

## Research Paper

# Organizational Factors Affecting Parents' Participation in Decision-Making for Neonates With Life-threatening Conditions: A Grounded Theory Study



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## ABSTRACT

**Background & Aims** Parental participation in decision-making for neonates with life-threatening conditions is morally and ethically approved. The health care team in the neonatal intensive care units is not prepared to involve parents in these decisions. Identifying factors affecting parental participation in decision-making can lead to removing the barriers and improving parents' participation. The present study aimed to identify organizational factors influencing parents' participation in decision-making for neonates with life-threatening conditions.

**Materials & Methods** This study is part of a comprehensive project based on Corbin and Straus's approach to grounded theory (GT) methodology (Corbin & Strauss, 2015) explored the process of parental participation in DM for neonates with LTC. Participants included 23 people (10 parents, 10 healthcare providers, 1 official in the Neonatal Health Office of the Ministry of Health and Medical Education, 1 professor of Jurisprudence and Principles of Islamic Law, and 1 insurance agent). The study field included level III neonatal intensive care units of 4 teaching hospitals. Data were collected using in-depth, semi-structured interviews and observation and simultaneously were analyzed through constant comparison utilizing the approach of Corbin and Strauss, 2015. The core category and the related categories reflecting contextual and structural factors, parents' strategies, and the outcome of the adopted strategies were identified. The contextual and structural classification reflected various factors affecting parents' participation in DM. Since it was impossible to publish all findings in one article, the current study focused on the organizational factors influencing parents' participation in DM.

**Results** Organizational factors affecting the process of parental participation in decision-making consisted of 5 main categories, including 1) power imbalances, 2) ethics committees' deficiencies, 3) hospital regulations deficiencies, 4) resource constraints, and 5) ongoing hospitalization, the only choice.

**Conclusion** Organizational factors play an important role in parental participation in decision-making. Providing parents of neonates with life-threatening conditions with accommodation and, developing instructions to encourage the presence of parents in the hospital, creating rules for selecting NICU nurses is necessary. Employing an interdisciplinary team of psychologists, social workers, and trained individuals to provide parents with spiritual care is recommended. Appointing hospital ethics committees to investigate cases of critically ill infants and employing experienced and knowledgeable ethicists about the end-of-life issues in these committees are also recommended.

### Keywords:

Parents' participation, Decision-making, Neonates, Life-threatening conditions, Organizational factors

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## Extended Abstract

### Introduction

**N**eonates with life-threatening conditions have complex and challenging clinical situations. Parental participation in decision-making for these neonates is morally and ethically approved, as it is the parents who live with the consequences of their neonate's illness. There is much debate about the role of parents in making decisions in complex and challenging medical settings. Since infants are unable to make decisions, the family bears the primary responsibility for decision-making. Parents are generally the best advocates for their children and, in most cases, are actively involved in decisions for their infants.

The health care team in the neonatal intensive care unit is not prepared to involve parents in these decisions. In Iran, there is no formal decision-making clinical guideline for children with life-threatening conditions, and parents are highly doubtful about decision-making. Parental participation in decision-making has also not been considered. Few studies have examined the factors affecting parents' participation in decisions for neonates with life-threatening conditions. Further studies have examined the factors related to parents and the structure of the health system, particularly those related to health workers that affect parental participation in decision-making.

Factors related to the organizational system remain unknown. No study was found in this field in Iran. In addition, very few studies have examined factors related to neonates with life-threatening conditions in neonatal settings. Identifying factors affecting parental participation in decision-making can lead to removing the barriers and improving parents' participation. Conducting qualitative research in this field can clarify various aspects of parental participation in decision-making and create a deeper understanding of this phenomenon. The present study aimed to identify organizational factors affecting parents' participation in decision-making for neonates with life-threatening conditions.

### Materials & Methods

As part of a comprehensive project based on Corbin and Straus's approach to grounded theory (GT) methodology (Corbin & Strauss, 2015), this study explored the process of parental participation in DM for neonates with LTC. Given that involvement in decision-making occurs in an interactive process, participants included 23 people (10

parents, 10 healthcare providers, 1 official in the Neonatal Health Office of the Ministry of Health and Medical Education, and 1 professor of Jurisprudence) Principles of Islamic Law, and 1 insurance agent). Data were generated using in-depth, semi-structured, and face-to-face interviews and observation (68 hours) and simultaneously were analyzed through constant comparison using the approach of Corbin and Strauss, 2015. It includes: 1) identifying concepts (open coding), 2) developing concepts in terms of their properties and dimensions, 3) analyzing data for the context, 4) bringing the process into the analysis, and 5) integrating categories. Data were managed by MAXQDA software v. 12.

The core category and the related categories reflecting contextual and structural factors, parents' strategies, and the outcome of the adopted strategies were identified. The contextual and structural category reflected a wide range of factors affecting parents' participation in DM. Since it was impossible to publish all findings in one article, the current study focused on the organizational factors influencing parents' participation in DM.

### Results

Organizational factors affecting the process of parental participation in decision-making consisted of 5 main categories, including 1) power imbalances resulting from two sub-categories of "power imbalances between parents and physicians" and "power imbalances between physicians and nurses," 2) ethics committee's deficiencies resulting from three sub-categories including "unavailability," "structural deficiencies" and "functional deficiencies," 3) hospital regulations deficiencies resulting from two sub-categories including "restricting rules of parental presence" and "lack of rules for selecting a NICU nurse" and 4) resource constraints including two sub-categories of resource constrain for parents and resource constraints for staffs, and 5) ongoing hospitalization the only choice under the three categories including "lack of palliative care option," "lack of home care services" and "lack of community-based palliative care services"

### Dissection

Organizational factors play an important role in parental participation in decision-making. Providing parents of neonates with life-threatening conditions with accommodation and, developing instructions to encourage the presence of parents in the hospital, setting rules for selecting NICU nurses are necessary. Employing an interdisciplinary team of psychologists, social workers, and trained individuals to provide parents with spiritual care

is recommended. Appointing hospital ethics committees to investigate cases of critically ill infants and employing experienced and knowledgeable ethicists about the end-of-life issues in these committees are also recommended. Providing healthcare providers with courses on palliative care and neonatal ethics is suggested. It is recommended to conduct action research studies to implement neonatal palliative care programs and situation analysis of the quality of care for neonates with life-threatening conditions. Establishing home care services and community-based palliative care centers for neonates with life-threatening illnesses with the discharge criteria may facilitate timely decision-making and parental participation in decisions. Interdisciplinary studies are also necessary to develop clinical guidelines for decision-making in infants with life-threatening conditions.

## Ethical Considerations

### Compliance with ethical guidelines

Ethical permission for this study has been obtained from the ethics committee of [Iran University of Medical Sciences](#) with the code IR.IUMS.REC.1397.388.

### Funding

This study is taken from the doctoral dissertation of the first author in the Department of Pediatrics and Psychiatric Nursing, [School of Nursing and Midwifery](#), Iran University of Medical Sciences.

### Authors' contributions

Research: Marjan Banazadeh; Drafting, editing, finalizing the writing and project management: Seyedeh Fatemeh Haghdoošt Oskooi and Marjan Banazadeh.

### Conflict of interest

The authors declared no conflict of interest

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