

# Parental barriers to implementing family-centred care in a neonatal intensive care unit in Islamic Republic of Iran

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## Abstract

**Background:** Studies have shown short-term and long-term positive effects of family-centred care interventions on neonatal and maternal health, and developmental outcomes in neonatal intensive care units. However, some challenges and barriers limit implementation of family-centred care.

**Aim:** To investigate parental barriers to implementing family-centred care in a neonatal intensive care unit in Islamic Republic of Iran.

**Methods:** A conventional content analysis was conducted at a neonatal intensive care unit in Tehran, Islamic Republic of Iran from 2020 to 2021. Twenty semi-structured interviews and 9 field notes were conducted. The interview data were analysed using the Graneheim and Lundman method and the demographic data were analysed using SPSS version 21.

**Findings:** Two themes emerged from the data analysis. The first theme was “inefficiency of playing the parental role”, with 2 main categories of “face unpleasant feelings” and “inappropriate presence and participation”. The second theme was “ineffective involvement of parents in the care”, with 3 main categories of “lack of effective communication with personnel”, “interference of parents in the treatment process”, and “given insufficient information by parents”.

**Conclusion:** Parental barriers to the provision of family-centred care featured prominently in the study. Therefore, to improve neonatal and family health, there is a need for involvement, coordination and effective communication between the medical teams and parents to create a supportive and friendly environment in neonatal intensive care units.

Keywords: Family-centred care, family health, parents, barriers, neonatal intensive care, neonatal health, maternal health, Iran

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## Introduction

Recent studies have reported a notable increase in neonatal intensive care unit (NICU) admissions globally (1-3). NICU admission is a traumatic event for the neonate and their family who spend 30 days or more in the NICU. These extended hospital stays disrupt normal family functioning daily, compounded by emotional, financial, and other stressors, including inadequate communication with other family members. Coping with these challenges begins upon hospitalisation and continues for a period after the infant's discharge (1-3).

Family-centered care is a philosophical and practical approach to promoting health worker–parent collaboration and partnership by treating parents or guardians with dignity and respect, sharing relevant information, and empowering parents to be part of the planning and delivery of intensive care for their neonates (4,5). Family-centered care has been shown to have many positive effects on outcome for both infants and parents (6-9). This cost-effective and practical model of care has been adopted in many NICUs worldwide, but despite its advantages, its application varies widely and can be challenging to implement.

The most common obstacles to parent–neonate bonding and attachment are related to the reactions of parents while visiting their neonates in the NICU. Commonly observed behaviours are: (i) avoiding holding the neonate and (ii) trying not to “love” the neonate. In addition to the challenges of extended hospital stays and coping with stressors, anticipating neonatal loss can contribute to insecurity in the infant and negatively impact natural cognitive, social, psychological, language, and intelligence development of the neonate while in the NICU (8). We assert that it is vital to incorporate local social and cultural knowledge into family-centred care programmes to improve performance of such systems in each society.

In the Islamic Republic of Iran, despite the familiarity of nurses and doctors with family-centred principles of care and having the support of the Iranian Ministry of Health, these principles cannot be fully implemented without adequate numbers of care staff, sufficient resources, policy, and training, and improvements in parental conditions. Unfortunately, we have limited academic knowledge about the typical obstacles faced by parents, particularly physical, emotional, financial or social circumstances of the parents, especially from the

perspectives of the parents themselves (4,7,10). The aim of our study was to better understand the obstacles faced by parents and stakeholders involved in family-centred care of neonates in the Islamic Republic of Iran; and in limited resource settings in general.

## Methods

### Study design and sample selection

Conventional qualitative content analysis was used to evaluate and categorize the opinions of NICU care staff and parents about obstacles to implementing family-centred care in the NICU of a central hospital in Tehran. For our purposes, qualitative in-depth analysis of parent and care staff interview data provided a cultural and contextual description and interpretation of social phenomena that could not be obtained using the quantitative research method (11).

We used an analytic process to generate our study design (surveys and participant-observation), which included formulating the research questions *a-priori*, selecting verbatim text from recorded interviews to be analysed, defining the categories found in such data, describing the coding process and coder training, implementing the coding process, integration of field notes, and determination of the accuracy of the results of the analytic coding process. We coded the interview data to identify categories and sub-categories within each theme and gain new insights on how to improve family-centred care in our setting (12).

Inclusion criteria were, parents and care staff who provided consent to take part in our study and agreed to freely express their opinions and experiences. We selected participants using targeted sampling of parent and care staff characteristics such as work history, education, job position, and positive and negative attitudes of parents and care staff towards implementing family-centred care. One head nurse, 1 matron, 2 supervisors, 3 medical professors, 8 nurses, and 5 mothers of newborns in the NICU provided informed consent to participate in our qualitative study.

### Ethical approval

Our report was extracted from the data of an already published PhD thesis by the first author. This PhD research study was approved by the institutional research ethics committee of Tarbiat Modares University (IR.MODARES.REC.1398.020). Before the start of each interview, participants were provided with an oral explanation of the purpose and method of the research, assured of confidentiality, informed about the use of audio recording to assist in textual content analysis and the right of participants to withdraw from the study at any time. Each participant provided informed consent before speaking with researchers.

### Data collection

We conducted 20 semi-structured interviews and gathered 9 days of participant-observational notes. Our research team observed various obstacles, events, and other information related to the implementation of family-centred care during work shifts of care teams and recorded them as field notes to be used during data analysis. After obtaining informed consent, interviews were conducted individually in a private room at a predetermined time, and the length of each interview depended on the willingness and tolerance of each participant (average of 50 minutes). We began each interview with a set of open-ended questions about challenges in implementing family-centred care. Subjects were probed for more in-depth answers with follow-up questions such as "Please explain more, what does this mean and why?".

### Data analysis

We performed our data analysis using the method of Graneheim & Lundman (13) which includes the following steps: (i) record interviews verbatim and transcribe; (ii) read verbatim text until reaching a general understanding of the themes and subcategories; (iii) assign meaning units and codes; (iv) classify main themes into categories and subcategories; and (v) extract and interpret themes, categories and the central concepts. Samples were collected simultaneously with data analysis. The interviews were conducted until we reached data saturation and obtained no new information. We used SPSS version 21 to analyse quantitative data; for example, demographics and length of stay.

### Rigour and trustworthiness

According to Lincoln and Guba's criteria, the criteria of transferability, credibility, dependability, and confirmability were used to increase accuracy (14). To improve scientific rigour, we made a substantial effort to spend adequate time collecting and analysing the data, including periodic meetings with the research team and participants to validate findings. Also, we requested the opinion

**Table 1** Characteristics of NICU healthcare workers

Demographics	N (%)
<b>Education level</b>	
Bachelors degree	6 (40.0)
Masters degree	6 (40.0)
Sub-specialist	3 (20.0)
<b>Work experience (years)</b>	
5–10	3 (20.0)
10–15	3 (20.0)
15–20	5 (33.3)
≥ 20	4 (26.7)
<b>Marital status</b>	
Single	5 (33.3)
Married	10 (66.7)

of experts in qualitative research during the data analysis process to ensure accuracy and clarity.

## Results

Our analysis of the interview and observational data resulted in the construction of 2 qualitative themes, including 5 main categories, 16 subcategories and 210 primary codes from participants in the family-centred care in neonatal intensive care unit (Table 2). Although summarised in Table 2, we have also provided detailed textual examples of statements from care staff and parents for each theme.

### Theme 1: Constraints in parental roles

We identified 2 distinct categories under Theme 1: "encountering emotional discomfort" and "challenges in engagement and participation".

#### Category 1.1: Encountering emotional discomfort

Parents reported feeling afraid, stressed, disappointed, guilty and depressed because of the poor condition of their neonates, making many of them either avoid the baby or reject the situation and the advice of care staff.

##### Subcategory 1.1.1: Fear and worry about future medical problems for the neonate

One mother said: "When I saw my baby first time, I couldn't control myself or do anything at all, I was crying all the time, I thought when my baby was admitted to here, he might not be able to see, or hear, and his brain would have problems."

##### Subcategory 1.1.2: Fear of unintentionally harming the neonate

One mother stated: "Because of the transmission of infection, I preferred not to touch my baby, even though the staff said it was necessary."

##### Subcategory 1.1.3: Anxiety from mis-interpreting hypothetical medical training examples as diagnosis at the bedside

One of the care nurses recalled the reaction of a parent to mis-interpreting a training lesson: "Here is an educational centre and the doctors' visit is an educational visit. When a professor was teaching around the baby's bed, about hypoglycemia, and complications like convulsions, cerebral palsy generally. Because of the incomplete information the parents' stress increased 3-4 times, they were constantly worried the baby might have a seizure, and were afraid to touch the baby."

**Table 2 Peri-partum statistics for neonates (n=5)**

Peri-partum statistics	N (%)
<b>Gestational age (weeks)</b>	
Week 28 ≤	1 (20.0)
28–32	4 (80.0)
<b>Neonate's length of hospitalization (days)</b>	
10–15	3 (60.0)
15–30	2 (40.0)

#### Subcategory 1.1.4: Facing negative emotions

A mother related her negative feelings about having a preterm baby: "I have a lot of guilty conscience that my baby was born early. I cry all the time and I can't get close to her because it was my fault; if I hadn't lifted the carpet, my water bag wouldn't have broken and my baby wouldn't have been born early."

#### Category 2.1: Challenges in engagement and participation

All participants said parents were reluctant to present and participate in the neonate's care because of their emotional, physical and mental health or denying the reality of their neonate's emotional, tactical and spiritual needs, even after invitation and encouragement by care staff.

##### Subcategory 2.1.1: Parents' disinterest in caring for the neonate

A NICU care nurse said: "Many times, you train mothers but they do not cooperate. For example, during the first 10 days, because of the delivery conditions, the mother thought she must only bring milk, or just look at the baby and leave, without emotional support or caring."

##### Subcategory 2.1.2: Attending to personal issues in the ward and neglecting the neonate

Frustrated care nurses said: "Parents think their presence in the ward means being in the ward, with no caring role, they think they should sit in the ward and work on their phones or read book."

##### Subcategory 2.1.3: Parents busy and not visiting the neonate

One mother stated: "I have another child at home and there is no one to take care of him, so I can't come to be with my baby very often."

### Theme 2: Limitations in parental involvement in care

In Theme 2, we identified categories within the theme related to parental obstacles to collaborative involvement in care of the neonate with nursing staff. Participants mentioned the following major categories: deficient communication with care team, parental interference in treatment procedures, and inadequate provision of information by parents to care staff.

#### Category 2.1: Deficient communication with care team

Parents with neonates in the NICU are under a lot of unusual stress. Some parents are unable to regulate their emotions and react negatively towards care staff or have unrealistic expectations. These conflictual and dis-regulated interactions hinder effective cooperation between care staff and parents.

##### Subcategory 2.1.1: Emotionally dis-regulated parents

A NICU nurse explained: "We have seen aggressive behaviours from parents who were insulting to nurses and doctors. For example, for transferring the baby to another ward, the parents yelled: 'we want the baby to be here and the same system model of care to be provided here'."

**Subcategory 2.1.2: Unrealistic expectations from nursing staff**

One nurse recalled: “Parents have many expectations, they think the nurse attends only to their baby, while we cannot divide ourselves into several parts at the same time, in one hour we cannot feed two neonates, they have to wait a little bit.”

**Subcategory 2.3.1.: Parents reject caregiving due to perceived inequalities**

One mother told us: “Here, the nurses told me to change my baby's diaper. Why should I take care of my baby when they get paid to do it?”

**Category 2.2: Parental interference in treatment procedures**

Parents interfere with the treatment process by demanding non-expert actions or requesting unnecessary procedures.

**Subcategory 2.2.1: Commanding or forbidding medical procedures**

The head NICU nurse said: “Parents sometimes cause many problems in our ward. They tell the doctor to prescribe or not to prescribe an ultrasound or test for the baby. They search issues on the internet and behave like experts, misleading other parents and making them to change their views.”

**Subcategory 2.2.2: Manipulating settings of neonate's equipment or devices**

A NICU physician told us: “I have seen several parents manipulating the ventilator, equipment, or the baby's position without informing us. For example, I have even seen a father turning off the infusion pump. I asked why are you doing this? He answered: 'I think the baby received too much serum'.”

**Subcategory 2.2.3: Disobeying NICU ward and staff rules and regulations for neonates**

A NICU nurse complained: “Some parents do whatever they want. One time, a mother gave her baby rock candy (water of Nabat) to decrease colic. She did not pay attention to anything we said. I told her not to do it because the doctor was going to take care of it, but she continued doing it.”

**Subcategory 2.2.4: Giving untimely or inappropriate advice to other parents in the ward**

Our field researcher recorded the following participant observation note: “I saw two mothers who were talking about their babies, one of them was massaging her baby with oil and explaining the benefits of massage for all babies. Then the other mother borrowed some oil and went to her baby who was under phototherapy to give a massage. I warned the mother that if she used the oil during phototherapy, the baby's skin may burn, and I told her to ask the nurse before doing anything.”

**Category 3: Inadequate provision of information by parents to care staff**

Related experiences of the care staff revealed that barriers to family-centred care can occur when parents do not give information or give incorrect information to care staff, especially during shift changes.

**Sub-category 3.1: Giving inaccurate information to care staff**

One care nurse recalled: “It happened you were reading a report during the handover, at that moment the mother said to other nurses: 'My baby had an oxygen saturation drop, or my baby vomited.' The mother does not know many things but she gives false information and influences the action of the next shift nurse.”

**Subcategory 3.2 : Inciting fear in other parents due to group misinformation**

A NICU physician related the following example: “When we are visiting a neonate, the other mothers present in the ward can't hear the conversation clearly, but they go to the mother's room and give her incomplete and incorrect information about her baby, or when the baby's health deteriorates, they quickly call the baby's family at home and get them worried and agitated”.

**Discussion**

Family-centred care in NICU units around the world face various obstacles that can negatively impact the outcome of care and cause lack of mutual respect and

**Table 3 Themes related to family-centred care in the NICU**

Theme 1: Constraints in parental roles	Theme 2: Limitations in parental involvement in care
<b>Categories</b>	
<ul style="list-style-type: none"> <li>• Encountering emotional discomfort</li> <li>• Challenges in engagement and participation</li> </ul>	<ul style="list-style-type: none"> <li>• Deficient communication with care team</li> <li>• Parental interference in treatment procedures</li> <li>• Inadequate provision of information by parents to care staff</li> </ul>
<b>Sub-categories</b>	
<ul style="list-style-type: none"> <li>• Fear and worry about future medical problems for the neonate</li> <li>• Fear of unintentionally harming the neonate</li> <li>• Anxiety from mis-interpreting hypothetical medical training examples as diagnosis at the bedside</li> <li>• Facing negative emotions</li> <li>• Parents' disinterest in caring for the neonate</li> <li>• Attending to personal issues in the ward and neglecting the neonate</li> <li>• Parents busy and not visiting the neonate</li> </ul>	<ul style="list-style-type: none"> <li>• Emotionally dis-regulated parents</li> <li>• Unrealistic expectations of nursing staff</li> <li>• Parents reject caregiving due to perceived inequalities</li> <li>• Commanding or forbidding medical procedures</li> <li>• Manipulating settings of neonate's equipment or devices</li> <li>• Disobeying NICU ward and staff rules and regulations for neonates</li> <li>• Giving untimely or inappropriate advice to other parents in the ward</li> <li>• Giving inaccurate information to care staff</li> <li>• Inciting fear in other parents due to group misinformation</li> </ul>

dignity among parents and staff; lack of collaboration and partnership; mis-communication and inappropriate or inaccurate information sharing (6).

Based on our content analysis, unpleasant feelings is one of the most critical barriers to family-centred care of the neonate. Other Iranian studies have reported high stress levels among parents following hospitalisation of the neonate, fear of injury or transmitting an infection to that neonate and fear of being emotionally attached to a neonate that may die. In the same studies, parents expressed fear of society's judgments and feeling guilty about having a premature neonate (4,8).

Reports from the United States of America reported parents being afraid to hold, touch, and care for their newborns because of their fragile appearance and size (15). In a study in China, some mothers believed the delivery of a premature baby was considered a "failure" because of a societal notion of female perfectionism. These mothers felt stigma, stress, anxiety and depression which hindered their desire to face and hold the neonate daily (16). In a study in western France, 64% of NICU specialists reported that they perceived that parents experienced increased anxiety about their neonates if they were present during daily medical rounds, which includes teaching interns and residents using patients in the wards as examples (17).

Consistent with our identification of the category of challenges in engagement and participation, similar studies in the Islamic Republic of Iran have indicated that parents did not want to stay in the ward for a long time, and they were more interested in providing emotional support than direct care for their neonates (4). These families focused on interacting with the nurses while performing their tasks for the neonate rather than paying attention to the baby. Other challenges include the distance between the family's place of residence and the hospital, poverty, drug addiction, unemployment, and sole responsibility for other children in the home (4,8).

There are problems of this type in other cultures as well. The biggest challenge mentioned in a Chinese study was that most families still observed the "zuo-yue-zi" culture, where the new mother has to stay indoors under bed rest for 20 days or more postpartum and is unwilling to come to NICU before the confinement ends (16). Other studies in United States of America showed that family visitation of neonate was limited because of parental health issues, distance from the hospital, separated or divorced parents who live apart, parents with other children or parents on public assistance. Although we could not query fathers in our study, other studies found that fathers tended to focus on the technological aspects of their neonate's care, such as advanced life support NICU devices, rather than the baby themselves, which could lead to dysfunctional emotional and physical bonding or attachment alienation (15,18).

Effective communication between parents and health care providers about the unique or advanced care practices used for their neonates is a major challenge in

the NICU (19-21). Foreign studies and a study from the Islamic Republic of Iran have reported parents becoming aggressive and hostile towards the health team if the neonates experienced serious medical complications such as recent decompensation, malformations, high medical complexity or a long NICU stay (19,22). Challenging parental behaviours such as investigating ward issues, asking untimely and frequent questions or manipulating nurses' behaviour, especially during busy and unstable hours puts unnecessary pressure on already stressed nurses (10).

Some of the treatments that must be administered on neonates are very traumatising for parents and cause them to interfere with procedures if they are present. Consistent with this finding, Yue et al. reported medical staff being concerned about parental interference in routine treatments or life-saving procedures including injections and emergency interventions. If the parents consider these actions too brutal, there will be conflicts between parents and the medical staff (16). Friedman et al. reported challenges for nursing staff such as suspicious parents, parents who interfere with equipment, parents who repeat questions or consider staff inaccessible, etc. (22).

Another finding in this category was providing untimely or inappropriate advice to other parents in the NICU. Peer to peer support by families who have or had a neonate in the NICU can be a valuable source of hope, information, support and advice; but nurses must ensure that mothers do not give false hope or misinformation to other mothers (23).

We found various studies that evaluated the need for care staff to communicate with parents during family-centred care to avert problems related to untimely or insufficient interactions or information, but no study about parents misinforming care staff. In our study parents may have over-stepped their boundaries with care staff because of fear, misunderstanding of their role and participation in family-centred care plans, lack of trust in care staff, unusually high stress levels of the parent as well as inappropriate or unsafe comments, information or behaviours among parents while visiting their neonates in the wards.

## Study limitation

Due to the timing of the study (2020–2021), we had to comply with the hospital's COVID-19 restrictions regarding who could visit the neonates in the neonatal intensive care unit and therefore we could not interview or observe fathers of the neonates in this ward-based study.

## Conclusion

Considering the comprehensive examination of the parental barriers to family-centred care provision, we recommend that health authorities pay attention to and address the identified barriers through participatory action research tailored

to the specific context of each NICU ward. Educating the care teams and parents regarding family-centred care principles is advocated to improve overall neonatal and familial health outcomes.

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**Competing interests:** None declared.

## Obstacles parentaux à la mise en œuvre de soins centrés sur la famille dans une unité de soins intensifs néonataux en République islamique d'Iran

### Résumé

**Contexte :** Des études ont montré les effets positifs à court et à long terme des interventions de soins centrées sur la famille sur la santé néonatale et maternelle, et les résultats de développement dans les unités de soins intensifs néonataux. Toutefois, certains défis et obstacles entravent la mise en œuvre des soins centrés sur la famille.

**Objectif :** Étudier les obstacles parentaux à la mise en œuvre de soins centrés sur la famille dans une unité de soins intensifs néonataux en République islamique d'Iran.

**Méthodes :** Une analyse de contenu classique a été réalisée dans une unité de soins intensifs néonataux à Téhéran (République islamique d'Iran) en 2020-2021. Vingt entretiens semi-structurés ont été réalisés et neuf notes de terrain ont été établies. L'analyse des données des entretiens et celles des données démographiques ont été réalisées à l'aide de la méthode de Graneheim et de Lundman et au moyen du logiciel SPSS version 21 respectivement.

**Résultats :** Deux thèmes sont ressortis de l'analyse des données. Le premier thème était « L'inefficacité dans le jeu de rôle des parents », avec deux catégories principales : « Faire face aux sentiments désagréables » et « Présence et participation inappropriées ». Le second thème était « L'implication inefficace des parents dans les soins », avec trois catégories principales : « Manque de communication efficace avec le personnel », « Interférence des parents dans le processus de traitement » et « Informations insuffisantes données par les parents ».

**Conclusion :** Les obstacles parentaux à la prestation de soins centrés sur la famille se reflétaient clairement dans l'étude. Par conséquent, pour améliorer la santé néonatale et familiale, une participation, une coordination et une communication efficace sont nécessaires entre les équipes médicales et les parents afin de créer un environnement favorable et convivial dans les unités de soins intensifs néonataux.

### عوائق متعلقة بالوالدين تحول دون تنفيذ الرعاية التي تركز على الأسرة في وحدات الرعاية المركزة لحديثي الولادة في جمهورية إيران الإسلامية

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#### الخلاصة

**الخلفية:** أظهرت الدراسات أن لتدخلات الرعاية التي تركز على الأسرة آثاراً إيجابية قصيرة المدى وطويلة المدى على صحة حديثي الولادة وصحة الأم، وعلى مخرجات النمو في وحدات الرعاية المركزة لحديثي الولادة. ولكن بعض التحديات والعقبات يحد من تنفيذ الرعاية التي تركز على الأسرة. **الأهداف:** هدفت هذه الدراسة إلى استقصاء العوائق المتعلقة بالوالدين التي تحول دون تنفيذ الرعاية التي تركز على الأسرة في وحدات الرعاية المركزة لحديثي الولادة في جمهورية إيران الإسلامية.

**طرق البحث:** أُجريَ تحليل تقليدي للمحتوى في وحدة للرعاية المركزة لحديثي الولادة في طهران بجمهورية إيران الإسلامية، في الفترة 2020-2021. وأجريت 20 مقابلة شبه منظمة و9 ملاحظات ميدانية. ثم خضعت بيانات المقابلات للتحليل باستخدام طريقة جرانهايم ولوندمان، وخضعت البيانات السكانية للتحليل باستخدام برنامج SPSS، الإصدار 21.

**النتائج:** انبثق من تحليل البيانات موضوعان. الموضوع الأول كان "التقصير في أداء دور الوالدين"، وله فئتان رئيسيتان: "مواجهة مشاعر غير سارة" و"عدم ملاءمة الحضور والمشاركة". أمّا الموضوع الثاني، فكان "عدم فعالية إشراك الوالدين في الرعاية"، وله 3 فئات رئيسية: "غياب التواصل الفعال مع العاملين"، و"تدخل الوالدين في عملية العلاج"، و"نقص المعلومات التي يقدمها الوالدان".

**الاستنتاجات:** برزت بوضوح في هذه الدراسة العوائق المتعلقة بالوالدين التي تحول دون توفير الرعاية التي تركز على الأسرة. ولذلك، فإن تحسين صحة حديثي الولادة والأسرة يتطلب مشاركة وتنسيقاً وتواصلاً فعالاً بين الفرق الطبية والوالدين، لتهيئة بيئة داعمة وملائمة في وحدات الرعاية المركزة لحديثي الولادة.

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