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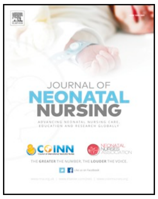

Original Article

Immigrant parents' experiences of communicating with healthcare professionals at the neonatal unit: An interview study

Katarina Patriksson[a,b,*,1], Stefan Nilsson[a,2], Helena Wigert[a,c,3]

[a] *Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden*
[b] *Division of Pediatrics, NÄL Hospital, S-46185, Trollhättan, Sweden*
[c] *Division of Neonatology, Sahlgrenska University Hospital, S-46185, Gothenburg, Sweden*

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ABSTRACT

Background: When newborn children of immigrants require care in a neonatal unit, parents frequently encounter not only a new language, but also a new healthcare organisation.
Aim: To examine parents' experiences of communication with healthcare professionals in a neonatal unit when language barriers are present.
Method: Twenty interviews were conducted with families who spoke Arabic and had a child who had been cared for at one of five neonatal care units, level II-III in western Sweden. The interviews were analysed using a phenomenological hermeneutic approach.
Results: The main theme, having the opportunity to exercise one's parental role, included four themes encountering emotional warmth, feeling accepted, encountering a lack of understanding, and compensating for inadequate language skills.
Conclusion: It is not only language barriers that affect communication between parents and healthcare professionals; different expectations and pre-understandings are also of importance.

1. Introduction

When newborn children of immigrant parents require care in a neonatal unit, parents frequently encounter not only a new language, but also a new healthcare organisation and culture, one that endeavours to enable them to participate in their child's care (Wigert et al., 2014). However, a parent's ability to actively participate in their child's care is dependent on the healthcare professional's ability to communicate with and support them in caring activities (Nyqvist and Engvall, 2009). According to the Patient Act (2014), information should be adapted to the parents' linguistic background and individual circumstances (Patient Act, 2014). Furthermore, according to the Swedish Health Care Act, it is the responsibility of healthcare professionals to give parents the opportunity to attend and be involved in their child's care (Swedish Statute, 2017).

Language barriers can be an obstacle to the interaction between health professionals and the family, which makes understanding of a family's culture important for staff in order to better understand their needs and optimize communication (Hendson, et al., 2015).

Immigrant parents may not speak or understand the local language, hampering both verbal communication and the parents' opportunity to be involved in their child's care and treatment (Patriksson, 2017). Parents often agree when asked a question by the healthcare professional, but it later may turn out that the parents did not actually understand the question asked (van Rosse et al., 2016). It is important that healthcare professionals know if parents understand the information they receive about their child's situation (Wigert et al., 2013). A lack of understanding may simply be due to language barriers or the parents may have a low level of education and health literacy, making it difficult for them to understand the information that is provided (Jungner,

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[*] Corresponding author. Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Arvid Wallgrens Backe, Box 457, S-405 30, Gothenburg, Sweden.

E-mail addresses: katarina.patriksson@vgregion.se (K. Patriksson), stefan.nilsson.4@gu.se (S. Nilsson), helena.wigert@gu.se (H. Wigert).

[1] Katarina Patriksson, PhD student, RN. Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Arvid Wallgrens Backe, Box 457, S-405 30 Gothenburg, Sweden. Norra Älvsborgs Länssjukhus, Lärketorpsvägen, 46185 Trollhättan, Sweden.

[2] Stefan Nilsson, Associate Professor, RN, PhD, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Arvid Wallgrens Backe, Box 457, S-405 30 Gothenburg, Sweden. Centre for Person-Centred Care (GPCC) at the University of Gothenburg.

[3] Helena Wigert, Associate Professor, RN, MSc, PhD, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg. Arvid Wallgrens Backe, Box 457, S-405 30 Gothenburg, Sweden. Centre for Person-Centred Care (GPCC) at the University of Gothenburg.

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Granhagen, Tiselius, Lützén, Blomgren and Pergert, 2016).

Studies show that healthcare professionals are not always aware that parents are experiencing language barriers and this needs to be made clear in the patient's record and communicated clearly among staff (van Rosse et al., 2016). Healthcare professionals are often inexperienced in conducting conversations through an interpreter (Patriksson et al., 2018). Earlier studies show that healthcare professional under-use professional interpreters (Bischoff and Hudelson, 2010), particularly in conversations involving neonatal care (Patriksson et al., 2018). Instead, they prefer to engage multilingual healthcare professionals who are easily available and cost-effective (Bischoff and Hudelson, 2010). Multilingual healthcare professionals are generally willing to act as interpreters (Krupic et al., 2016), but doing so can add to their stress since the pace of work is often high (Krupic et al., 2017). When relatives are used as interpreters, the neutrality afforded by a certified interpreter is lost, confidentiality is a concern and misunderstandings often occur as a result of inadequate linguistic knowledge (Eklöf et al., 2015).

A previous study by Patriksson et al. (2017), explored the experiences of health care professionals in Swedish neonatal care units regarding communication with parents of foreign origin when language barriers existed. Their results demonstrated that health care professionals' experiences were summarized in one main category: "Powerlessness in the face of inadequate care routines leading to failure to communicate." The main category was constructed through three categories. "*Inability to perform their work properly*" meant that staff experienced frustration when they could not convey important information to parents. "*Finding their own strategies*" meant that staff found their own ways to communicate using body language and assistive technology. "*Dependence* on others" meant that staff were dependent on others, primarily talking through an interpreter. They concluded that there is a need for organizational changes to increase parents' participation in their child's care in daily practice at neonatal care units. To ensure that parents who do not speak or understand the Swedish language are given sufficient time and possibilities, routines must be established in which interpreters are used more frequently.

1.1. Aim

The aim of this study was to examine parents' experiences of communication with healthcare professionals in a neonatal unit when language barriers are present.

2. Method

2.1. Design

In order to describe the phenomenon of lived experiences, a phenomenological hermeneutics approach was chosen. This approach was inspired by Ricoeur's (1976) interpretation theory, as described by Lindseth and Norberg (2004). By integrating the phenomenological view of the lifeworld with the interpretation in hermeneutics, the peoples lived experience is elucidated (Dahlberg et al., 2008).

2.1.1. Participants and settings

Twenty families whose children had been cared for in a neonatal unit participated in the study. Inclusion criteria were Arabic spoken families who could not communicate in the local language. The selection was designed to represent a variation in gestational age, parental age, child diagnosis, and parents' country of origin (Table 1). Two of the families didn't know their child's gestational age. The interviews were in the family's home so there was no access to the child's medical journal. The families themselves decided whether they wanted to be interviewed as a couple or if only one of them would participate in the interview. A total of 37 parents participated in 20 interviews. The families were recruited from four hospitals, all based in a region in western Sweden. These hospitals collaborate with each other, and neonatal patients are transferred between the units according to care needs and availability of beds. The neonatal units are divided into three levels of care. Level I, basic neonatal care, Level II, specialist neonatal care, and Level III, the subspecialty of neonatal intensive care which is further subdivided into A–D, where D is full intensive care for extremely preterm babies (Stark, 2004). In this study no Level I unit hospital was included.

Table 1
Demographics of the families.

Characteristics	n
Families	20
Interview with mother and father	17
Interview with mother only	3
Father's age in years at time of interview, mean (min–max) SD	38.2 (29–50) 6.4
Mother's age in years at time of interview, mean (min–max) SD	32.3 (21–40) 3.9
Father's education	
University (higher education)	3
School (elementary education)	17
Mother's education	
University ((higher education)	2
School (elementary education)	18
Type of living accommodation	
House	0
Apartment	19
Hidden by relatives	1
Country of origin	
Eritrea	1
Iraq	2
Palestine	2
Syria	15
Child's diagnosis	
Asphyxia	1
Icterus	1
Infection	5
Prematurity	13
Gestation week, mean (min – max) SD	34.3 (25–41) 4.8
Missing	2
Number of children in the family, mean (min–max) SD	2.2 (1–8) 1.9

A study coordinator was selected at each unit. When there was a family who did not speak the local language, the study coordinator contacted them. The parents received information in Arabic about the purpose of the study. Once the parents' consent to participate in the study was obtained, the study coordinator contacted the first author who by phone (via Arabic interpreter) made an appointment to participate in the interview.

2.2. Ethical considerations

Ethical approval was obtained from the Regional Research Ethics Committee in Gothenburg, Sweden (Registration number T443-15). The study complied with internationally accepted ethical principles for medical research involving human subjects, the purpose of which is to protect individuals and ensure respect for human dignity (WMA, 2015).

2.3. Data collection

Data were collected by the first author via narrative interviews conducted between April and October 2017. The same interpreter was used in all interviews, regardless of hospital site. The parents were interviewed at their convenience in their own homes, except two families who were interviewed at the hospital. The interviews were digitally recorded and lasted for 35–90 min (mean = 54 min). The parents were asked broad open-ended questions and encouraged to speak freely about their experiences of having a child in the neonatal unit.

The opening question was "Tell me about your experience of having a child in the neonatal unit and communicating with the staff there." Additional follow-up questions such as "Can you tell me more about" were posed to clarify the parents' statements and to confirm that the interviewer had understood correctly.

Table 2
Example of how the subthemes and themes were constructed.

Meaning unit	Subtheme	Theme
They usually talked only with my wife because she'd been there for two months. It was challenging for her – really difficult – so they usually sat beside her, chatted with her, and communicated a little as well.	Encountering a caring approach Encountering sensitivity to one's needs	*Encountering emotional warmth*

2.4. Data analysis

Interviews were transcribed and the resulting texts analysed, interpreted, and described. The data analysis used a phenomenological hermeneutic approach, as described by Lindseth and Norberg (2004). The interpretation of the text entailed a shift from comprehension to interpretation, in three phases: naïve reading, structural analysis, and comprehensive understanding.

In the naïve reading, the text was read several times to obtain an immediate sense and broad picture of its contents and to grasp its meaning as a whole. For transparency, the authors' pre-understanding was discussed openly before the structural analysis. During the structural analysis, the text was read carefully, and meaning units that were relevant to the purpose were identified with a view to similarities and dissimilarities. The patterns that appeared between meaning units were grouped into sub-themes that were in-turn, grouped into themes (Table 2). In the comprehensive understanding, the main theme, and sub-themes were summarized and reflected on in-relation to the research question and the context of the study.

3. Results

3.1. Naïve understanding

In the naïve understanding, the text was read several times to grasp its meaning as a whole and to gain an overall impression of the phenomena. The parents who did not speak the local language experienced 'a sense of understanding situations' in different ways. Communicating only through an interpreter involved some difficulty in making themselves understood and getting information about their child's condition was delayed or did not occur at all. Alternative communication solutions, such as using body language or pictorial aids enabled the parents to understand and make themselves understood. Parents were extremely grateful for the comforting attitude of the healthcare professionals, which was expressed non-verbally in gestures such as a hug. It was often the father who spoke for the family and supported his wife by helping with communications.

3.2. Structural analysis

The structural analysis and interpretation led to the emergence of a main theme: *having the opportunity to exercise one's parental role* and four sub-themes were formulated from the condensed descriptions: *Encountering emotional warmth*, *feeling accepted*, *encountering a lack of understanding*, and *compensating for inadequate language skills* (Table 3).

3.3. Encountering emotional warmth

Parents reported experiencing emotional warmth from the healthcare professional. Given the anxiety they felt when their child was being cared for in the neonatal unit, they were grateful for this and for the care their child received.

3.3.1. Encountering a caring approach

Families felt that the healthcare professional cared about them even if they could not communicate with them. A smile or a hug helped the parents feel inwardly calm, even in high-stress situations. Some of the mothers experienced an existential loneliness during their child's time in hospital care but received support from healthcare professionals. One father said that he felt calm even though he was not present at the hospital.

Table 3
Overview of the themes and subthemes.

Themes	Subthemes
Encountering emotional warmth	Encountering a caring approach Encountering sensitivity to one's needs
Feeling accepted	Wanting to make oneself understood Lacking networking with others
Encountering a lack of understanding	Being met with ignorance Being the family's spokesperson
Compensating for inadequate language skills	Needing help from others Being dependent on support

> *If a nurse knocked on the door and asked if you had had anything to eat, it was just like my mother when she calls me — 'Have you had anything to eat? (M14)*

3.3.2. Encountering sensitivity to one's needs

Parents had difficulty communicating with the healthcare professional, misunderstandings often occurred, causing parents to be worried. Their worry was lessened by the healthcare professionals' understanding of their situation, and the parents felt they were invited in to participate in their child's care.

> *You may think that for you this is actually ordinary life, but there's a huge difference between what we've experienced here and what we experienced in our home country. (F16)*

When an interpreter was engaged in a conversation between parents and a healthcare professional, the interpreter was often sensitive to the parents' needs and could help with other matters too, such as translating documents that the family had received by mail but could not read.

> *Interpreting [what the parents needed to do] – do this, do that, provide some papers, too. You need to sign here. Yes, not just interpreting other practical things, too. (F11)*

Since the parents could not communicate verbally with the healthcare professional, they were extra-sensitive to non-verbal communication. By paying attention to the professional's gestures, facial expressions, and tone of voice, the parents tried to get a sense of whether the conversation was about their child having a serious medical condition or if everything was normal.

3.4. Feeling accepted

Parents expressed a desire to make themselves understood and communicated with the healthcare professional through an interpreter. Being able to communicate allowed them to feel accepted as parents, both by the healthcare workers and by the other parents in the neonatal unit.

3.4.1. Wanting to make oneself understood

Parents were dependent on the interpreter in order to obtain information about their child's care and treatment, and to be able to ask questions of the healthcare professional. Some parents claimed that it made no difference whether the interpreter was physically present or interpreted by telephone. On some occasions, parents felt that the interpreter they were given had inadequate knowledge of medical terminology or the Swedish language. The parents were given odd answers to their questions and the interpreter left key information out of the conversation. When errors occurred, the parents felt it was embarrassing to correct the interpreter so the conversation was allowed to continue.

> *But I note that when I ask them something I get a different answer. The answer doesn't relate to the question. And I … it felt embarrassing to say to the doctors that I don't understand the interpreter, because I noticed that whenever I ask something, the answer I get doesn't really relate to the question. (F12)*

3.4.2. Lacking networking with others

The typical lengthy care time for the child in the neonatal unit meant that the parents experienced loneliness. They felt isolated from the other parents in the ward, since they could not communicate with each other. There was an involuntary loneliness among all other parents.

> *You know, we've been new here in Sweden, we have no friends, and she doesn't know the language either. Alone in the hospital – she needs someone to support her. (F9)*

3.5. Encountering a lack of understanding

When communication between parents and a healthcare professional could only occur through an interpreter, there was a risk of misunderstanding. Some parents felt that the healthcare personnel did not understand this risk.

3.5.1. Being met with ignorance

Some parents felt they were a burden on the healthcare professional since they could not speak the local language. It was time-consuming for the healthcare professional to provide information to the parents about their child's treatment. For example, the healthcare professional sometimes took the child for tests without telling the parents in advance. When this happened, the parents became afraid of what might have happened to their child.

> *They would never tell me what they were going to do in the treatment. They simply went ahead and did it. (F12)*

Parents expressed understanding for the healthcare professionals high work-load and parents were afraid to disturb the healthcare professional in their work. Parents sometimes encountered ignorance in their communication with hospital personnel; for example, when they were never allowed to speak to the physician about their child's condition, despite asking repeatedly. Some parents felt that they were treated differently than Swedish-speaking families in the neonatal unit. This manifested itself in the healthcare professional giving each other non-verbal “looks” over their heads, and the parents getting a sense that they were not liked. Parents felt that healthcare personnel spoke about them in unflattering terms. One father described how they had lost their joy over their newborn child.

> *I mean, I don't know if it's part of their rules, the hospital rules, I mean, but there's something lacking in how they treat people who can't speak Swedish. (F9)*

3.6. Being the family's spokesperson

During their time in the neonatal unit, it was common for fathers to feel that their responsibility was to protect and support the family. For example, sometimes a father wanted information about his child's condition to be given to him first, with the mother receiving only limited information to avoid her having to worry. These fathers had difficulty understanding why the healthcare professional insisted that their wives should be given the same information as they received.

> *I was actually worried about her – I didn't want her to be affected. She's already been through so much hardship, and as her husband it's my right to decide whether she's told now or not. (F19)*

3.7. Compensating for inadequate language skills

When language barriers existed, parents had to find alternative ways to communicate with the healthcare professional to obtain information about their child's care and treatment.

3.7.1. Needing help from others

Parents explained that they often had to get help from other people or use different languages to communicate with healthcare professionals. Parents who spoke good English tried to communicate in that language, but sometimes the healthcare professional's English proficiency was limited. At other times, parents declined the offer of an interpreter for conversations, but the healthcare professional insisted that an interpreter be engaged. It also sometimes happened that parents' relatives or the child's older siblings interpreted during conversations between parents and healthcare personnel; however, these individuals often had limited knowledge of Swedish or of medical terminology.

> *I got so scared when they said we have to print out this paper because the child is your responsibility when you go home. They just want to get rid of us. (F2)*

3.7.2. Being dependent on support

Parents said that being proficient in Swedish would have been a great advantage when their child was being treated in the neonatal unit. Since they could not communicate with the professional, they tried to quickly learn Swedish words and teach the healthcare workers words in their native language. Parents often used ‘Google Translate’ on their phones, as well as a translation application called ‘Lexin’ (Google Translate, 2019; Lexin, 2019).

> *Because I look at it this way – if you're an interpreter it's almost impossible to precisely say whatever it is I want to explain. I mean, to say it exactly the way I mean it. The most important thing is for me to learn Swedish. (F13)*

3.7.3. Comprehensive understanding

Parents' experiences of communication with healthcare professionals when there were language barriers varied from receiving caring attention to being met with ignorance. Parents were grateful that their children were given the best opportunity to receive excellent care. When parents were unable to make themselves understood and had to depend on an interpreter to obtain information about their child's care and treatment, they found this difficult. Parents who could not make themselves understood felt lonely among the other parents in the ward. When parents encountered a healthcare professional's ignorance and the healthcare professional talked about them, instead of to them, their joy over their newborn child disappeared. Fathers who took on the role of the family's spokesperson found it difficult to comfort their anxious wives when they themselves were dealing with feelings of anxiety and anger. In order to communicate with the healthcare professional, parents resorted to using translation applications and pictorial supports. Immigrant parents' experiences of communication with healthcare professionals in a neonatal unit can be summarized in the main theme of *having the opportunity to exercise one's parental role.*

4. Discussion

This study highlights that communication difficulties go beyond that of utilizing interpreters, as the interpreter cannot solve all challenges in dialogues between parents and healthcare professionals. Immigrating to a new country and encountering an entirely different healthcare system and culture can result in parents feeling simultaneously vulnerable while at the same time grateful that their child was born in a new country where care is easily accessed. Understanding the local healthcare system and culture was difficult for most of these parents as the healthcare system and culture was entirely different from that in their home country (Nkulu, Kalengay, Hurtig, Ahlm and Ahlberg, 2012).

Parents in the present study felt that even if there were communication barriers, healthcare professionals conveyed a sense of reassurance and care that gave the parents a sense of being included in the care of their child. Parents had a strong desire to make themselves understood and considered that learning the local language quickly was a top priority. In a study by Patriksson et al. (2017), healthcare professionals also expressed a desire to make themselves understood in order to be able to provide information and to support parents in caring for their child. When there were language barriers, it was particularly difficult for parents to understand what was expected of them (Nkulu Kalengay et al., 2012).

Something that made it more difficult for parents to communicate with healthcare professionals was when the interpreter failed to interpret what they had expressed, or was not sufficiently familiar with medical terminology. Gulati et al. (2012) describe that language barriers are an obstacle in communication pertaining to medical terminology that relates directly to the child's care.

Studies show that healthcare professionals are often asked to serve as interpreters because of the difficulty in recruiting certified interpreters. When parents encounter inadequate interpreting, they usually choose not to complain about it, as they do not want to hurt the feelings of the person who provided the interpreting (Steinberg et al., 2016).

On some occasions, parents felt they were treated differently than other parents who spoke and understood Swedish. Steinberg et al. (2016) claim that a poor reception and sense of discrimination were usually due to language barriers. It is important to make clear that because of this perception, parents were unable to feel joy about their newborn child.

Sometimes it appeared that the father did not want the mother to receive information about the child's condition which could make her upset and sad. While the fathers meant well, and this practice complies with the family's culture where fathers are the protectors of the family, receiving several difficult messages could be a huge burden to the father. A father's sense of being the family's spokesperson and feeling that the family must be protected sometimes appears when the family's requests are ignored, or when the family's expectations are not met (Pergert et al., 2012).

The strength of this study is that all interviews were carried out with the same interpreter, which meant that the interpreter was thoroughly familiar with the purpose of the study. Since the interpreter had booked the interview with the parents, they had the opportunity to ask direct questions about the purpose of the study in their native language.

A weakness of this study could be selection bias due to families who experienced frustrations with language barriers might be more likely to participate. Another weakness could be that only families whose native language was Arabic were interviewed, therefore generalizations cannot be made to other languages. The results could possibly have been different if parents from smaller language groups had been included, since for these parents there is usually no-one in the neonatal unit who speaks their language. It is also unknown whether native speaking parents had similar or different feelings and experiences.

5. Conclusion

Parents found it difficult when they were unable to communicate directly with healthcare professionals and were always dependent on some form of interpretation and translation support, yet it is essential that parents who do not speak or understand the Swedish language be offered interpreters to ensure that communication regarding their child's care is clearly understood. This study shows that it is not only language barriers that affect communication between parents and healthcare professionals, even different expectations and pre-understanding are of importance. Future research is needed to describe other communication barriers between health care professionals and parents on a neonatal ward in the presence of language barriers.

Author contribution

Author contribution for the study conception and design: Katarina Patriksson, Stefan Nilsson and Helena Wigert.

Collection and analysis of the interviews: Katrina Patriksson, Stefan Nilsson and Helena Wigert.

Drafting of manuscript, Katarina Patriksson and Helena Wigert.

Critical revision Katarina Patriksson, Helena Wigert and Stefan Nilsson.

Ethical approval

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Appendix A. Supplementary data

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