indirectly involved in DM for neonates with LTC. They were 10 parents of hospitalized neonates, four nurses, and five physicians working in the NICUs, an official in the Neonatal Health Office of the Ministry of Health and Medical Education (MOHME), a forensic physician, and an expert on Jurisprudence and Principles of Islamic Law (JPIL). Participants were Iranian- and Farsi-speaking informants who were willing to participate in the study and share experiences. Professionals who had at least 1 year of clinical experience with these neonates were included. The study was conducted in four-level III NICUs in Tehran, where neonates  $\leq 28$  days old or weighing  $\leq 2.5$  kg were admitted. All NICUs provided care to neonates with a gestational age of over 24 weeks, and only two NICUs admitted neonates in need of surgical procedures. None of the NICUs had facilities for performing heart surgical operations.

The study used purposeful sampling<sup>[14]</sup> to select parents of neonates with LTC, including prematurity, complex congenital anomalies, and severe asphyxia. In-depth, semi-structured, face-to-face interviews<sup>[15]</sup> were conducted at a suitable place, date, and time for participants. Participants were interviewed from September 2018 to October 2019. Interviews began with a general question that was specific to the participants and continued based on their answers and lasted between 43 and 102 minutes and were audio-recorded with the participant's permission. The research team discussed the appropriateness of the questions and added probing questions to get a more thorough understanding of the phenomenon and data and concept saturation [Table 1]. During the interviews, field notes were taken to accurately describe and interpret the participants' responses.

**Table 1: Interview guides**

Interview guide of parents
1. Please talk about your baby's condition.
2. How did you participate in decisions being made for your neonate?
3. How would you like to be involved in these decisions?
4. What barriers prevent you from participating in DM?
5. What are the facilitators of your participation in DM?
Interview guide of healthcare professionals
1. How do you involve parents in DM?
2. What barriers prevent parents from participating in DM?
3. What strategies do you use to overcome these problems?
4. What are the facilitators of parents' participation in DM?
Interview guide of individuals indirectly involved in DM
1. What do you think about parents' participation in DM for neonates with life-threatening conditions?
2. How do health system policies prevent parents' participation in DM?
3. How do existing laws and rules prevent parents' participation in DM? What strategies do you recommend to overcome these problems?

Sampling continued until data saturation occurred, and the researchers concluded that further interviews would fail to provide new data. Finally, twenty-two interviews were conducted.

### Reliability and validity

The study employed Lincoln and Guba's (1985)<sup>[15]</sup> criteria for trustworthiness, including credibility, member checking, peer review, and debriefing. Credibility was enhanced through persistent observation and prolonged interaction with participants,<sup>[16]</sup> while member checking involved delivering a summary of emergent codes and themes to participants for verification. Data and method triangulation were used to further enhance credibility.<sup>[15]</sup> Reflexivity strategies were employed through field journaling.<sup>[16]</sup> Four impartial faculty members reviewed the process to confirm the study's dependability,<sup>[15]</sup> and detailed documentation was maintained for future researchers.<sup>[16]</sup>

### Ethical consideration

The ethics review committee at Iran University of Medical Sciences approved this study (IR.IUMS.REC.1397.388). Initially, the study aims were explained both verbally and in writing and informed consent was obtained. Pseudonyms were used to protect participants' identities. Participants were assured of data confidentiality, the right to refuse or withdraw at any time, and that participation was voluntary and anonymous.

### Data analysis

Using a conventional content analysis approach, data were analyzed. First, the recorded interviews were fully transcribed verbatim. Before coding began, the researchers thoroughly read the transcriptions multiple

times for familiarization with the data. During initial coding, labels were assigned that used the participants' own words to form condensed meaning units, and 297 codes were yielded and then grouped into thirteen subcategories based on similarities and differences. This process was repeated for all interviews until the four main categories were identified. The research team reached an agreement on the coding and categorization process [Table 2]. The analysis was managed in MAXQDA software (10).

## Results

### Demographic information of participants

Participants' demographic information is shown in [Table 3a and b].

### Main results

Four **main categories** consisting of "**parental capabilities**," "**a sense of parental self-efficacy**," "**convictions**," and "**living conditions**" were found [Table 3].

### Parental capabilities

The **main category** of **parental capabilities** encompassed three subcategories including "**level of health literacy**," "**emotional state**," "**paradoxical feelings**," and "**perception of the situation**" that affected the parental ability to participate in DM.

### Level of health literacy

Parents' lack of knowledge about procedures, treatments, diagnosis, and prognosis led them to take a passive role in DM and consider physicians more qualified. "*I like to participate, but I don't know about diseases. They do what is better. I'm pleased. The doctors know better*" (mother 4).

However, professionals also considered parents incapable to make decisions, which affected their practice to involve them in decisions. One participant stated, "*Well, neonatology is so specialized, it's difficult to involve parents in some decisions. No matter how much you explain at the end they say it's up to you*" (neonatologist 17).

Parents' higher level of knowledge was a driving factor to search for different sources of information and actively participate in DM. One participant stated, "*Some parents constantly search the internet and books, consult with the doctors in other hospitals. Well, you can involve them in decisions better*" (neonatologist 15).

### Emotional state

Facing the birth of premature or critically ill neonates, parents were in a confused state of mind. Parents' negative emotional states such as stress, concern, anxiety, and aggression acted as barriers to their participation. Participants stated, "*Parents are so stressed and anxious*."

**Table 2: Parental factors affecting their participation in DM**

Main categories	Subcategories
Parental capabilities	Level of health literacy
	Emotional state
	Paradoxical feelings
	Perception of the situation
A sense of parental self-efficacy	Perception of parental role
	Awareness of self-abilities
	Willingness to accept the parental role
	Convictions
Living conditions	Religious beliefs
	Cultural values
	Job balance
	Household management
	Caring for siblings
	Commuting

**Example of codes related to the subcategory of perception of the situation**

- Inadequate attention to signs of the child's improvement
- Inadequate attention to professional interactions
- Inadequate attention to the child's behavior
- Inadequate attention to surrounding events
- Failure to identify the situation
- Incomplete understanding of the situation
- Unrealistic understanding of the situation
- Unprofound understanding of the situation
- Failure to identify existing risks
- Giving tailored meaning to surrounding events
- Personal interpretation of surrounding events
- Personal interpretation of the child's behavior
- Failure to predict the heavy costs of illness
- Failure to predict the poor quality of future life of the child
- Failure to predict the emotional burden of a disabled infant on the family
- Failure to predict the psychosocial burden of a disabled child on the family

*They behave emotionally and are unable to make a rational decision" (neonatologist 13). "I've been told nothing to my wife about our baby's condition. The situation is stressful for a woman. Mothers may act emotionally" (father 8). "Some parents are very aggressive and constantly nag, complain and insult staff. It's very difficult to communicate and involve them in DM" (neonatologist 10).*

**Paradoxical feelings**

Parents were placed in a dilemma between their desires and feelings. They experience a paradoxical feeling from the child's life-saving to the prevention of suffering. One participant noted, "Parents are not in the right situation to decide. They are under pressure and have opposite feelings. They both want everything done for their child and do not want the child to survive with a severe disability" (neonatologist 10).

**Perception of the situation**

Parents' perception of the situation was based on their conditions and desires. The depth of their perception of the severity of illness and surrounding reality influenced the way they participate in DM. In a critically ill neonate who was born after 8 years of infertility and seven times *in vitro* fertilization (IVF), the mother persistently

asks physicians to do all treatments although they were expensive. She noted, "Thank God. My baby is getting well. Fortunately, it is not a genetic disorder. The liver transplantation will then be done. I think is not too difficult" (mother 2). The father of a neonate with a severe metabolic disorder stated, "The first day, we didn't know it was so serious. The ammonia level was high and I consented to dialysis. Now he isn't better, like a piece of meat lying on the bed. I prefer treatments not continue" (father 6).

More realistic and perceptive perceptions of parents about surrounding events led them to actively decide. One participant noted, "I found doctors aren't frank. My baby has many problems with his heart, brain, and breathing. Doctors decided to transfer him to the heart hospital for heart surgery, even though it was useless. The point is physicians do their best to save the baby because of their fear of the law but I don't agree with a surgery" (father 9).

**A sense of parental self-efficacy**

The main category of a sense of parental self-efficacy contains three subcategories including "perception of parental role," "awareness of self-abilities," and "willingness to accept the parental role."

**Table 3a: Participants' demographic background**

Participants' number	Parents and their neonates						Neonates					
	Age	Gender	Education	Job	Parents	Neonates	Diagnosis	Gestational age	Length of hospitalization (day)	Interview duration (minute)		
					History of infertility (year)	History of infertility treatments (times)	Number of other children	Age (day)	Gender			
1	34	F	Elementary school Graduate	Housewife	—	—	2	22	B	Sever asphyxia	14	45
2	27	F	HG	Housewife	8	7	2	8	A	Complex anomalies	20	48
3	29	M	HG	Technical service technician	—	—	0	9	B	Complex anomalies	7	56
4	31	F	HG	Housewife	10	3	0	30	G	Prematurity	23	46
5	28	F	University graduate (BA)	Employed	—	—	1	13	B	Prematurity	13	52
6	28	M	HG	Driver	—	—	0	18	B	Severe metabolic disorder	15	75
7	35	M	HG	Housewife	—	—	1	36	B	Grade IV IVH	36	94
8	49	M	University graduate (doctoral)	Physician	—	—	2	9	G	Complex anomalies	6	102
9	39	M	University graduate	Teacher	5	—	0	30	G	Complex anomalies	23	61
16	43	M	HG	Worker	—	—	1	44	G	Complex anomalies	44	53

F: female; M: male; B: boy; G: girl; A: ambiguous; HG: high school graduate

**Perception of parental role**

Parents' limited perception of their role in their child's illness led them to inadequately participate in DM. Some parents perceived their parental role only as paying financially. Participants noted, "Some mothers know nothing about their parental role. They still don't believe they have given birth to a baby" (neonatologist 13). "After 10 years, God gave us a baby. No matter the costs of treatment, we will pay" (mother 4).

**Awareness of self-abilities**

Some parents were unaware of their ability and impact on their baby's outcome. Mothers noted, "I am not breastfeeding. No need I stay with her" (mother 7). "They feed her with a tube. My presence may be troublesome. I cannot help her heal now. I cannot breastfeed, or hug" (mother 4).

**Willingness to accept the parental role**

Some parents felt they were responsible for DM, no matter how unpleasant it could be. Participants noted, "I'm a mother. It is my right to know what they have done and what the outcome has been. Our opinions must be asked" (mother 5). "I told the doctor please tell me honestly what the matter is. I am the father. I'm ready to hear any news and decisions though intolerable." Some parents were uneager about participating. One participant noted, "I don't like to participate. It is stressful. Doctors do the best" (father 3).

**Convictions**

The main category of convictions spanned two subcategories of "religious beliefs" and "cultural values."

**Religious beliefs**

Regardless of the parents' background, religiosity was an important factor guiding them in DM. Particularly, during end-of-life (EOL) decisions, their religious beliefs influenced certain decisions. One participant noted, "Our decisions are based on our beliefs. Religion is the light of our path of life. I believe in God. Where the decision is crossing the religious rules, I draw a red line there" (father 8).

The functions of religious beliefs on parental preferences for DM varied from taking an active role to a passive one. Some parents believed that their neonate's health was under God's control and preferred to delegate DM control to the medical team to do everything at all costs. They sought a miracle. One participant noted, "We're not decision-makers in our lives. Allah has planned life for us to the end. Not a leaf falls but He knows it (Surah Al-An'am [59]). This is our belief. Allah would heal if it were his will. I'm in God's favor" (mother 1).

The other parents preferred the medical team to discontinue their neonates' ineffective treatments, but their religious beliefs made them hesitant. A mother who witnessed their child's suffering consulted with a

**Table 3b: Demographic Background of Participants**

Participants' number	Other participants						
	Age	Gender/ marital status	Number of children	Medical experience (year)	Experience with neonates (year)	Job/education/position	Time of interview (minute)
10	59	M/married	1	29	22	Neonatologist/head of NICU	44
11	35	F/single	—	15	5	Nurse/BS	78
12	43	F/married	2	20	8	Nurse/MS	43
13	48	M/married	2	19	8	Neonatologist	65
14	45	F/married	2	23	17	Head nurse/MS	60
15	40	F/married	1	15	13	Neonatologist	71
17	37	M/married	1	12	7	Neonatologist	66
18	57	F/married	1	27	13	Head nurse/BS	63
19	37	F/married	1	5	—	Forensic specialist	66
20	49	M/married	2	—	—	Associate professor of JPIL	67
21	49	M/married	2	19	24	An official in the neonatal health office of MOHME/neonatologist	53
22	57	F/married	2	28	25	Neonatologist/head of NICU	55

BS: Bachelor of Science; MS: Master of Science; MOHME: Ministry of Health and Medical Education; JPIL: Jurisprudence and Principles of Islamic law

religious leader about stopping treatments. She stated, "The religious counselor said [not at all. Islam has prohibited it. We are Muslims. It's like killing your child. You must strive for it as long as the heart is beating. You have to wait to see what God's will be]. If doctors frankly took the responsibility of stopping the treatments, we would accept." (mother 7).

Some parents were not guided by religious beliefs. However, they believed that child's health conditions were under God's control, they preferred professionals do in the best interests of their neonates, and they actively participate in determining these interests. One participant noted, "My wife and I are believers in God. However, we're now at a point where we can't tolerate our baby's suffering and don't like to keep him alive. We like our decision to be respected" (father 6).

### Cultural values

The cultural values of parents prevented the professionals from involving parents in DM. "Sometimes parents' values interfere with the course of treatment. Blood transfusion is an emergency. They don't accept their baby's blood mixed with other people's blood. We have to do it in contrast to parents' values" (neonatologist 13). On other occasions, cultural beliefs derived parents to take an active role in DM. One participant noted, "Parents have specific cultural beliefs. For instance, the LP (lumbar puncture) procedure is scary for them. Sometimes they take responsibility and do not consent. In this way, the disease processes will last" (nurse 12).

### Living conditions

The main category of living conditions encompassed four subcategories of "job balance," "household management," "caring for siblings," and "commuting." Parents' ability to balance living and working requirements and their presence in the hospital influenced their participation in DM.

### Job balance

Job responsibilities interfere with parents' presence and active participation in DM. One participant noted, "I work every day from morning to night. I cannot take time off. We can go to the hospital once or twice a week. I talked to doctors just 2 or 3 times" (father 16).

### Household management

Some neonates had long-term hospitalization. Parents' responsibility for housekeeping and care of other children decreased their presence and participation in care and DM. One participant noted, "I'm here every day. I leave at six and take the subway. I talk to doctors and then inform my husband" (mother 2).

### Caring for siblings

Parents' responsibility for the care of other children decreased their time for presence and participation in care and DM. One mother noted, "I have two other children at home. I have to do the housework and take care of them and check their homework" (mother 1).

### Commuting

Difficult transportation and traffic restrictions impact parental attendance and participation in DM, as one mother noted, "I'm here every day. I leave at six and take the subway. I talk to doctors and then inform my husband" (mother 2).

## Discussion

This study identified parental factors affecting their participation in DM for their child. Parental capabilities were one such factor. Consistent with the findings, a lack of medical knowledge among parents caused them to relinquish decision control to the medical team.<sup>[17]</sup> Our findings also indicated despite parents acknowledging

physicians' competence for DM, they tend to receive information. This demand highlights the need for informing parents as a prerequisite for their participation in DM. An initial assessment of parental awareness and capabilities is essential. Neonatal nurses should be educated and trained to meet the needs of neonates and their families.<sup>[18]</sup> They should be able to provide face-to-face information or in groups, posters, or films about the illness to the parents. It can help parents to participate in DM.

Parents of neonates hospitalized in NICUs may develop increased levels of stress and anxiety.<sup>[19]</sup> They might not be emotionally fit to make clinical decisions<sup>[20]</sup> because emotions influence information processing.<sup>[21]</sup> Parents with a high degree of distress did not achieve a sufficient understanding of their child's condition; however, they were provided with sufficient information.<sup>[11]</sup> The early orientation of parents toward the high-tech environment of NICUs and actively listening to their thoughts, and preferences can reduce their distress. The less distressed parents are, the more professionals are eager to interact and communicate with them. It can create a sense of mutual trust.<sup>[22]</sup>

Findings indicated that parents' paradoxical feelings were a barrier to their participation in DM. Parents have ambivalent emotions both hope for their child's comfort and simultaneously a fear of the child's death.<sup>[23]</sup> They may regret and experience feelings of guilt. Therefore, they should avoid the overburden of making decisions.<sup>[20]</sup> Using a shared DM approach that involves parents considering their neonates' best interests may reduce their paradoxical feelings.

Parents who had a more realistic perception of the neonate's condition and what was going around them tended to participate actively. Parents need an understanding of the situation and their expectations.<sup>[24]</sup> Parents' perception of their infant's at-risk status drives them to participate in DM.<sup>[25]</sup> Moreover, parents' perception of the neonate's appearance may lead them to get a false impression and have unrealistic interpretations and expectations about their neonate's outcome.<sup>[26]</sup> Parents' discussions with professionals about their neonate's behavior may contribute to their participation in DM.<sup>[27]</sup> Nurses should help parents develop realistic expectations of their child's behaviors and interpret their indications. Giving parents real hope can make them aware of the events surrounding and existing risks.

A sense of parental self-efficacy reflected confidence in their ability to participate in DM. Higher levels of self-efficacy have been associated with a shared style of decision control in parents.<sup>[28]</sup> The way parents perceive

their parental role<sup>[29]</sup> and their confidence and willingness to accept their role positively influence the parental ability to take their role.<sup>[30]</sup> Involving parents in care helps them determine their parenting role, increase their sense of control, and cope with their role.<sup>[31]</sup> Parents of neonates with LTC may not be provided with the opportunity to participate in care and may be challenged with their acceptance of their role.<sup>[32]</sup> Involving them in activities such as feeding, kangaroo care, changing a diaper, and attending medical rounds may change their perception of their role.

Parents' religious and cultural convictions influenced their participation in DM.<sup>[33]</sup> Muslims believe in the sanctity of life. In Islam, every moment in an individual's life is so precious; as such saving lives is regarded as a duty whereas taking a life deliberately is a grave sin and is strictly prohibited.<sup>[34]</sup> Findings showed that parents' religious beliefs positively and negatively affected their participation in DM. Individualized care that promotes parents' participation in DM and respects their cultural and religious beliefs is required to promote their autonomy and dignity. Awareness of parents' religious values function in critical DM could help professionals improve DM communication and parental support. Professionals' realistic stance on the use of medical technology and their acknowledgment of the limitations, as well as weaknesses of medicine to create desired outcomes, can affect parents' expectations. It seems a lack of specific regulations within national laws regarding whether to continue or discontinue life-sustaining treatment<sup>[35]</sup> led professionals to feel an exaggerated fear of legal action and act more legally than considering parents' illegal requests.<sup>[36]</sup> Seemingly, the unavailability of formal neonatal palliative care (NPC) services in the Iranian context prevents staff from initiating conversations with parents.<sup>[37]</sup> A formal NPC program constitutes legal support for caregivers to start open and clear communication with parents.<sup>[38]</sup>

The next affecting factor was the parents' living conditions. Studies reported influential factors including job responsibilities, home management, care for other children, and traveling between home and hospital.<sup>[30,39,40]</sup> Strategies help parents manage their presence at the hospital including creating a friendly and more accommodating environment for parents and moderating the limited visiting hours for fathers<sup>[41]</sup> and facilitating other family members' presence such as grandmothers. This can reduce their fatigue and chaos and improve their eagerness for their presence and involvement.

### Limitations and recommendation

The diversity of the sample was a strength, but potential

researcher bias is a common limitation of qualitative research. The researchers took steps to minimize bias through member checking and collaboration with coresearchers. Though the sample size was small compared with quantitative studies, the richness of the data helped compensate for the smaller sample.

## Conclusion

Findings provided a better understanding of parents' capabilities and diversities, preferences, and complexities they faced during DM. Parents of neonates with LTC were marginalized and inadequately participated in DM. Although factors were parental, professionals can help parents' participation with early identification of their capabilities and individual diversities. Providing professionals with NPC protocols can help them pursue a policy without fear of legal action. Professionals need to be more aware of their responsibility to facilitate parents' participation in decisions. They should be trained to be more sensitive to parents' needs and improve communication skills and cultural competence to include parents' values. Parents being present at the bedside may help them gain knowledge and a realistic understanding to facilitate involvement. Providing an accommodating environment, organizational support, and written guidance on FCC can also facilitate parental involvement in decisions for their neonate. Empowering parents through information, skills, and support is key.

## Ethics approval and consent to participate

The study is part of the first author's PhD thesis, was approved by the Iran University of Medical Sciences review board (No. IR.IUMS.REC.1397.388). An informed consent form was filled out by all participants.

## Abbreviations

LTC, life-threatening conditions; DM, decision-making; SDM, shared decision-making; NICU, neonatal intensive care unit; EOL, end of life; NPC, neonatal palliative care; FCC, family-centered care.

## Acknowledgment

The authors would like to express their gratitude to all participants who helped us by sharing their valuable experiences.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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