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RESEARCH PAPER



# Dealing with disability: challenges in Dutch health care of parents with a non-Western migration background and a child with a developmental disability

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## ABSTRACT

**Purpose:** Parents of children with developmental disabilities who have a non-western migration background often experience unique challenges in foreign health care systems. This study aimed to describe these experiences to better understand these challenges and thereby improve health care provision.

**Method:** Twelve parents were interviewed using in-depth, semi-structured interviews. Our data was analysed, and themes were identified using open, selective, and axial coding.

**Results:** Multiple parents in our study had a different perception of what constitutes a “handicap”, may regard it as something that is very severe and highly stigmatized and will be less aware of the complex system of care professionals that aim to support them in the care for their child. Additionally, communication with care professionals may be complicated because of language differences and expectations about the division of roles and responsibilities between parents and professionals. This may result in lower involvement in health care.

**Conclusion:** As a result of cultural differences in the meaning, information and interaction about disabilities, non-western migrant parents will have a harder time coping with the diagnosis of their child’s disability and will experience more challenges with their involvement in health care.<sup>1</sup>

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## KEYWORDS

Developmental disability; cultural sensitivity in care; parent-professional relationship; perception of disability; intercultural challenges

## ► IMPLICATIONS FOR REHABILITATION



- To be aware that non-western parents who are told their child has a disability are likely to experience more shame, fear of stigma and may have other definitions of disability than western parents.
- To pay specific attention to explain as much as possible about the causes, meaning and medical as well as societal future expectations for children with a disability to parents with another cultural background.
- To explore which knowledge parents have about their child’s disability and the Dutch health care system, so that information and support can be personalized.
- To make sure there are translators present who can not only translate in the correct language but who can also explain commonly used terms for disabilities and other medical concepts, diagnostic procedures, and other specificities of the health care system of the host country to migrant parents.
- To psycho-educate parents with a migrant background that they are expected to be actively involved in the professional care for their child with a disability without this having negative consequences for the care of their child.

## Introduction

Even before a child is born, parents have expectations about their child and the behaviour they perceive as desirable for it [1]. When parents have a child with a disability, they must adapt to the discrepancy between the child they expected or dreamed of having and the child they have [2,3]. For many parents, having a child with a developmental disability may induce feelings of grief similar to the grief parents experience when losing a child [4–6]. Common initial responses are shock, denial, blame/guilt, depression and anger [3]. The acceptance of a disability is a dynamic and circular process, meaning that the child aging and reaching new stages of life may cause the parent to go through the

acceptance process multiple times [7]. Parents often search for explanations or causes of the disability, thereby creating their own understanding of disability. This understanding includes but is not limited to parents’ perception of cause, perceived symptoms, and prognosis of the disability [8]. These elements are largely shaped by cultural discourses and the way disability is understood in the families’ community. Cultural discourses include the beliefs that are shared by the community and the way that “disability” is defined in a society, making “disability” a sociocultural phenomenon [9].

In western cultures, the term “developmental disability” is generally employed by care professionals. This term includes but is not limited to children who have a disturbance in one of the

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developmental domains, including cognition, motor skills, speech and language, social skills or activities in daily living [10]. An intellectual disability includes deficits in intellectual functioning, characterized by an IQ of 70 or below, as well as deficits in adaptive functioning with an onset in early childhood or adolescence [11]. However, this use of the term disability is not generalizable across societies, as what is perceived as a disability differs across cultures [9] and co-depends on which characteristics of people are valued in a society and which purpose the label serves. In many African cultures, for example, a translation for the general concept "disability" does not exist, and the terms that are used indicate a specific problem a person has, such as "blind" or "slow" [12]. Other studies showed that amongst African American and Puerto Rican American parents, only the most severe developmental or behavioural problems were recognized as a disability [13–15]. Similarly, Indian parents were found to recognize symptoms for developmental disabilities such as a speech delay, not as a disability or delay in development but as part of normal development [16,17]. All in all, parents in some non-western cultures were generally found to hold a broader range of normalcy regarding children with mild developmental disabilities, as the behaviour of the child had to be more severe, or the functioning more limited to be recognized as a disability than in a western culture like the Netherlands. As a result, being given a label such as "intellectually disabled" by western care professionals may result in shock and disbelief for parents with a different perception of disability [18]. When parents' perception of disability does not match with the diagnosis of a disability that was provided to them by care professionals, they may be less likely to access care or to believe in the effectiveness of medical treatment [17].

In a meta-analysis on the prevalence of intellectual disability, Maulik et al. [19] concluded that the worldwide prevalence of intellectual disability is 1.04%. However, in some low-income countries, such as Nepal and Pakistan, much lower prevalence rates were reported (0.06% and 0.09%) [20]. This contradicts the findings of the meta-analysis by Maulik et al. [19], who saw prevalence rates in low- and middle- income countries that were up to twice as high as in high income countries. Reasons for this higher prevalence of developmental disabilities in developing countries are factors such as malnutrition, lack of perinatal and medical care and limited resources and care [19,21]. The previously mentioned explanation of socio-cultural differences in the meaning of what constitutes a disorder, offers an alternative explanation for lower reported levels of disability. Moreover, the level of stigmatization of people with disabilities in various countries may lead to differences in reported levels of disability. People who are judged to be "disruptive" or "incompetent", may be stigmatized, hidden, or neglected, leading to an underrepresentation of intellectual disability [20]. For example, almost half of the parents in a low-income African country reported feeling ashamed about their child's disability and were worried their child would be treated badly because of it. As a result, a quarter of parents reported making an effort to keep their child's disability a secret [22].

Stigmatization is something every person with a disability faces, regardless of what culture they grow up in [23]. Although international comparative studies on attitudes towards people with intellectual disabilities are scarce [24], the few studies there are seem to indicate that having a disability is more stigmatized in developing countries than in western countries [25,26]. Although some stigma is still attached to people with an (intellectual) disability in the Netherlands, practices such as inclusive education, Supported Employment, through which people with a disability are supported to find paid employment, and housing

programs for social integration are common to normalize disabilities and integrate children and adults with disabilities into society [27–29]. Additionally, Dutch television presents programs on people with various kinds of disabilities and developmental delays, in which these are explained and, to a certain extent, normalized. This is important, as various studies indicate that familiarity with people with a disability reduces stigmatization [30,31].

Next to cultural differences in what is perceived as a disability and how people with a disability are judged, there are also differences in how societies organize their healthcare. In most western countries, an extensive health care system to support people with developmental disabilities is in place that even native parents find difficult to navigate, let alone people that are new in such countries. For example, in a study by Lindsay et al. [32], parents with a migration background were found to have limited knowledge about available services, such as what kind of health care is available to them and options for additional leisure activities promoting better health. Structural challenges, such as having to fill out various administrative forms, long diagnostic procedures involving various specialists from multiple disciplines and lengthy waiting lists can be obtained may cause parents to give up on getting help altogether, seek help from traditional healers, or seek help transnationally [33]. Indeed, Bellaart [34] found the Dutch health care system is founded upon the expectation of parents having full autonomy, leaving them responsible for getting the help they need. Parents who do not have or do not know how to get insight in the way health care services work, may not get the needed resources [13,35]. Additionally, a lack of knowledge may also lead to misconceptions about health care in the Netherlands, for example when parents feel care professionals could take their child away at any time or when parents question the effectiveness of care [33]. Feelings of distrust may cause parents to avoid seeking help or drop out of health care programs prematurely [36].

Moreover, parents may not be used to shared decision-making that is expected of parents in the Dutch health care system [37]. In the Netherlands, "client engagement", in this case parent engagement, is a standard practice. Parents are generally regarded as expert about their child and are supposed to function as part of a team and need to actively participate with care professionals [38]. Thus, parents are generally expected to partake in a "partner-based relationship" with care professionals, making decisions about treatment options and plans and parents have to give consent for implementing treatment plans in special education facilities. However, Lindsay et al. [35] and Harry [13], who interviewed professionals who provided care to culturally diverse families, reported that newcomer immigrant parents often assumed hierarchical roles, viewing the care provider as the "expert" who makes all the decisions [13,35]. Furthermore, care providers to immigrant families raising a child with disabilities in Canada suggested that these parents, often originating from poor countries, feel very fortunate to receive any kind of health care and thus felt it was inappropriate to express criticism or requests for additional care [39]. What complicates the interaction between parents with a non-western migration background and their child's care professional even further, is the language barrier that often exists between them [17,37,40,41]. A language barrier is widely acknowledged to hinder effective communication [42]. Although the use of an interpreter may help to partially overcome this barrier, it may also add challenges such as complications in the establishment of rapport and the additional time translation takes [32,35].

All in all, we can conclude that although all parents struggle with having a child with a disability, there are some elements that may make this harder for parents with a non-western migrant

background in the Netherlands. Many of them will have a different perception of what constitutes a “handicap”, may regard it as something that is very severe and highly stigmatized and will be less aware of the complex system of care professionals that are supposed to support them in the care for their child. Additionally, their communication with care professionals may be complicated because of language differences and various expectations about the division of roles and responsibilities between parents and professionals.

In this paper, we will focus on the experiences of parents with non-western migration background, as the literature we described shows that they potentially face multiple additional challenges in health care due to differences in cultural background between themselves and Dutch professionals. We aim to better understand parents’ experiences in the Dutch health care system for their children with a disability to improve health care for this particular population. Our research question is: “Which intercultural challenges do parents with a non-western migration background in the Netherlands face in dealing with their child’s developmental disability?”

## Methodology

### Study design

A phenomenological, qualitative design using semi-structured, in depth-interviews was used to explore the experiences of parent’s children with a disability in the professional healthcare for their child. This design is suitable for exploring a relatively little explored topic [43]. Parents were interviewed about their experiences in the Dutch health care system, and the challenges they encountered in interaction with care providers. The study received approval from the ethics committee of the Radboud University, serial number ECSW-2019-022.

### Participants and procedure

A sample of twelve families participated. Nine interviews were held with the mother of the family, two interviews were held with both parents and one interview was held with the father of the family. Participants were approached via a purposive sampling method, meaning that parents who were most likely to provide relevant information to the study were identified and approached [44]. Additionally, snowball sampling was used when one participant or care professional described the study to other parents. In order to participate, the respondents needed to be able to speak Dutch, English, Turkish or Arabic and had to be first-generation immigrants originating from a non-western country. The reason for migration varied and was not necessarily linked to having a child with a disability. All parents had a child with a developmental disability that ranged from mild to severe who currently received care from a professional care institution, including special education, institutional living, or specialized daycare.

Multiple institutions were contacted and asked to approach parents in their caseload, including schools for special education, institutions for specialized day care, and institutional living. Numerous problems occurred with this method of sampling. For example, institutions did not have any parents who met the interview criteria, did not get any replies when they approached parents, or did not want to participate because they felt it would overburden parents. Moreover, various parents were not fluent enough in the languages available to the research interviewers. Furthermore, multiple parents declined participation in the interview. Some expressed hesitation as they gave the impression of

being afraid that the interview would have negative consequences for the care for their child. Other parents did not have the time to participate: many parents experienced too much stress in the daily routines of living with a disabled child, to have time to participate in the study. In the end, only two participants were recruited through an institution that was contacted. The other parents who agreed to participate were approached through the research team’s social and professional network. Being able to contact parents directly and having some sort of personal bond, even if indirectly, seemed to be the most effective way to reach parents. For a description of our participants and their families, we refer to Table 1. To ensure anonymity, some of the participants’ personal information, such as the name of the care facility the child visits and the age of the child was withheld. To give an impression of the age of the child, children were categorized as belonging to either the age group 3–10 years or as having an age between 11 and 23 years old.

### Data collection

Twelve semi-structured interviews were conducted in the period from March 2018 to January 2020. The process of finding research participants was stopped once data and coding saturation were reached. To decide whether this was the case, interviews were transcribed and coded while new interviews were still being held.

The interview schedule contained 33 probe questions, as shown in Table 2. Prior to the interviews, the interviewers received training on the interview protocol by the second author, a Dutch senior researcher in cultural sensitivity. The interviews were as much as possible conducted in a language in which the interviewees felt comfortable. The first author, a Dutch master student who was at the time graduating in the field of child psychology (pedagogical sciences) conducted three interviews in Dutch and four interviews in English. Four interviews, two in Dutch and two in Arabic, were held by two Dutch master students also graduating in the field of child psychology. One interview was held in Arabic by a Lebanese-Dutch junior researcher specializing in mental health of refugees. Also part of the research team, was a Turkish-Dutch student undertaking a PhD in cultural sensitivity. The Arabic interviews were translated and transcribed in Dutch by the same researcher who held the interview. The Dutch interviews were transcribed in Dutch, and the quotes that were used in the analysis were translated in English. All quotes were translated as literally as possible, to stay as close as possible to how parents explained their feelings and experiences. In case of unclarities in the transcripts, the interviewers were asked to cross-reference the quotes.

During the interviews, we paid special attention to build rapport with the participants. First, the participants were contacted by telephone to get acquainted with the interviewer. Most of the parents seemed very willing to share their stories, and often already started sharing some of their stories on the telephone. The participants were asked what location they preferred to meet. All chose their own homes, which were located all over the Netherlands. During the appointment, the interviewer initially started with some introductory questions to build rapport with the parents. A consent form was created to ensure parents that the information they shared would be anonymized and that they could choose to withdraw from participation in the study at any time. The interviewer would emphasize that the information parents shared would not be reported directly to the care institutions. Then, parents were asked to consent to the interview being audio taped. Overall, the parents responded positively to the

**Table 1.** Case description of respondents: pseudonym, year of arrival in The Netherlands, country of origin, family situation, age, cause of disability, type of care, and language of the interview.

Parent & child	Case description
Loulou & Marwan	Loulou and her family arrived in the Netherlands from the Middle East region in 2014. Loulou has five children, two of whom have an (intellectual) disability. The interview is focused on the care for her son Marwan (aged 3–10 yrs old), who has severe multiple disabilities and epilepsy of which the is unknown to her. Marwan visits a school for special education. Loulou was interviewed in Arabic.
Lina & Leyla	Lina and her daughter Leyla arrived in the Netherlands from the Middle East region in 2015. Lina's daughter Leyla (aged 3–10 yrs old), has a delay in language development, of which the cause is unknown to Lina. She visits a school for special primary education. Lina was interviewed in Dutch.
Semira & Patrik	Semira and her son Patrik arrived in the Netherlands from Africa in 2001. They have lived in multiple asylum seekers centers. Semira has two children, one son and one daughter. Semira's son Patrik (aged 3–10 yrs old) has a developmental delay of which the cause is unknown to Semira. Patrik visits a school for special education. Semira was interviewed in English.
Aissa & Daren	Aissa and Daren are originally from Africa. She arrived in the Netherlands in 2009, her son Daren stayed in Africa and reunited with his mother in the Netherlands in 2016. Daren (aged 11–23 yrs old) has a moderate intellectual disability and epilepsy, resulting from oxygen deprivation during birth. Aissa also has a daughter. Daren lives in a residential institution and visits a specialized daycare center. Aissa was interviewed in English.
Ayla and Nawar & Hadiya	Ayla and her husband arrived in the Netherlands from the Middle East region in 1994. When they were in the Netherlands, their daughter Hadiya (aged 11–23yrs old) was born. Hadiya has a severe to profound intellectual disability, due to prenatal complications and/or a genetic syndrome for which she was tested in the period of the interview. Ayla and Nawar (Hadiya's sister) were interviewed in Dutch.
Yarah & Omar	Yarah arrived in the Netherlands from the Middle East region in 2017. Her son Omar (aged 3–10 yrs old) has a mild intellectual disability, caused by a rare genetic syndrome. They have lived in multiple asylum seekers centers. He visits a school for special education. Yarah was interviewed in English.
Danisha & Bradley	Danisha arrived in the Netherlands from Africa in 2016. In the Netherlands, they had two children. Her son Bradley (aged 3–10 yrs old) has a developmental delay of which the cause is unknown. Bradley Attends a specialized daycare center. Danisha was interviewed in English.
Eslem & Semi	Eslem arrived in the Netherlands from the Middle East region with her husband in 1996. In the Netherlands they had three children. Their eldest child, Semi (aged 11–23 yrs old) has a mild intellectual disability, caused by a genetic syndrome. Semi attends a specialized daycare facility. Eslem was interviewed in Dutch.
Saleen and Bashar & Renas	Saleen and Bashar arrived in the Netherlands from the Middle East region, it is unknown in which year they arrived in the Netherlands. Their son Renas (aged 3–10 yrs old), was born when the family was already in the Netherlands. He has a mild intellectual disability, of which the cause is unknown to his parents. He visits a specialized daycare facility. Saleen and Bashar were interviewed in Arabic.
Zofia & Nishan	Zofia arrived in the Netherlands from Eastern Europe. It is unknown when they arrived in the Netherlands. Her son Nishan (aged 3–10 yrs old) has a developmental delay and is diagnosed with autism spectrum disorder. He visits a daycare center specialized in children with a developmental delay. Zofia was interviewed in Dutch.
Rafiq and Zahra & Nemr	Rafiq and Zahra arrived in the Netherlands from the Middle East region. It is unknown when they arrived in the Netherlands. Their son Nemr (aged 3–10 yrs old) has a genetic syndrome which causes a developmental delay. They have another, older, son who has the same syndrome. Nemr visits a specialized daycare facility. Rafiq and Zahra were interviewed in Arabic.
Yusuf & Semih	Yusuf and his wife Fatima arrived in the Netherlands from the Middle East region in 2001. When in the Netherlands, they had two children. Their eldest, Semih (aged 11–23 years) has multiple disabilities and epilepsy. He was born with a birth defect, of which the cause is not mentioned in the interview. Semih visits a specialized day care facility. The interview was held in Dutch.

**Table 2.** Interview's categories with examples of probe questions.

Category	Example of question
Background information	What is your country of origin? For how long have you been living in the Netherlands?
Perceived causes for disability	When did you first notice [your child] developing differently? What is the diagnosis, do you agree with the diagnosis?
Experience in care	What was the best care provider you ever had? Why? (Probes: communication style/listening/contact/understanding) In what aspects could the care [facility] better match your wishes that are specific for your culture? (probes: diet, religion, language, recreation, holidays)
Care in the country of origin	How does care in the Netherlands differ from care in your country of origin? Do you miss aspects of care provided in your country of origin?

interviews. Some participants expressed they were glad someone would listen to their story. One of the participants invited the researcher for a second time and another told her contact person that she had experienced the interview as pleasant. Another mother spoke positively about the interview with the care professional that had approached her. All participants were thanked with a gift card or a box of chocolate.

### Analysis

All interviews were audio-taped and transcribed verbatim except for one, as the mother did not consent to her interview being audio-recorded. During her interview, handwritten notes were

made by the interviewer. Pseudonyms were created for participants and their children, and the files were saved in a secure location. In the quotes used in the analysis, some information is censored to protect the privacy of the parents who participated in the study. The transcripts were then imported into ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, 2019), a software program for the qualitative analysis of textual data. Both authors of this article independently coded interviews and compared codes to construct a code book. Open, axial, and selective coding were then used to organize our data [45]. Thematic analysis was used to map out key issues emerging from the codes during multiple discussions amongst the first and the second author [46]. During these discussions, current themes were



evaluated, and new themes were constantly formed and re-assessed based on further analyses. Some examples of the codes that were initially created are “perception of cause disability”, “miscommunication with care professionals”, and “care in the country of origin”. Then, appropriate codes were allocated to relevant key themes, which were then refined by sub-categories. For example, the code “interaction parent – care professional” was categorized into sub-codes “involvement in treatment” and “language issues”.

## Results

The analysis of the parents’ responses to the semi-structured interviews generated three themes: the meaning of having a disability, information about the disability and interaction with professional care takers.

### *The meaning of having a disability*

Parents recalled the moment they first heard that their child was developing abnormally as a shock, and the subsequent period as emotionally straining, in which they experienced strong emotions such as denial, blame/guilt, anger, and depression. Their emotions after hearing that their child had a disability, resembled emotions similar to the emotional stages when facing grief [4–6]. Eslem describes the shock she felt when she heard her child was diagnosed with a genetic syndrome:

You sometimes feel like hot water is being thrown on you. And then you feel very warm. But that feeling, you really feel that pain in your heart. (Eslem and Semi, aged 11–23 years old, mild intellectual disability, specialized daycare, Middle East region)

Shock was the most common response among parents when first hearing their child had a disability. Subsequently, various parents experienced difficulties with accepting the diagnosis. Parents who have a child with a disability generally struggle with acceptance, regardless of their cultural background [47,48]. However, we did find reasons to assume that parents with a non-western migration background encounter additional challenges in accepting the disability of their child. Firstly, because parents experience more stigma and shame in having (a child with) a disability in many of the countries from which the parents migrated [26,49].

Parents recalled situations in their country of origin in which children in general, or their own child in particular, was stigmatized, as explained by Lina: “Usually, if the child has problems, the mother and father do not want to say this. Because then, people will say bad things about this child.” In addition, Aissa recalls: “Some kids may throw something at [my disabled son]: ‘get out’. And other kids don’t want to play with him, saying: ‘he’s stupid’. Having a child [in Africa], with a disability, is really different. Better those children die than stay alive, really.” Although the parents we interviewed did not experience this kind of stigmatization in the Netherlands, they still reported difficulty with speaking about the disability of their child. Semira explained:

But if I tell it to God, nobody can hear my story. When I cry to Him, sometimes I cry in my room and when I finish crying nobody can see my tears. Only God sees my tears. (Semira and Patrik, aged 3–10 years old, moderate intellectual disability, special education, Africa).

From the conversation, it became clear that Semira found support in sharing her grief with God, and she did not want any human to know about her son’s disability. She mentioned that during her stay in the asylum seeker centre she would not speak with other people and stayed inside her room with her children,

as she was afraid other people would laugh or talk about her child: “People see my son as a cursed boy, people see him like that. People say negative things about him. People used to tell me ‘your son can never talk, your son can never do this.’” Several other parents shared this feeling, and withheld from telling friends their child goes to special education or did not let their child play outside, afraid of negative responses. Another parent had refused an interpreter when speaking to Dutch professionals because she said she felt uncomfortable with an extra person in the room when she was sharing her personal story: “It’s always better to explain your situation to one person, not too many.” Moreover, as we wrote in the methodology section, it was very hard to find parents willing to accept the invitation for the interview to speak about their child, and some still seemed embarrassed during the interview to talk about their child’s disability, which also points to a fear of being stigmatized.

A second reason why it may have been harder for some migrant parents to come to terms with having their child labeled with a disability is that several of them had not expected such a label for their child, because they were less familiar with the concept of “developmental delay” or were used to a broader diversity as still being part of “normal” development. For example, Danisha explained that in her culture, it is normal when a child starts speaking when he is aged five or older, so she had not expected her child to be diagnosed with a “developmental delay”, something for which her son must go to a special education class, making him different from other children. Moreover, she was surprised to hear that he was not only delayed in his language development, but in his cognitive development as well. She seemed to be unaware of the concept of “delay in cognitive development”, and consequently did not recognize the symptoms in her child as these were explained to her by care professionals. Similarly, Semira said:

When the woman was expressing the situation to me I was really kind of, I was not expecting what I was hearing. (...) So when I got home I cried and cried because he couldn’t say nothing (.). So I was just in my room, I was checking him, I would raise his clothes, I would try to see, I was trying to listen to his words, the way he cried, I was trying to... At that moment I broke down, I started crying. (Semira and Patrik, aged 3–10 years old, developmental delay, special education, Africa)

Clearly, Semira was not expecting her son to be labeled with a disability. Moreover, her expression of disbelief, “checking him” by raising his clothes expresses another element which we found amongst more parents in not expecting their child to have a disability. Various parents seemed to have a different definition of “disability” than Dutch care professionals:

We all [in our country of origin] have such a stereotypical image: someone in a wheelchair, that is disabled person, and also, if you can see it in his face, then he is disabled. But you couldn’t see it with her. That makes it extra tough. (Eslem and Semi, 11–23 years, mild intellectual disability, the Middle East region)

For Eslem, the concept “disability” includes physical disabilities and disabilities that you can recognize in a persons’ face, or, as we saw in the quote of Semira, on her son’s body. Consequently, both struggled with coming to terms with having a child who physically looks normal and still gets labelled with a disability.

In this section we saw that, although it is hard for all parents to come to terms with, and go through the mourning phases of having your child labelled with a disability, this may be particularly the case for parents who migrated from a non-western country. For many parents from non-western countries, there is relatively more often a stigma and another meaning attached to having a child with a handicap in their home country.

### Getting information about the disability

In the next two sections, we will discuss two elements of intercultural care that may make it more difficult for parents with a migration background in the Netherlands: unfamiliarity with language and the Dutch care system which may cause immigrant parents to be insecure about diagnosis, treatment plan and future perspectives of their child, and uncertainty regarding the role and responsibilities of Dutch professionals which may prevent immigrant parents from being as involved in their children's care as they might want to be.

As described by Truit et al. [50], regardless of cultural background, uncertainty about their child's disability causes significant psychological distress amongst parents. More than half of our respondents was uncertain about the cause of the disability of their child:

No one really knows [what caused the disability], but the first [epileptic seizure] came after the vaccine, the day after the vaccine. Fever started and crisis happened and they didn't find a medicine for it, so basically he started regressing and his growth stopped completely. (...) He wasn't born with oxygen deficiency so there is no cause to explain why he is [disabled]. (Loulou and Marwan, aged 3–10 years old, severe multiple disabilities, special education, the Middle East region).

Having no clarity about the cause of the disease also made it hard to treat, as "they didn't find a medicine" or to have a prognosis for the future, which makes it harder for parents to deal with and accept the disability of their child.

Similarly, Semira described during the interview a range of possible causes for her son's developmental delay that various professionals had mentioned to her in the course of time, such as emotional shock in early childhood, oxygen deficiency during birth, genetic defect or hearing disability. Thus, a large number of hypotheses about what could have caused the disability were proposed by medical professionals. Nevertheless, or, because of this, Semira mentions that she still does not know the cause of her child's disability:

Maybe because he was not hearing good, he couldn't talk. So from there I was taking him [to a specialized institution for speech- and hearing problems] every month, to see what they can do, to see what causes his problem. But even there, they couldn't figure out anything. The woman was just [saying] "Something is wrong with this boy". It's not easy to not know what is happening. (Semira and Patrik; aged 3–10 years old, developmental delay; special education, Africa)

Semira expresses how she is still desperately searching for the real cause, as according to her, the professionals have not been able to find it. Semira was referred to a range of specialists and care facilities to investigate the cause for her son Patrik's developmental delay, as were several of the other parents. Parents were confronted with numerous appointments in different medical disciplines involving phases of extensive diagnostic testing, resulting in varying explanations regarding the cause and diagnosis of their child's disability. Several parents experienced this process of visiting multiple disciplines as a much more complicated system than they were used to in their country of origin. Yarah explains: "In [our country of origin], you don't have to wait for your general practitioner to transfer you to a specialist, you can go by yourself." For some parents, their unfamiliarity with the Dutch medical system and the range of sometimes opposing messages they received from multiple specialists enhanced their feelings of uncertainty about the diagnosis of their child.

For the other half of our respondents, the cause of the disability was known, meaning they received a medical diagnosis such as a genetic syndrome, or a diagnosis of a developmental disorder such as autism spectrum disorder. Aissa received a medical

diagnosis for her child's disability, as he suffered from oxygen deficiency and epilepsy during birth:

He could not breathe, he was almost dead. (...) People say, they have resuscitated to wake him up, it didn't work. Hours it took. Then, he starts breathing. Breathing and then epilepsy. (...) And from this moment, he was not normal. (Aissa and Daren, aged 11–23 years old, moderate intellectual disability, daycare and institutional living, Africa).

Knowing the cause of the disability seemed to facilitate the acceptance process, as Eslem explains: "I am not happy to hear that Semi has [a genetic syndrome], but I am glad to know what she has." Yarah, who also heard her son has a genetic syndrome, mentions: "I know that his situation won't be healed or be better, so ... But I know at least what is wrong with him." Similarly, Hatton et al. [51], stressed the relevance of providing clear and practical information using words and language that parents themselves also use and understand. This is particularly important in the period parents are most uncertain: when they are, for the first time, confronted with their child's disability. Good and intelligible information reduces uncertainties and facilitates parents' understanding of their child's disability and consequently the emotional acceptance of the diagnosis. Eslem recalls vividly how emotionally taxing the period was, in which it became clear that something was "wrong" with her child but for a long time it was unclear to her what the diagnosis was: "since five/six years, I don't even get goosebumps anymore when I have to tell [about that period]. Then I think, yes I have passed this threshold." All in all, having clarity and certainty by understanding what professionals say about the diagnosis and prognosis of the disability of their child helped parents to cope.

The fact that fully half of the parents said they did not know the cause and diagnosis of the disability of their child may be because the cause was still unknown. However, we deduced from our interviews that in some cases, Dutch health care providers may have had more certainty about the diagnosis of the children than the parents felt they were given. For even parents who did have clarity on the diagnosis expressed a lot of uncertainty about their child's disability. For example, because of specialists not being able to explain the outcome of the diagnostic tests to the parents, or for being less familiar with commonly used terms for those disabilities than native Dutch parents. One parent, for instance, received the diagnosis of "autism spectrum disorder" for her child:

When I first heard it in [the hospital], it really was hard for me. How is that possible? My child has autism. Then, I didn't know much about autism. I have not known a lot of things about autism. Then, I came back, I did everything: Google, YouTube, watching everything. Because there are certain things that resemble autism with him. But also, there are many things that don't look like autism with him. (Zofia and Nishan, aged 3–10 years old, specialized daycare centre, Eastern Europe)

The parents we interviewed were unfamiliar with people with disabilities, nor were they familiar with concepts and labels of disability, as was found in previous studies [52]. Zofia explains how she is not familiar with the term "autism" and turned to the internet for more information, which may have increased her confusion. As Ayla stated: "those names of the diseases and the translations are really not that easy". Indeed, parents who have just learned that their child has a disability, must gain a substantial amount of knowledge that they were likely unfamiliar with before [50]. Concepts like "developmental delay", "intellectual disability" or "autism spectrum disorder" are complex and difficult to understand, particularly for people from a country where developmental delays are less publicly discussed or familiar to a broader public.

What complicated this even further was the language barrier between parents and care professionals. As there presently is no legal obligation for providing interpreters for Dutch health-care providers, various parents we interviewed struggled to understand what care professionals said. In a surprising number of cases the care professionals who did arrange an interpreter, had appointed interpreters who could not speak the language of the parents. Bashar recollected:

It was our first conversation. [The health care professionals] brought an interpreter. (...). The interpreter was not very good. We didn't understand anything he said. His Dutch was bad and he was Somali. His language was different. (Saleen & Bashar and Renas, aged 3–10 years old, moderate to severe intellectual disability, special education, the Middle East region)

Yarah tells about a similar situation: "Sometimes they brought to us some Moroccan translator, or from Iraq. But you know, in [our country of origin] we speak a totally different language". Semira shared she felt the translator misinterpreted or mistranslated her words, which made her uncomfortable with using an interpreter in the future. However, not all parents had negative experiences with the use of interpreters. Despite their negative experience with a translator described above, Saleen and Bashar still preferred an interpreter being present at important conversations:

We speak with [health care professionals] in Dutch, but of course we cannot speak Dutch very well. We try to explain what we can, and then sometimes they help us with the translation, through google. (...). If there is a doctor's appointment, or an important meeting, then, an interpreter is useful, so we can understand exactly and bring our ideas across exactly. Then, that is better. (Saleen & Bashar and Renas, aged 3–10 years old, moderate to severe intellectual disability, special education, the Middle East region)

Saleen and Bashar expressed the use of an interpreter would be a quick and effective way to facilitate communication between them and the care professionals. Even parents that were good in English, or even Dutch, did express the need for an interpreter when speaking about the mostly unfamiliar medical terms encountered by parents. For instance, Ayla describes: "About the diseases, those names of the diseases and the translations, they are really not that easy". However, in contrast to the positive expectations parents had of an interpreter, the actual use of one was rare:

An interpreter is needed so that we can understand exactly what is going on. What they want from us, and what we want. If there is no interpreter, we will not be able to understand each other. (...) [The specialized daycare centre did] not offer an interpreter. They told us we could bring an interpreter ourselves. We explained that it is difficult. Where should we get an interpreter, there is nobody... (Rafiq & Zahra & Nemr, aged 4–10 years old, moderate intellectual disability, special education, the Middle East region).

Only one parent in our study indicated that there was a translator present at every conversation they had with care professionals. For two other parents an interpreter was arranged only for the intake and the most important conversations. The main reason for this was that the care facility did not offer to arrange an interpreter, and parents did not know how to arrange one themselves.

Summarizing, for parents with a migration-background, feelings of uncertainty about the disability, the cause of the disability, and the prognosis may be greater than for native Dutch parents, because they are less familiar with terms and concepts for disabilities, less used to the elaborate and complicated diagnostic procedures in Dutch health care with many, often conflicting hypotheses about the disability, and because only a few conversations between professionals and parents were properly translated. These results will probably also be valid for the Dutch health care

system more generally, where non-western migrants are confronted with similar problems with translation and a lack of familiarity with medical and mental health terms and procedures.

### *Interaction with professional care takers*

In this section, we will discuss another potential reason for why parents were left with a sense of uncertainty about their child's disability. In the Dutch health care system, a certain level of assertiveness and influence is expected of patients as the Dutch health care system builds on the notion of cooperation between professional and "client", as patients are often referred to. During the interviews, it became clear that particularly parents that had more recently migrated to the Netherlands were unaware of the active role that was expected of them in the communication with professionals, nor did they seem to be aware of the rights they had in posing questions and being critical in their communication with professionals. This may offer an additional explanation for the large number of interviewed parents that lacked clarity on the cause and diagnosis of the disability of their child. In this section, we will discuss how parents felt about their interaction with professionals and whether they would ask for adjustments in the care for their child.

From our analysis of the interviews it became clear that parents were reluctant to ask anything from professionals. Ayla, for instance, did not even request any kind of professional support when she was informed her child has a genetic syndrome: "No, because we did not know [we had the right] to get help somewhere, or ... We did not know that". Parents also had not been informed about what their professionals were teaching their children and what the schools or institutes tried to achieve with their child:

I have no idea. I don't know what he is doing, I haven't been, to see what he's doing. I don't know because he can't read. He can't do his shoes with those laces. He cannot do anything. (Aissa and Daren, aged 11–23 years old, specialized daycare and institutional living, Africa).

During the interview, Aissa realized that she does not know what her son is learning at his care facility. It seemed that through the interview, she realized that she has the option to find out: "I have to make an appointment to see, that's good (...) Really important. I really need to know, what's going on there. Because he doesn't learn anything." In this quote, Aissa also says that "he doesn't learn anything". More parents made similar remarks, from which it became clear that they were disappointed by what their children was taught by the professionals, or where they stated that they preferred that their children would learn something else than what they were taught. Most of them had, however, never told this to the professionals. Another parent explained how, even when he does not agree with care professionals, he still obliges as he believes this is how "the system" works. He explained that he finds it difficult to talk, and would not mention it if he disagrees with something:

There is a difference between our countries, Arab countries and the Netherlands. Here you have a system, there is a system for the child. The child has got to do something, but maybe I don't want to [follow this system], do you know what I mean? (...). Of course, if there is something and they don't like it, I just follow the system. I have a hard time talking. If I know that I am wrong and they are right [according to the system] then I won't say anything even if I don't like it. (Rafiq and Zahra & Nemr, aged 4–10 years old, moderate intellectual disability, special education, the Middle East region).

Similarly, parents did not share with care professionals the need for elements of their religion to be integrated in the care of



their child, even though many of them indicated in the interviews that religion was very important to them. Denisha, for instance, allowed her son to participate in Dutch religious holidays and ceremonies at his specialized daycare centre. Though she does not celebrate those holidays herself, she feels “[we] have to follow the rules”. Eslem also did not discuss her religious needs for her son and said that she was ok with her son not following her religious rules like fasting, special dietary requirements, and prayer, as these rules are “more flexible for people with disabilities”. However, Dutch institutions for people with disabilities can, in many cases, easily manage to follow various religious preferences, if they are aware families would prefer that [53].

We found several explanations for why parents would not discuss their requests or criticize professionals taking care of their child. For example, Loulou expressed that at the care facility her son visits, she does “not know what my rights and obligations are”. One of the main reasons was that parents seemed unaware that they not only have these rights, but that it is common for Dutch parents to actively inquire and intervene in the care of their child. As Lindsay [32] also argued, it may be more difficult for parents with a migration background to express their wishes or requests as they lack knowledge about their resources and rights. Similar to the abovementioned study by Lindsay et al. [32] regarding parents’ advocacy for their child, immigrant parents were often found to show more reluctance to advocate for their children as it was not deemed appropriate in their culture to show assertiveness in interaction with figures of authority. Another reason for parents not sharing their wishes or requests was that some parents expressed the notion that they viewed the care professional as “the expert” who knows best:

Saleen: I assume that [the care professionals] are experts. They must discover what this child likes; football, swimming....

Bashar: After all, they are the experts. They know more than us. (Saleen & Bashar and Renas, aged 3–10 years old, moderate to severe intellectual disability, special education, the Middle East region).

As we know from previous research [13,32,35], in several of the home countries of the parents we interviewed, the relationship between health care professionals and their patients is much more hierarchical and it could convey bad manners to ask questions, let alone criticize, in a conversation with a professional. It is telling that quite a large number of the participants we interviewed did come up with examples of questioning and even criticizing and intervening in the taxi services with which their children were transported to the care institute. It seemed much easier for them to ask questions and be critical with a driver than with professionals whom they considered to be experts.

Another element that might explain why parents were more hesitant to express criticism or present their questions or requests for the care of their children is the gratitude parents felt for the health care their child receives in the Netherlands. Most parents described not having access to care facilities for children with disabilities in their country of origin, as these do not exist or are limited to selective disorders such as physical handicaps. For example, Lina said about her country of origin: “There is no place for [children with a disability]. If a child has a problem, then she has to stay home, then the mother has to take care of her.” Loulou said:

Our schools [in our country of origin] they don’t care. (.) there are no special schools for her. Where should I put her? With the handicapped? With the deaf, blind/visually impaired, and mute people? She is not deaf nor mute nor handicapped. (Loulou and Marwan, aged 3–10 years old, severe multiple disabilities, special education, the Middle East region)

Because some parents were not used to having facilities and support for the care of their child, they were happy with any kind of support they could get. Nawar and Ayla, who had been in the Netherlands for quite long already, were one of few parents who expressed their dissatisfaction to the health care professionals. Nevertheless, they also expressed their gratitude:

So we try to emphasize that for ourselves: Yes, we are still better off in the Netherlands compared to [our country of origin]. (...) Because how care is organized here, we have just been very grateful for that. (Nawar & Ayla and Hadiya; aged 11–23 years old, severe multiple disability; specialized daycare facility; the Middle East region)

During the interview, it became clear that Nawar and Ayla’s gratitude caused them to be selective and careful in their expression of criticism, i.e., in “trying” to remind themselves “we are still better off”.

A last major reason we found which withheld parents from questioning or criticizing the professional care of their child was fear. Three respondents were concerned that expressing criticism would have negative consequences for their child’s care:

Then also, I didn’t know the right words to say to her, so then I was a bit afraid if I say bad words, they are coming to take my son from me. So I was just quiet. (Semira and Patrik, aged 3–10 years old, moderate intellectual disability, special education, Africa).

Similarly, Nawar and Ayla were concerned that the health care for their child and sister would reduce in quality if they expressed their criticism:

And you also have a relationship where you couldn’t be too direct, because they still take care of your sister or daughter. So whatever you say, you say with some caution. Because yes, you do not know how the other party will take it and yes, would the care remain just as good after that? (Nawar & Ayla and Hadiya; aged 11–23 years old, severe multiple disability; specialized daycare facility; the Middle East region)

Similarly, Denisha explained that she did not feel comfortable to speak to the care professionals about things that she was dissatisfied with, even about a relatively small issue she had with the way the teachers contacted her. When she was asked why she did not want to speak to the care providers about this, she explained that she is afraid this may have consequences for the care for her child. These fears seemed to extend to this study’s interview, as she also did not want the interview to be audio-recorded and did not feel comfortable with writing her name on the consent form. Another parent requested the audio recording to be stopped before disclosing information about a conflict she had with a care professional and only shared the information when the interviewer emphasized again that she has no relation with the care facility. This mother did express to her care professional that she was dissatisfied with an aspect of care, but showed great discomfort talking about this. It seemed some parents were so concerned about negative consequences for the care for their child that they were very reluctant in communicating about what they needed from professionals in the care for their child.

However, we did notice that parents who had lived in the Netherlands for a longer period seemed to have less problems in expressing what they wanted from professional caretakers. Two respondents, who had arrived in the Netherlands more than 20 years ago, were more proactive towards the professionals: Nawar and Ayla even took their complaint about there not being permanent staff available for their daughter to the management level.

All in all, we can conclude that particularly parents who had recently migrated to the Netherlands withheld themselves from asking questions, making requests or criticizing the professionals

and institutes taking care of their child. Many of them did not know that the Dutch system entitles and even expects them to be actively involved in this way, some felt that because they now live in the Netherlands, they should completely conform to all elements of the Dutch system, several thought they should not question or comment on an “expert”, felt that it would be ungrateful if they commented or were afraid it would harm the care of their child. It is very likely that similar challenges will also be faced by (recently) migrated people in other areas of the Dutch health care system.

## Conclusion

Our research question was: “Which intercultural challenges do parents with a non-western migration background in the Netherlands face in dealing with their child’s developmental disability?” The aim of this study is to improve health care to better match the specific needs of these parents. The emergent themes in this study provide insight into the meaning of having a child with a developmental disability, as well as in experiences interacting with health care professionals who take care of their child. Based on our analysis of interviews with 12 parents with a non-western migration background of children with a developmental disability, we found that they face several intercultural challenges in dealing with the disability of their child. As a result of cultural differences in the meaning of, and information and interaction about disabilities, non-western migrant parents will have a harder time coping with the diagnosis of the disability of their child and they will experience more challenges with their involvement in the professional care for their child. This finding is consistent with past research showing that several social, cultural and structural barriers exist between health care professionals and their clients of non-western backgrounds [17,33,39,40].

First, we studied cultural specificities in the meaning of having a child with a developmental disability for the parents we interviewed. In analysing what parents said, we found that as a result of cultural differences in the meaning and stigmatization of disabilities, it is likely that non-western migrant parents have a harder time accepting the diagnosis of disability of their child. Similar to the study by Harry [13], parents in our study had a broader range of seeing behaviour as normal. Accepting that their child was labelled as “disabled” may be more difficult for these parents, as their concept of disability did not include the symptoms their children were showing. Furthermore, their experience with stigmatization in their country of origin could have caused a greater shock and problems in coping with the diagnosis than in people of countries where diagnoses of disability are less exceptional and less stigmatized.

Secondly, a challenge we found included parents’ unfamiliarity with the host country’s health care system, including the lengthy diagnostic procedures and complex concepts that are used for identifying a disability. The number of, and diversities in, specialists and services involved in diagnosing and caring for children with disabilities were found to be more complex than parents were used to in their country of origin, where care facilities were often not or less available. They were less aware of what sort of health care was available to them [37,41]. Together, these factors enhanced feelings of uncertainty for immigrant parents about diagnosis, the cause of disability, treatment plan and future perspectives of their child. The language barrier enhanced this uncertainty as it hampered clear and effective communication and mutual understanding, as was also found by King et al. [52]. In the experience of most parents we interviewed, hardly any good

translator services were made available to them. Previous research shows that the more uncertainty parents experience, the more difficulty they have with coming to terms with or accepting their child’s diagnosis of disability [51].

Lastly, we have analysed how parents with a non-western migration background perceive the role of, and interaction with care professionals. In general, the parents we interviewed expected a hierarchical position of health care professionals, as they saw the care professional as the expert about their child. This prevented them from contributing their own experiences and expectations of (the care of) their child, which is part of most western countries’ partnership-based approach. Similarly, many parents felt they had to “follow the rules” set by the care facility [13], partially also because they felt they now live in the Netherlands and so have to conform. Similar to the study by Lindsay et al. [37], parents in our study also withheld from expressing criticism or requests, because of the gratitude they felt for the care they received. Lastly, parents reported experiencing dependency on and mistrust of the professional care takers of their child, whom they felt could take away (good care of) their child at any time. All these elements together made immigrant parents uncertain about their role and prevented them from discussing requests or criticism about the professional care of their child and of being as involved in their child’s care as they might want to be. This was also reported in a study by Lindsay et al. [32,35,37], who found that care professionals shared the views that are mentioned above.

This study also has some limitations. Although we did reach data saturation with the present sample, the backgrounds of the participants were not as diverse as we hoped, due to our difficulty finding participants who were willing and able to participate. Future research could increase the diversity of the research participants e.g., the length of time resident in the Netherlands and in their cultural backgrounds, as some challenges parents face may be culture specific or dependant on their level of integration in the Dutch culture. Secondly, although we included researchers from various cultural backgrounds who spoke different languages, most participants in this study were interviewed in a language in which they were not native speakers. Particularly with sensitive topics like this, the option to express yourself in the language you feel most comfortable with would have been preferable.

Which recommendations can we draw from our study? To start with, we think it is crucial that professional care takers are aware of the additional challenges parents with a migration background may experience in dealing with (the care for) their child with a disability. It is crucial to establish a relationship of trust and an open environment in which parents feel comfortable to discuss criticism and requests [37,54,55]. Parents and care professionals should both be able to present their expectations and discuss them, to reach mutually agreeable treatments [56]. Care professionals should explore which knowledge parents have about disability and the host country’s health care system, so that they can adjust their information and advice to help parents access available resources [32,37,52]. Similarly, using professional translators who not only translate (in the right language), but can also explain specific mental health concepts or differences between health care systems to both parents and care professionals is crucial. Furthermore, care professionals should pay particular attention to check the extent to which parents have understood the diagnosis of their child’s developmental problem and give additional information when needed. Generally, care-professionals and parents should be made explicitly aware of the different expectations each has of their contribution and role in the

process, so that parents feel they can join the relationship with care professionals on equal grounds. Moreover, psychoeducation should give parents more insight and knowledge about how common diagnoses of disability are in their host country and help them attain knowledge about expectations for their child's future. Indeed, according to a study by Mak and Cheung [57], stigma should explicitly be addressed in psychoeducation, as fear of stigma can act as a major barrier for parents to get help for their child. Furthermore, parents should be taught which rights they have and what kind of role, interaction and contribution is expected from parents. Lastly, parent support groups could be launched to enable parents to share experiences with each other and offer mutual support [7].

Only parents who were willing to share their story and who felt comfortable talking about their experiences with care participated in our study. It is likely that parents who declined participation in this study struggled even more with dealing with the disability of their child, and so either did not have time, did not feel comfortable speaking about the disability of their child, experienced a language barrier, or held more fear of negative consequences if they expressed criticism. So, although we spoke with a limited number of migrant parents, we are confident our results will be even more applicable to more parents with a similar background. This study contributes to understanding the intercultural challenges parents of children with a disability from a non-western migration background encounter in their host country's health care. Some of these challenges may not be specific only to people from a non-western migration background. Challenges, e.g., in understanding the language of care professionals or the intricacies of the health care system in a new country, may just as well be faced by western migrants or by parents with a lower educational background. Other challenges may not just be specific for parents of a child with a disability, but can also be faced by non-western migrants who come into contact with the health care system in their host country. Issues with specific relevance to them could be that they are unaware or unfamiliar with the partnership-based approach where patients are treated as "clients" who are expected to be actively involved in their own care process, are unfamiliar with terms and procedures used in the Dutch healthcare system or suffer from problems as a result of not getting (competent) translators. Other topics we addressed, such as fear of stigma, or unfamiliarity with a broader or other conception of disabilities, are generally relevant for non-western migrants with a child with a disability, not just in their contacts with Dutch healthcare organizations. All in all, we hope to have inspired professionals to be more aware of, and adjust their care to the specific challenges vulnerable groups experience in getting the health care they need.

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