

Disabled and immigrant, a double minority challenge. A qualitative study about the experiences of immigrant families raising a child with a disability and navigating the Norwegian healthcare system.

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Abstract

Background: Immigrants and their Norwegian-born children make up approximately 18% of the total population in Norway. The legitimacy of the healthcare system is a product of its ability to provide timely and appropriate services to the entire population. While several studies have been conducted on migrants' utilization of healthcare services, immigrant families are systematically underrepresented in international studies of children with disabilities. This study, by focusing on experiences of immigrant families of children with disabilities who are navigating the Norwegian healthcare system, will generate knowledge of how accessible and tailored the services are from their point of view. **Methods:** This study took a qualitative approach, using semistructured interviews to explore the experiences of immigrant parents of children with disabilities from non-Western countries. The interviews were transcribed, coded, and analyzed via an inductive thematic analytic approach. **Results:** The findings show how the "immigrant experience" influenced the way the parents looked at, experienced, and even praised the services. The parents appreciated the follow-up services provided by the pediatric rehabilitation centers, which they experienced as predictable and well-organized. While navigating the services, they experienced several challenges, including the need for information, support, and timely help. They felt exhausted because of the years of struggle in the healthcare system to gain access to the help and services they needed. The feeling of being treated differently from the majority was another challenge they experienced while navigating the services. The findings also show how the parents' experiences of communication with healthcare providers were influenced not only by their own language and communication skills but also by the healthcare providers' intercultural communication skills and dominant organizational culture. **Conclusions:** The parents' experiences show that there is still a gap between the public ideal of equal healthcare services and the reality of the everyday lives of immigrant families of children with disabilities. By exploring immigrant families' experiences, this study highlights the importance of mobilization at both the individual and system levels to fill the current gap and provide tailored and accessible services to the entire population. **Keywords:** Immigrant families, Children with disabilities, Healthcare system.

Background

The composition of the Norwegian population, as in other countries in Europe, has been changing (1, p. 3). Immigrants and their Norwegian-born children comprise approximately 18% of the total population in Norway. More than 80% of all immigrants in Norway come from non-Western countries (2). The immigrant population, like the rest of the population, is not a homogeneous group (1, p. 4). They come from 221 different countries and independent regions for many different reasons (3). They vary in ethnic, cultural, educational and socioeconomic backgrounds, as well as the length of their stay in Norway (2).

An inclusive and equal society is an important goal of the Norwegian government. It is important both for the individual and for the society that everyone feels a part of the society. An equal healthcare service is a

very important part of and a condition for achieving this goal (1, p. 3). However, the consumption of healthcare services in Norway varies both within different immigrant groups and between immigrants and the general population (4).

Increasing ethnic diversity in the population and differences in the utilization of healthcare services pose challenges to the authorities' stated goal of equitable healthcare. Improving knowledge of what influences immigrants' use of healthcare services will therefore be beneficial for planning policies and delivering healthcare services (4). While much research has been conducted on immigrants' utilization of healthcare services, immigrant families are systematically underrepresented in international studies of children with disabilities (5).

A critical review of the literature on immigrant and refugee families of children with disabilities revealed an absence of information about their access, utilization and service experience of both community-based healthcare and rehabilitation services (6). Generally, awareness and utilization of services varies considerably among families of children with disabilities. Characteristics of the child, such as the severity of the disability; characteristics of the family, such as their knowledge of the available services; and characteristics of the community, such as the availability of the resources, are factors that cause this variation (7).

Learning about and gaining access to services are demanding tasks for families of children with disabilities, especially for those who are not members of the majority culture (7). A recent systematic review revealed increased barriers to access to care for immigrant families of children with special healthcare needs, partly due to the difficulty in navigating a challenging and changing healthcare system (8).

Immigrant families of children with disabilities not only face the same barriers as majority families but also encounter additional challenges (9, 10). They face challenges due to language barriers (9, 11, 12), a lack of familiarity with cultural expectations regarding the proper way in which to seek help (7, 13), and professionals who are not fully aware of the implications of ethnic diversity with regard to values, goals, and behavior (7, 14). Several studies have shown how service providers' stereotypical perceptions of immigrant families create challenges during these families' encounters with the healthcare system (15-17). Service providers largely explain the challenges they face while interacting with immigrant families

as being the result of cultural and religious differences (17, 18). Because of this, service providers may easily overlook other matters of importance and instead create stereotypical images of "the others" with reference to their culture or religion (17). This generalization can hinder the building of individual relationships to meet the unique needs of each family.

The legitimacy of the healthcare system is a product of its ability to provide timely and appropriate services to the entire population (19). Increasing ethnic diversity in the population necessitates a great deal of flexibility, creativity, and professional expertise on the part of the healthcare services to provide equal access, usage, and outcomes for the entire population (10). Research shows that lack of use of services has more to do with how the services are organized than with the characteristics of the families (5, 15, 16). There is, however, limited literature that tells us about the stories of immigrant families who have children with disabilities (20). A lack of knowledge of these families' experiences interacting with the healthcare system limits the cultural integrity of practices within healthcare services (17, 20). McKay (8) notes a lack of data about the best practices with regard to immigrant children with special healthcare needs. According to Fellin et al. (14), there is an absence of formal procedures for developing approaches and treatment plans based on interactions between professionals and immigrant families who have children with disabilities, despite their importance for the support of those families.

It is, therefore, important to conduct research focusing on diverse populations to enhance the further development of healthcare services and provide appropriate care and guidance to immigrant families who have children with disabilities. This study sheds light on the experiences of immigrant families raising children with disabilities who are navigating the Norwegian healthcare system in general and the pediatric rehabilitation services in particular.

Methods

This study was conducted with a qualitative approach, using semistructured interviews to explore the experiences of immigrant families of children with disabilities who are navigating the Norwegian healthcare system. By focusing on experiences of immigrant families from non-Western countries, this study generates knowledge of how accessible and tailored the services are from their point of view.

This study builds on experiences gained during a former developmental project, which was intended to inform and encourage immigrant families living in the Oslo area to participate in the pediatric rehabilitation program at a Norwegian rehabilitation center. At the time, the first author had partial responsibility for informing the healthcare providers in the Oslo area about the project and its aim. The healthcare providers could then refer the families who were interested to the first author to access more detailed or practical information about the rehabilitation center and its program.

Participants

By applying convenience sampling, this study included immigrant parents of children with disabilities from non-Western countries who had participated in the pediatric rehabilitation program between 2015 and 2017. The participants were recruited through the rehabilitation center via an information letter about the study that was sent after or prior to their three-week stay at the center. The potential participants who lived in the Oslo area were additionally informed about the study verbally by phone by the first author in simple language after they had received the information letter. The sample included 23 parents, with 6 fathers and 17 mothers who were immigrants from 14 different countries (Table 1).

Table 1 Number of participants and countries of origin

Country of origin	Number of participants
Afghanistan	1
Bosnia	1
Bulgaria	1
Chechnya	2
Iran	1
Iraq	2
Jordan	1
Pakistan	4
Poland	1
Serbia	1
Somalia	4
Sri Lanka	2
Tunisia	1
Zimbabwe	1

Some participants were familiar with the first author prior to the study commencement due to her role in the former project. One of the families was already familiar with the first author due to her role as their child's physiotherapist.

Although we used convenience sampling, the participants varied in their educational and socio-economic backgrounds, Norwegian language skills, and the length of their stay in Norway (Table 2). Because the healthcare system in Norway is organized similarly across the whole country, the experiences of the services would remain largely the same regardless of the city of residence in Norway.

Table 2 Sociodemographic characteristics of the participants

	Sex	Age	Education	Norwegian language skills (estimated by the first author)	Length of stay in Norway (years)
1	F	30–40	University	Very good	15
2	F	40–50	High school	Good	15
3	F	30–40	Primary school	Very basic	15
4	F	30–40	High school	Very good	28
5	F	40–50	High school	Very basic	18
6	M	50–60	University	Very basic	8
7	F	40–50	University	Very good	17
8	F	30–40	High school	Good	8
9	F	40–50	Primary school	Very basic	28
10	F	40–50	Primary school	Almost none	9
11	M	40–50	High school	Basic	29
12	M	50–60	High school	Basic	12
13	M	40–50	University	Very good	29
14	F	40–50	Primary school	Good	22
15	F	30–40	High school	Basic	15
16	F	40–50	University	Basic	8
17	M	30–40	High school	Basic	7
18	F	40–50	High school	Basic	23
19	F	30–40	University	Very basic	10
20	F	40–50	University	Very good	20
21	F	40–50	University	Very good	21
22	F	30–40	High school	Very good	19
23	M	30–40	University	Very basic	4

Data collection and analysis

Twenty-three interviews were conducted from April 2017 to January 2018. All interviews were conducted by the first author in Norwegian, except one that was conducted in English. The first author is an immigrant from the Middle East herself. She worked as a physiotherapist in the primary healthcare system in a multicultural district in Oslo for several years. Both as an immigrant herself and as a health professional, she was familiar with some of the challenges that the participants may have experienced while navigating the Norwegian healthcare services. The shared experiences and cultural familiarity was a foundation for building trust between her as a researcher and the participants.

Professional interpreters contributed while interviewing six participants. The use of interpreters was based on the first author's perception of the participants' language skills during the telephone conversation prior to the interviews, if the participants did not mention the need themselves. The interpreters explained their roles and their duty regarding confidentiality, and they signed a declaration form prior to each interview.

Prior to each interview, the first author explained the purpose of the study and the study regulations regarding confidentiality, and then she obtained written informed consent from all participants. She also emphasized that they could withdraw their consent without giving any reason if they wished to later. The participants were also informed of the interview procedure and the recording of the interviews. Interviews lasted for approximately 25-65 minutes and were performed at a place and time that were convenient for each participant, including participants' homes, a café, Oslo Metropolitan University, the rehabilitation center, and the Family House health and educational service providers in the participants' local districts. While interviewing two participants, their spouses were present during parts of the interviews.

All interviews were recorded and transcribed verbatim by the first author. Transcription of the first four interviews took place immediately after conducting the interviews, which was useful for fostering reflection on the applied terms, and construction of interview questions based on participants' understanding and responses. Then, the interview questions were modified, and new questions were added to the interview guide. However, adjustments of the interview guide were constantly made while conducting the interviews depending on the participants' responses and the context of the interview. The interview guide explored three domains: (1) the experience of services in terms of both strengths and challenges; (2) the experience of interacting with healthcare providers; and (3) the experience of receiving information.

The transcription of interviews was an ongoing process as was conducting the interviews; the process of transcribing the interviews lasted a while after completing the interviews. Therefore, the first author listened to all audiotapes again right before analyzing the transcripts and refamiliarized herself with the context of each interview and the content of the data as a whole. An inductive thematic analytic approach (21) informed by interpretive description (22) was applied to explore the potential patterns in the data. Each interview transcript was read individually in an active way, searching for potential patterns, and initial data-driven coding was performed. The initial codes were defined broadly to bring together a group of data extracts that could be related. As a result, the data were ultimately organized into 17 codes relating to the strengths of the services,

the experience of communication, and the interpreter. At the same time, a “quotable quotes file” was created including the particularly powerful pieces of data to ensure that they would not be lost while also preventing them from dominating the evolving analytic process (22, p. 149). A file named “reflection notes” was also created to register the first author’s reflections and thoughts while analyzing the data.

After organizing the data extracts into different codes, the analysis involved making sense of the relationships among the various groups by moving within and across the groups. A repetitive thinking and reasoning process and shifting attention from similarities between certain cases to the differences between other cases led to the deconstruction of the initial groups. By linking data elements together across the different codes and discarding some codes, data extracts were reorganized into six initial themes: 1. The alienation of immigrants; 2. communication between immigrant families and healthcare professionals; 3. gratitude towards the healthcare system; 4. the battle to access help; 5. access to information; and 6. prejudice as an extra challenge while navigating the healthcare system. Thereafter, the data within each initial theme were further analyzed, and subthemes were generated to give structure to the themes by elucidating the variation and details within the themes. For instance, three subthemes were identified within the theme “access to information”: “lack of information”, “challenges to accessing information”, “facilitators of accessing information”. Next, the initial themes and subthemes were reviewed by all four authors to ensure that the themes were appropriate with regard to the data set, that the data within the themes cohered meaningfully and that there was a clear distinction between the themes. Subsequently, the themes were refined; one theme that did not fit with the others was discarded (“alienation of immigrants”), and two themes were combined to form a new theme (“the battle to access help” and “prejudice as an extra challenge while navigating the healthcare system”). Finally, four themes were identified, and representative quotes were selected to generalize the descriptions of the participants’ experiences. The four themes were further interpreted in the context of previous literature. Although the different phases of the analysis are described here as being linear, the process of analysis was actually done by moving back and forth throughout the different phases.

Results

Each participant had a unique story, and their experiences of the services and challenges were diverse. However, four main themes emerged after analyzing the data: 1) immigrants’ gratitude for the services, 2)

communicating beyond language, 3) finding a way through the service system, and 4) accessing help as a battle.

1. Immigrants' gratitude for the services

The participants were mainly satisfied and grateful with regard to the services, especially the follow-up services provided by the pediatric rehabilitation centers. They experienced the follow-up services as continuous, predictable and well-organized. They also felt safe that their children were in good hands and would receive follow-up services from by caring and competent healthcare providers. Some participants were even cautious of talking about the challenges they had experienced while navigating the healthcare system because they were afraid of being perceived as ungrateful or demanding.

One participant explained how satisfied she was with her son's checkup routines and her ability to stay in touch with his physicians over many years. She expressed her trust in and gratitude for the healthcare providers as follows:

They (the healthcare providers) have done the best they could do...I feel that one should not criticize and be very picky about things that are unnecessary because people who are ungrateful to humans are ungrateful to God, too. (P 9)

A culture of gratitude and appreciation is a major part of the values that this participant, like many others in this study, grew up with and believe in. Thus, this participant, like many others, was initially hesitant to talk about what she had struggled with over the years while navigating the healthcare system. Some participants also experienced that the follow-up services had a holistic approach and included several important dimensions with regard to their children's development. They were satisfied with how their children's wellbeing and progress at school had been followed by the healthcare providers. Their experience was that the healthcare providers supported them in overcoming the challenges that their children faced at school by cooperating and participating in the school meetings. One participant explained his satisfaction with the services as follows:

I am satisfied with the follow-up program. You know for sure how the pediatric rehabilitation works; they follow the children's health conditions, behaviors and schooling. (P 11)

This participant pointed out his appreciation of how the follow-up services took care of his child's needs comprehensively.

The immigrant experience was highlighted when the participants praised the services. A participant explained that in her home country, her child could not even go to the ordinary school with the other kids, and they had to pay a substantial sum of money to buy her a wheelchair.

I'm satisfied with everything ... we have different assistive devices and exercise equipment. She is riding, she is very happy, she goes to the physiotherapy, and she goes to the school, which is also important. We cooperate with the school and the hospital, and there is a lot of responsibility. (P 8)

She deeply appreciated the services, acknowledging that her child would not have the same opportunities in their home country because of her disability. She appreciated her child's happiness participating in the different activities like other children. Similarly, several participants compared their experiences of services in their home countries with the Norwegian services, which reinforced their gratitude and satisfaction. Some participants appreciated being involved and informed about their children's condition while receiving well organized follow-up services, which was not common in their home countries.

They always plan what the next step is going to be and how. The doctor discusses her (condition), and they inform us of what they think has to be done. We are grateful for it because not all countries give these opportunities. (P 1)

Coming from countries in which the doctor-patient relationship is based on the idea that doctors exert professional authority through medical expertise, the participants appreciated the opportunity to be involved in the physicians' decision making and follow-up procedures. Some participants experienced being involved in this process as informative and educational. Participants also appreciated how attentive the healthcare providers were with the children and how well they handled and took care of them. One participant explained how she, as a newcomer to Norway, experienced their first meeting with the healthcare providers:

The way they talk to the kids; the kids feel so safe here. They are not afraid. I don't know; it was a total shock. And in the beginning, when they started talking, I wanted to cry. Because I felt like a

human being, like a real human being. This was really new to me. Also when you feel that everyone will help you ... I'm so grateful. (P 16)

The participant was grateful for the way the healthcare providers approached her and her child calmly and with respect. She explained how she used to be very emotional in the beginning because this type of approach was quite unfamiliar to her. Furthermore, she explained how differently they used to be treated by the healthcare providers in their home country. She could remember the day that she was kicked out of the hospital because she complained about what she perceived to be wrong treatment of her child. She experienced that the healthcare providers did not listen to her at all. She explained how in their first meeting with the physician here in Norway, she did not talk because she was afraid of being treated the same way she was in her home country.

The participants' statements illustrate how the immigrant experience made them look differently at the services available to them in Norway. Comparing the services with those in their home countries made them even more appreciative of the Norwegian healthcare system, knowing that their children's needs were being met by qualified and empathic healthcare providers.

2. Communicating beyond language

The participants experienced communication with the healthcare providers differently; while some perceived it to be good or very good, others perceived it to be difficult or stilted.

Several participants experienced communication difficulties because of language barriers, especially during their first years in Norway. They experienced communicating through the interpreters as challenging and emphasized how disturbing and frustrating it was to communicate through interpreters, whom they perceived as unprofessional. A participant, who was dependent on having an interpreter to communicate with the healthcare providers, shared her experience as follows:

Sometimes they (healthcare providers) order a good interpreter, but sometimes they order an interpreter who misinterprets! Then, the healthcare providers misunderstand, and it bothers me for the rest of the day... It is important that they order a professional interpreter... It is about a human life. (P 10)

The experience of being misinterpreted by unprofessional interpreters, given the importance of the content of the conversation, was disturbing to the participants. They also felt insecure about how

correctly the information from the healthcare providers was relayed to them. Participants stated that they did not give feedback to the healthcare providers about their experience with the interpreters, rather relying on the hope that they would have a different interpreter the next time. However, there was a participant who got frustrated having the same interpreter several times in row.

Participants also occasionally used to communicate with the healthcare providers through their spouses or their children, who could speak Norwegian. Although they did not complain about that, the following experience shows how damaging it could be to communicate through relatives in the context of the healthcare system.

They found out that the baby was not normal when they did an ultrasound (during pregnancy); however, my husband asked them to not tell me about it because it could upset me! Also, when the baby was born, his face was different! A week after birth, the doctor told me about the baby's condition. (P 9)

While interviewing this participant, her husband confirmed that he knew about the baby's condition before his birth. Although the participant justified her husband's decision to not inform her, the fact that she the right to know about the baby's condition during her pregnancy is undeniable. It is the healthcare providers' responsibility to ensure that their clients have understood the content of the conversation and to use a professional interpreter instead of relatives.

On the other hand, there were participants who were satisfied with their communication with the healthcare providers despite the language difficulties. They explained how their ability to ask questions, the healthcare providers' patience, and their ability to explain contributed to overcoming language barriers while communicating. A participant with basic language skills who was satisfied with the communication shared his experience as follows:

We had good communication. We did not have communication difficulties! But if I do not understand what they say in Norwegian, I'm not just going to pretend I understand. I have to understand what this is about ... I ask them to explain. (P 11)

Although these participants were confident about their communication with the healthcare providers, there is no guarantee that they truly understood the conversation completely. Speaking a language

partially can be more challenging than not speaking the language at all. The reason for this is that neither the clients nor the healthcare providers ask for a professional interpreter, which could lead to the loss of important information. Some participants believed, however, that communicating in the same language was not enough to experience good communication in the context of the healthcare system. They believed that the healthcare providers' engagement, empathic listening and even their body language influenced the experience of the communication. A participant who could speak a little Norwegian explained what he believed about communication:

I remember there was a professional doctor at the hospital, where we communicated through an interpreter, but it was still difficult to get to the point and communicate. Conversely, there was a social worker who was also professional, and we understood each other quite well and were on the same page, even though we did not use an interpreter... I think culture plays an important role. Possibly, the doctor has not been in touch with immigrants like me, perhaps we communicate differently, maybe they have been educated differently... (P. 6)

This participant noted culture and experience as important dimensions of communication. To him experiencing good communication was not only about speaking the same language but also about the healthcare providers' intercultural communication skills because culture and communication are strongly intertwined. One of the participants even perceived that belonging to different cultures affected the communication with healthcare providers by making both parties more cautious than they might otherwise be. Some participants also noted how the dominant organizational culture, especially time pressure, influenced communication despite management of the language barrier. A participant who speaks Norwegian fluently shared her experience with us:

Even though we are physically present, mentally we are almost not there, because it is an unfamiliar language and things happen very quickly, and it is not natural to stop very often and ask them what something is, because they have to go through everything in an hour and a half ...it's too short a time... the last few times, it became more like writing what they need in relation to the CPOP (The national Cerebral Palsy Surveillance Program). It was the program that was the focus rather than what we would need in the future. (P 20)

Time pressure, routine tasks and the surveillance program were perceived as challenges by this participant while communicating with healthcare providers. She also experienced medical terminology as an unfamiliar language, which affected her ability to completely follow the conversation with the healthcare providers. Participants' experiences reveal that communication in the context of the healthcare system depends not only on the communication skills of both the clients and the healthcare providers at an individual level but also on the dominant organizational culture at a system level.

3. Finding a way through the service system

Knowledge of the laws, their rights and the services they were entitled to was important to the participants. They experienced that healthcare providers did inform them about the rules or their rights. Furthermore, language barriers made it difficult for them to access and comprehend this type of information themselves. One of the participants who also experienced that information was not made available to immigrants reflected on the possible reasons:

There is no information, or if there is, it is hidden, maybe it is in Norwegian. I don't know, but a lot of information is not readily available to immigrants, I don't know why. Perhaps the health caregivers just assume that you know what to do or where to get the information from. (P 19)

This participant's statement reveals the need to make information available in different languages. Furthermore, healthcare providers need to be aware of the importance of informing and enabling immigrant families who are trying to navigate the services. Several participants also experienced that they received information randomly by meeting other parents on different occasions. Some others said that they received some information by being associated with different organizations for children with disabilities. A participant who had tried to access the services, which they were entitled to, through their general practitioner (GP), shared her experience with us:

We have experienced that many healthcare providers, even our regular GP, who is absolutely fantastic, do not have information about our rights... So I think if healthcare providers who are supposed to provide information to us do not know about it themselves, it would be very random how multicultural families get access to information. (P 20)

This participant noted the importance of being prepared as a healthcare professional to provide the information that immigrant families need to access the services that they are entitled to. Lack of information about the services available and how to access them limited the participants' abilities to navigate the services. It was not easy for some of them to know what to ask healthcare providers about either. Some participants stated that the healthcare system was structured in a way that only benefited privileged clients who were already able to participate fully. They emphasized the importance of tailoring the services to different groups in society to offer accessible and equal services to the entire population. A well-educated participant who defined herself as a resourceful and well-integrated citizen noted the need to enable the immigrants she defined as disadvantaged:

There are immigrants who have less knowledge and do not know what to ask about. They do not know which services are available, so maybe it would be good to inform them... I think society expects that this group of immigrants will integrate well, but the society is responsible for informing them. (P 7)

The participant's statement highlights the importance of enabling the immigrants to not only navigate the services but also integrate into the society. As this participant noted, access to the services is an important element of the integration of immigrants into society.

Among the professionals referred to, social workers stood out. Participants met social workers mainly after their children were diagnosed. The participants were mostly satisfied with the information and support they had received from the social workers. Some of them noted that receiving the information was not helpful if they did not receive the guidance and help they needed to access and navigate the services. One participant shared her experience as follows:

I was in touch with a social worker earlier; she told me about our rights, and how to access the services ... I cannot write very much, like proper letters, so after receiving the necessary medical documents from the GP, I used to go to the social worker and she helped me with that. (P 15)

As this participant noted, navigating the services demands special skills, such as an appropriate level of writing skills, to apply for services. Application letters have to be well documented and convincing. The

participant used the social workers to not only obtain the information but also navigate the services. Some participants, however, experienced that the information provided by social workers was not comprehensive or continuous. Despite the fact that the participants' need for information was continuous as their children grew up and entered new stages of development, their relationship with the social workers was not continuous. They stated that they met the social workers only a couple of times in the very early years after their children were diagnosed. Considering that family situation and healthcare options vary over the years, the participants' need for information was not completely met by the social workers either.

4. Accessing the help as a battle

Years of struggling to get help were what some participants had experienced and talked about. They felt that their concerns had been underestimated and had not been taken seriously by the healthcare providers. They described how they consistently had to insist on their need for help, and they were even wondering if they had been perceived as nagging or rude. They felt exhausted, and they experienced their attempts to get help as stressful, frustrating and demanding in terms of resources. They stated that the struggle over the years had affected their mental and physical health. Some participants described it as challenging to obtain access to the specialist healthcare system through GPs, who acted as gate keepers. One of them, who had felt that her worries about her daughter had been underestimated by their regular GP for several years, described her experience as follows:

We really experienced from the beginning that she was very uneasy, cried a lot and was delayed in her motor skills, so we arranged an appointment with our regular GP, and she told us that there was no reason to worry... when she turned 3 years old, we still experienced challenges; then we arranged a new appointment with the GP, and she still said that it was normal until she turned 5 years old. (P 20)

She then explained how they kept being worried because they observed that their child fell a lot. Then, they decided to reach out to their regular GP again to obtain a referral to the orthopedic outpatient clinic. Although the GP referred their child to a specialist this time, she was not prioritized.

... but we did not receive any response, so we called them, and they said she was not a priority... Again we went back to our regular GP, it was already over one year later, so she sent a reminder of

the referral ... then we got an appointment at the orthopedic outpatient clinic, and the physician recognized what was wrong, so she sent us to the children's department at the hospital immediately.... She was 5 at the time. (P 20)

Five years of being sent back and forth to access help from the healthcare system was a burden on this family. This participant described how they could not pay enough attention to their son because they were focused on getting help for their daughter. She believed that this entire burden could have been alleviated if their concern had been taken seriously by the healthcare providers in the beginning. Another participant, who described access to help as a battle, was wondering if healthcare providers perceived the parents' concerns as excessive. She experienced her attempt to access help through their regular GP as continually hitting a wall. One participant even generalized her experience of not being taken seriously by the doctor as a common pattern while seeking help in Norway.

We used to receive an appointment with the doctor. We went there and talked to the doctor, but as you may know, he kept saying that everything is fine. As you may know in Norway, the doctors always say that everything is fine. (P 5)

Some participants felt that healthcare providers did not always pay attention to their concerns or were not interested in listening to their worries. They described how healthcare providers used to interrupt them or change the subject of the conversation, which they might have thought to be irrelevant. One of the participants, who had experienced his worries about his family's situation not interesting healthcare providers, described it in this way:

I have experienced that it is not important for them to know or hear about my financial situation or about my residential situation, or when I am talking about transport, I have noticed that they do not care. In my opinion, our financial and residential situation is related to my children's health, but they do not see it, they do not understand it. I have always talked about it to my regular GP.. (P 11)

This participant felt that the healthcare providers ignored and overlooked what this family truly struggled with. He believed that the healthcare providers did not consider his worries to be of interest or relevant to their jobs. He then described how exhausting it had been not to receive timely help:

...The problem is that it takes so long, you get help when you have become completely exhausted. You have to approach them and complain again and again, they do nothing until you fall down ... then they will help you. (P 11)

He finally described how the demanding and stressful process of getting help over the years had caused him a lot of stress and disturbed his mental balance. This type of experience among the participants underlines the importance of listening and responding to the families' perceptions of their own resources, challenges and needs. These experiences highlight the need for a coordinated approach to the assessment of need and the provision of services appropriate to all aspects of the family as a whole.

Language barriers and lack of knowledge of medical conditions made it even more challenging for some participants to get timely help. One participant, whose daughter suffered from seizures for several months before she received help, shared her frustration as follows:

Every time I went to the hospital, I explained how she used to lose consciousness and started kicking and how disturbing it was for her. Every time I told them, they replied that it has something to do with her nerves. (P 10)

She explained that she did not know anything about seizures, and this condition was quite unfamiliar to her. The participant's difficulty in describing her child's condition precisely caused significant delays in receiving a proper diagnosis and specialized services for her daughter. The participant explained how, after several months of suffering and trying to navigate the healthcare system, her daughter finally received the treatment that she needed. This family's experience illustrates how important it is for healthcare providers to be aware of language barriers and inadequate knowledge about medical terms among immigrant families. Being curious as a healthcare provider and paying enough attention while interacting with immigrant families would prevent some families from experiencing what this family had been through.

When interpreting and reflecting on their experiences with healthcare services, some participants brought up their position as immigrants. They believed that the way they were treated by the healthcare providers was important. One participant explained how her regular GP refused to give her a referral for X-ray, despite the fact that she was suffering from back pain. The GP considered it unnecessary and a waste of

tax money. This participant referred to her own experiences at the same time as she referred to attitudes towards immigrants in general:

I am wondering, if the same happened to an ethnic Norwegian, would it be treated the same way?... It was her attitude, that it was a waste of tax money... So this was a special attitude that I can speculate about. ...I think there is a lot of discrimination, and having a child with a disability causes a lot of challenges, being multicultural in addition, it becomes twice as much. (P 20)

Being an immigrant and raising a child with a disability are experienced as particularly challenging by immigrant families because of discrimination. Some participants also perceived that their skin color and religion influenced how they were treated and the services they had received. Thus, healthcare providers must be aware of their attitudes while interacting with a group of people, as immigrants have experienced many years of stigmatization and discrimination in society. This would be a step toward providing the services that are available and appropriate for the whole population, regardless of ethnicity, religion, function or social status.

Discussion

This study sheds light on the experiences of immigrant families of children with disabilities navigating the Norwegian healthcare system in general and the pediatric rehabilitation services in particular. The aim of the study was to generate knowledge of how accessible and tailored the services are from the families' points of view. Although the findings of this study are derived from a Norwegian healthcare context, they may be relevant for understanding immigrants' experiences in other healthcare contexts beyond Norway because the Norwegian healthcare system is comparable to those in other Western countries.

Previous studies on immigrant families mostly explored their experiences of challenges while utilizing services. This study aimed to explore the experiences of the services' strengths as well as the challenges. The immigrant families were mainly satisfied with the follow-up services provided by the pediatric rehabilitation centers. Although participants' satisfaction may reflect the quality of the health services provided to them (23), it is important to consider the fact that the participants in this study came from countries with very different services or even countries lacking a public welfare system. They had varied experiences of healthcare services in their home countries, which may have influenced their expectations, the way they experienced the Norwegian healthcare service and their level of satisfaction

(24). Mangrio et al. (25) also showed how non-European parents felt gratitude and thankfulness when comparing the services received from the child healthcare centers in Sweden with those in their countries of origin. They appreciated the way the service was organized and how well the children were cared for, the same way the parents in our study did. They expressed that the Swedish child healthcare system was good and that they could not find similar healthcare in their home countries. Czapka et al. (26) also noted how most of the Polish migrants in their study compared Polish and Norwegian healthcare systems and drew both positive and negative conclusions about the services provided to them in Norway.

Interestingly, a study on Turkish-speaking families of children with disabilities who were immigrants in the United Kingdom (UK) showed how the parents appreciated the services they were given, even if they did not meet their expectations (27). Sandhu et al. (27) interpreted the immigrant families' appreciation as a reflection of their assumptions that health and social care support are privileges that can be withdrawn, rather than rights. This interpretation may also explain why some participants in our study were so grateful and hesitant to talk about the challenges they faced while navigating the services. Sandhu et al. (27) perceived that assumptions of the services as privileges, rather than rights, could also explain why immigrant families tended to respond to the challenges they faced with a stoicism, which was less usual among non-immigrant families.

Despite their satisfaction with the follow-up services, participants in our study experienced several challenges while navigating the services. The challenges that the participants in this study spontaneously shared were mostly about accessing help during the time before their children were diagnosed. At that time, they felt that their concern had not been taken seriously by the healthcare providers, and they did not receive the help they needed. A former study conducted in the Netherlands also shows how mutual understanding and compliance is often worse in doctor-patient consultations with ethnic minority parents of pediatric patients than with their socially dominant counterparts (28). The study suggests that the large differences in explanatory models of health and illness used by physicians and ethnic minority parents could be a reason for this poor mutual understanding. The same study found that consultations that ended without mutual agreement more often resulted in noncompliance with the prescribed therapy. As Wieringen et al. (28) stressed, healthcare providers' communication skills when exploring the explanatory model with parents and their open attitude to models other than a scientific medical paradigm are important when interacting with immigrant families.

Eriksen et al. (13), in their book "Cultural difference in practice", also explain how some immigrants express their symptoms in a way that reflects their cultural background, which is minimally influenced by Norwegian medical thinking. These immigrants are unable to express themselves in a way that a Norwegian doctor is likely to take seriously. They struggle with getting the treatment they need over a long period of time. Eriksen et al. (13) pointed to how Norwegian doctors and immigrant patients used the same word to describe two different conditions. According to them, in these cases, misunderstandings persisted partly because the doctors never tried to determine what the patient truly intended to say, and their conversation was not constructive.

The participants in our study also expressed unmet needs for information about their rights, the rules, and the services available to them and to which they were entitled. Sandhu et al. (27) found that although immigrant families of children with disabilities expressed gratitude for the services they were receiving in the UK, they felt that they were overlooked and not kept informed by service providers.

However, the experiences of needing information (29-32) and facing challenges due to a lack of access to timely help do not only belong to immigrant families. Sloper et al. (33), in their study about the service needs of families of children with severe physical disabilities, showed how the difficulties in obtaining appropriate help by parents caused those parents additional anxiety. Surprisingly, what Sloper et al. (33) noted in 1992 about the need for information, help in obtaining services, and a coordinated approach to providing services appropriate to all aspects of the family is still relevant and consistent with our findings.

Providing information about the services and their availability is a crucial determinant for parents to take an active role in the care process, obtaining appropriate help and decision-making (33-35). Research shows, however, that healthcare providers are not always aware of the resources available to the families of children with disabilities (12, 30). In addition, parents may find it difficult to define and express their information needs and may instead wait for healthcare providers to address a subject (36, 37). These challenges explain how some participants in our study experienced accessing information by chance. While providing information itself seems to be a challenge for service providers (38), immigrant families in our study expressed the need for guidance and support in addition to the information. Paperwork and the need for adequate writing skills, as well as knowing where to go or whom to contact, were challenges faced by several families in our study. Fellin et al. (9) also found that social workers act as facilitators of health and social services by assisting immigrant families who are navigating the health and social

systems. Interprofessional collaboration and connecting immigrant families with social workers is therefore important for their ability to manage navigating the health and social systems and connect with the appropriate resources (39).

Navigating systems with multiple organizational and access issues has also been indicated as being difficult according to parents belonging to the majority of the population (29).

While these common challenges can complicate gaining access to and navigating the healthcare system for any family, the interaction with certain challenges that are the result of being immigrants exacerbates the difficulties faced by immigrant families. Language barriers were noted by Lindsay et al. (12) as one of the main obstacles to accessing, receiving, and utilizing healthcare services for immigrant families of children with disabilities. Our findings show language difficulties and issues with perceived interpreter quality and the accuracy of the translation are barriers experienced while navigating the healthcare system (40, 41). Therefore, while communicating with immigrant families in their nonprimary language or through an interpreter, healthcare providers should be aware of how this process may influence the quality of care and services provided to the families. Improvement of access to and the use of professional interpreters is also important for both linguistic and cultural reasons (42).

The use of medical terminology (42, 43), the lack of intercultural communication skills, and the lack of training pertaining to working with families from diverse backgrounds were also communication challenges that immigrant families in our study faced. Healthcare providers may unintentionally devalue immigrant families' perspectives and perceptions, assuming that the 'Western way' is the 'best and only way' (44). According to Söderström (10), the communication between healthcare workers and minority families occurs in the context of the healthcare providers' perspectives and sense of reality. Healthcare providers need, therefore, to utilize culturally sensitive communication, which involves listening to and respecting the family, reflecting on their own knowledge and biases, and sharing their beliefs with the families with diverse backgrounds (45). Although ensuring equal access to public healthcare services for culturally diverse families of disabled children involves applying culturally sensitive communication (10), it is widely recognized that healthcare providers lack the skills to have culturally sensitive conversations with these families (46). Therefore, enabling healthcare providers to use culturally sensitive communication by equipping them with the required knowledge and skills is important (45, 46).

Another important barrier to communication was the families' perceptions of the lack of adequate time to address their questions and concerns. Improving communication with immigrant families requires new and innovative solutions at the system level to provide enough time and/or make more efficient use of the time spent with these families, ensuring that the families' needs are being met (12, 45). A systematic review of thirty-seven articles showed how the perceptions and practices of healthcare providers in the provision of healthcare services for migrants were mainly influenced by cultural and language differences as well as restricted institutional capacity in terms of time and/or resources (47). King et al. (48) also noted how the context of the workplace can strongly affect the ability of therapists to deliver culturally sensitive care. They pointed out how the structured and time-limited therapeutic sessions and the organizational methods in the practice could restrict the time therapists had to get to know the family situation and build a collaborative relationship.

Last, the findings of this study, in accordance with those of other research, show how perceived stereotypical attitudes towards immigrants can act as a barrier to immigrant families navigating the healthcare system (26, 40). Even the feeling of being treated differently than the majority may be experienced as being offensive and can cause emotional distress among minority families. Such a sense of discrimination in addition to other barriers related to the immigrant experience can even cause immigrants to avoid using the healthcare system (26). A survey conducted at a Danish hospital showed that most of the healthcare providers considered immigrant patients to be a specific strain on the Danish healthcare system, which affected the attitudes towards immigrants held by some healthcare providers. The same study showed how healthcare providers characterized some "immigrant" patients as being overly dramatic when ill (49).

As Penchansky et al. (50) note, the access to services is about the fit between the characteristics of providers and health services and the characteristics and expectations of users. Our findings show how the characteristics of healthcare providers and the characteristics of immigrant families influence the immigrant families' access to and utilization of the services. Therefore, practicing strategies that contribute to increasing the coherence between healthcare providers and immigrant families is important. Our findings also show how the discrepancy between the organization of services and the needs of immigrant families make it challenging for families to use and navigate services.

Study strengths and limitations

While previous research conducted in Norway and internationally has mainly focused on particular minority populations, the participants in this study were families with varied linguistic, cultural and religious backgrounds. They came from different parts of Africa, Asia and Eastern Europe, which together compose the largest immigrant group in Norway. There is also little research exploring the experiences of immigrant families with pediatric rehabilitation services (9), as this research does.

This study did not reach newly arrived families because only immigrant families who had participated in an intensive pediatric rehabilitation program at a rehabilitation center were included. Applying for this program demands familiarity with the healthcare system and some language skills. Thus, the participants did not face the same challenges as newly arrived families might, and the results do not reflect on the challenges and experiences of newly arrived families when seeking assistance from the healthcare system in Norway. However, the participants described their experiences of navigating the services during the very first years of their time in Norway, and those were included, analyzed and reported in the results of this study.

Furthermore, Norwegian is not the first language of the first author (Interviewer) or the interviewees. This might have affected the quality of the produced data, despite the fact that the first author did her best to make sure that there was a mutual understanding of the interview questions and the responses.

Conclusion

This study was conducted to generate knowledge of how accessible and tailored the Norwegian healthcare system is from the perspective of immigrant families of children with disabilities. The immigrant families were mainly satisfied with the follow-up services provided by the pediatric rehabilitation centers, but they experienced several barriers while navigating the healthcare system. The barriers from the perspective of immigrant families were associated with both the system and individual levels. At the individual level, the barriers were related both to family characteristics and those of the healthcare providers. Insufficient competence in the majority language, a lack of knowledge of the services and a lack of understanding of how to navigate those services were some of the barriers related to family characteristics. Applying medical terms, a lack of experience and intercultural communication

skills, and perceived attitudes on the part of the healthcare professionals were among the barriers related to the service providers' characteristics. At the system level, the barriers were related to the use of interpreters who were perceived as being unprofessional, organizational routines, and insufficient time allotted for interactions with immigrant families. The lack of effective strategies to inform, empower, and enable immigrant families to manage navigating the complex and growing healthcare system was another barrier at the system level.

This study therefore highlights the importance of mobilization at both the individual and system levels. There is a need to reach out and educate immigrant groups to enable them to meet the complex demands of navigating the healthcare system in modern Norwegian society. Healthcare providers should particularly be aware of immigrants' need to be informed and supported, even though they may not ask for it, so that they can make educated decisions while navigating the services. Healthcare providers should also be aware of the importance of effective communication and engagement and the impact of their interaction style on immigrant families of children with disabilities. Workplace teaching strategies and other training methods can be used to provide therapists with the training they need to develop the approaches needed to delivering care in a culturally sensitive manner.

This study adds to the current literature on the experience of accessing and utilizing healthcare services by showing how the "immigrant experience" affects the way the families look at, experience, and praise the services. The study also reveals immigrant families' need for support in addition to information to manage navigating complex and changing services. Our findings show that there is still a gap between the public ideal of equal healthcare services and the reality of the everyday lives of immigrant families of children with disabilities. The current gap challenges public policy both on the disability front and the immigrant front. This study, by exploring the immigrant families' point of view, contributes to the opportunity to improve and adjust the services and the overall health and quality of life of these families and their children with disabilities.

Further research is needed to guide service providers and inform policymakers about the best ways of meeting the needs of immigrant families and their children with disabilities. Determining effective strategies for enhancing information transfer to immigrant families of children with disabilities is a relevant research field.

Abbreviations

GP General practitioner

CPOP The national cerebral palsy surveillance program

REK Regional Committees for Medical and Health Research Ethics

NSD Norwegian Centre for Research Data

UK United Kingdom

WHO World Health Organization

Declarations

- Ethics approval and consent to participate

The project was registered with and approved by the Norwegian Centre for Research Data (NSD) and received permission for implementation with reference number 51764. The project was also submitted to the Regional Committees for Medical and Health Research Ethics (REK) but was considered to be outside the remit of the act on medical and health research and could therefore be implemented without the approval of the REK with reference number 2016/1764. Prior to participating, the potential participants received an information letter describing the study, the study purpose and that participation was voluntary. The letter also stated that they could withdraw their participation without giving any reason and that the participants' contributions would be unidentifiable in the final report. Furthermore, the potential participants received information verbally over the phone in simple language after they had received the letters and had the opportunity to ask questions if so desired. The participants gave written consent to participate in the study. The consent form was approved by the NSD.

- Consent for publication

The participants were informed in writing and verbally that the findings would be published in scientific journals.

- Availability of data and material

The datasets generated and analyzed during the current study are not publicly available due to the need for participant anonymity but are available from the corresponding author on reasonable request.

- Competing interests

The authors declare that they have no competing interests.

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- Authors' contributions

SA contributed to the study design, conducted the interviews, performed the transcription, analyzed the data, and prepared the manuscript. RJ contributed to the study design, analyzed the data, and prepared the manuscript. PKS contributed to the study design, analyzed the data, and prepared the manuscript. BB contributed to the analysis of data and prepared the manuscript. All authors read and approved the final manuscript.

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