

Experiences of mothers caring for a child with an intellectual disability during the COVID-19 pandemic in the Netherlands

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Abstract

Background During the first COVID-19 lockdown period, various restrictions led to diminished access to both educational and professional support systems for children with an intellectual disability and their families. The aim of this study was to explore the experiences and needs of parents caring for a child with an intellectual disability during the first lockdown period in the Netherlands.

Method Five mothers caring for a child with an intellectual disability participated in this qualitative study. The participants were interviewed using a semi-structured interview guide. The interviews lasted between 26 and 48 min. The interview recordings were transcribed verbatim, and the transcripts were analysed thematically.

Results Three overarching themes emerged: (1) *We need to stay healthy*, which centres on the mother's urge to protect their child's well-being; (2) *We make it work*, which provides insight into how the mothers were handling the drastic changes in their family; and (3) *My child's and family's place in the world*, which focuses on the mothers' experienced position in the world around them.

Conclusions The current study provides valuable insights into the experiences and needs of mothers caring for a child with an intellectual disability during the COVID-19 pandemic.

Keywords coronavirus, COVID-19, experiences, mothers with a child with an intellectual disability, pandemic

Introduction

In late 2019, the novel coronavirus SARS-CoV-2, causing the coronavirus disease 2019 (COVID-19), spread from Wuhan, China, to become a pandemic with a major impact on the way we all live our lives (World Health Organization 2020). Various preventive measures (e.g. closure of public places and instruction to stay at home and keep social distance) have been taken in an attempt to reduce the risk of infections, which is likely to impair the mental health of many people (Brooks *et al.* 2020; Courtenay 2020). The specific vulnerabilities of particular groups of people for COVID-19 have been emphasised in the course of the pandemic, including those of people with an intellectual disability (World Health Organization 2020), as they are more likely to experience social disadvantage, health problems and psychiatric disorders (Courtenay & Perera 2020). Moreover, during the first period of the pandemic, schools and

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day services were withdrawn, and residential facilities were closed for all visitors, which had a significant impact on the lives of people with an intellectual disability (Embregts *et al.* in press). This meant that people missed their usual daily routines and having contact friends and others they enjoyed close relationships with. In addition, Embregts *et al.* reported that it was hard for people with an intellectual disability to understand the preventive measures.

Although all families with children are affected by the COVID-19 pandemic, the sudden change to remote education, along with preventive measures such as social distancing and self-isolation, has been particularly challenging for families caring for a child with an intellectual disability, given their reliance on professional and informal support (Summers *et al.* 2021; Toseeb *et al.* 2020). In addition, there are likely to have been instances where these changes have led to an increase in the challenging behaviours presented by individuals with intellectual disabilities in the family home (Alexander *et al.* 2020; Courtenay & Perera 2020). Moreover, many people with an intellectual disability have significant underlying health conditions (Cuypers *et al.* 2020), meaning that their family members will have particular reason to worry about their child contracting the COVID-19 virus (Gulati *et al.* 2020). Therefore, the COVID-19 pandemic has also had a major impact on the families of those with an intellectual disability (Alexander *et al.* 2020). This is partly because under normal circumstances, they enjoy the support of schools and day services (UNESCO 2020). However, during lockdown, their children were at home in a confined space without other social contacts for a long period of time, which might have significantly increased their level of stress (VGN 2020). Although some initial family reports have described advantages of living a less complicated lifestyle during the pandemic, and the opportunities to interact more with their child with an intellectual disability (Rose *et al.* in press), these advantages may be negated by the continuing closure of schools, day services and respite care (Courtenay & Perera 2020). Combining the care of a child with an intellectual disability with continuing work commitments at home also posed considerable challenges to families (Rose *et al.* in press).

General family research has focused on the impact of having a child with an intellectual disability on parental well-being or family quality of life

(Hastings 2016). One of the main contributing factors to positive parental outcomes, in terms of stress and family quality of life, is having adequate social and professional support (Davis & Gavidia-Payne 2009). The level of satisfaction with the professional support provided to families, in particular, is found to be good predictor of the family's quality of life (Balcells-Balcells *et al.* 2019). Moreover, parents themselves have also indicated that professional support is a key element of their quality of life (Steel *et al.* 2011). As such, being expected to provide week-long care and support to their son or daughter, without any paid support, may place considerable strain on families and have an impact on their well-being (Rose *et al.* in press). Of course, it is not merely the loss of paid support in itself that may place strain on families. Their sons and daughters' daily lives will also have been disrupted, with the loss of routine activities and valued social contacts (Embregts *et al.* in press). This, in turn, will have an impact on the family dynamics.

Based on the above, it is clear that the COVID-19 pandemic has had a significant impact on the lives of many families caring for a child with an intellectual disability, although the exact impact has to be determined yet (Courtenay & Perera 2020). Therefore, research into the potential challenges and benefits parents have experienced in the current COVID-19 pandemic is vital in order to gain insight into how to support families at this difficult time. The exploratory research question for the current study was: What were the experiences and needs of parents caring for a child with an intellectual disability during the first lockdown phase of the COVID-19 pandemic? This study will focus on the experiences and needs of parents during the first lockdown period in the Netherlands, which took place between March 15 and May 11.

Method

Participants

A sample of five parents caring for a child with an intellectual disability was interviewed. The inclusion criteria were (1) having a child or adolescent under the age of 20 with an intellectual disability (regardless of the level of intellectual functioning) and (2) who lives at home and is now, due to the temporary closing of special education schools and day-care centres

because of the COVID-19 pandemic, staying at home during the daytime.

After the interview, demographic information was obtained from the participants by email about themselves and their children. This information is shown in Table 1. The participants and their children have been given pseudonyms. All participants were the biological mothers of their children and lived with their partner. Two mothers temporarily stopped working to support their child and one mother continued her job (Christine); the two remaining mothers did not have a paid job (Diona and Eveline). Prior to the COVID-19 pandemic, four of the participants' children attended school, and two attended a day-care centre. During the COVID-19 lockdown, as schools and day-care centres were closed, all mothers were involved in homeschooling (e.g. helping their child with schoolwork and supporting them to actively participate in online classes with the teacher). Before the COVID-19 pandemic, some children received additional support at home, up to 14 h a week, for nursing care and speech therapy. One of the children (Famke) received after-school care twice a week and had a sleepover weekend once a month. A formal diagnosis of intellectual disability was recorded for two of the

children based on IQ assessments; no formal assessments were available for the children of three of the participants (Amy, Christine and Eveline), but they were attending schools for children with an intellectual disability.

Interview

A semi-structured interview guide was developed by the research team to explore the participants' experiences and needs during the first lockdown period of the COVID-19 pandemic. The guide had three main topic areas, with opening questions that could be followed up with additional questions or prompts. The topics consisted of (1) the impact of the preventive measures towards COVID-19 on the participants' family, and the child with intellectual disabilities in particular; (2) to what extent the participants feel supported by their families and professionals; and (3) participants' potential concerns with the current COVID-19 situation. The goal was to establish a dialogue with the participants using the interview guide to ensure that the main topics were discussed while being open to other relevant issues raised by participants.

Table 1 Demographic information of participating mothers and their child with an intellectual disability (ID)

Mother's name	Mother's age	Type of family	Number of children	Name of child with ID	Gender of child with ID	Age of child with ID	Level of ID of child	Additional diagnosis	Child's type of school
Amy	42	Nuclear family	2	Bas	Boy	10	Moderate to severe	Down syndrome	Special education
Bernadette	47	Nuclear family	3	Paula	Girl	18	Profound intellectual and multiple disabilities	SMC1A	Day-care centre
Christine	52	Nuclear family	3	Famke	Girl	17	Mild to moderate	Down syndrome	Secondary special education
Diona	27	Nuclear family	2	Peter	Boy	5	Profound	-	Day-care centre
Eveline	39	Nuclear family	2	Susie	Girl	7	Moderate	MECP 2 duplication syndrome	Special education
				Chris	Boy	4	Profound intellectual and multiple disabilities	MECP 2 duplication syndrome	Special education

Due to the COVID-19 pandemic, all interviews were conducted by the second author through video calls using Skype for Business. Although in normal times face-to-face interviews might have been preferred, telephone interviews have been found to generate similar quality data (Braun & Clarke 2013). The interviews were recorded using the record function in Skype for Business. Interviews lasted between 26 and 48 min.

Procedure

Ethical approval for this qualitative study was obtained through the Ethics Review Board of Tilburg University (RP149). A convenience sampling procedure was used. Participants were recruited through a parent who the principal investigator works with about the involvement of parents in the support of people with intellectual disabilities. The parent approached five mothers that met the inclusion criteria and, after their approval, provided their names to the researchers. The parent assured that the selected mothers agreed to this voluntarily; there was no coercion. The second author then contacted these five mothers by phone and informed them about the study and provided them with the study information sheet. They all voluntarily agreed to participate in the study and provided written informed consent. All mothers received a gift voucher for their participation.

The interviews were conducted during the first lockdown period in the Netherlands (March 15 to May 11). Schools and public places were closed during this period, as well as work and day services for people with an intellectual disability. Residential support services for people with intellectual disability only allowed face-to-face contact with relatives under very strict conditions. Shops were allowed to remain open, yet with the necessary precautions, such as a strict maximum number of shoppers. Moreover, groups with more than three people were forbidden, and people were instructed to keep 1.5 m apart at all times; failing to comply could result in fines up to €400 for individuals.

Data analysis

In line with a constructivist approach (Denzin & Lincoln 2011), the analyses explored mothers' perceptions of their experiences with respect to

COVID-19. Inductive thematic analysis was used to identify themes (Braun & Clarke 2006). Thematic analysis is a method for identifying, analysing and reporting salient patterns within qualitative data. Thematic analysis, which consists of six consecutive steps, is a useful method to examine participants' perspectives, emphasising similarities and differences and generating unanticipated insights (Braun & Clarke 2006). A careful audit process was built into each stage of the analysis, involving different members of the research team. Firstly, the transcriptions of the interviews were read in detail by two of the authors to become familiar with the data. Secondly, these two authors inductively generated initial codes relating to relevant text in the interviews (i.e. related to the experiences of mothers regarding the COVID-19 pandemic). Codes identify a feature of the data (semantic content or latent) that appears interesting to the analyst and refer to 'the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon' (Boyatzis 1998, p. 63). For example, the sentence 'It's nice that I don't have a job now, because now I can focus on my son' received the code 'mother is happy to currently not have a job so she can focus on her son'. Both authors discussed the two sets of initial coding with two other authors, and an agreed version of the final set of codes was established. Thirdly, two authors subsequently grouped all similar codes together and then collated them into potential themes. That is, the authors considered how different codes could be combined to form an overarching theme. This step resulted in a collection of candidate themes and subthemes. Fourthly, these candidate themes were reviewed by all authors to identify whether the data within themes cohere together meaningfully and that the different themes are identifiable and distinctive from each other. This step involved two levels of reviewing the themes: (1) reviewing at the level of the codes, by reading all the codes for each theme, and considering whether the codes and related themes form a coherent pattern; and (2) reviewing the codes in relation to the entire data set, by considering the validity of individual themes in relation to the participants' complete narratives and the overall story these themes tell. Care was also taken to ensure that the codes and themes could be illustrated by verbatim quotes from the participants. Fifthly, after the themes were

established, they were defined, named, and a narrative structure with accompanying descriptions was produced. Finally, a scientific report of the themes was produced by writing up the thematic analysis.

Results

Three overarching themes emerged from the data: *We need to stay healthy*, *We made it work* and *My child's and family's place in the world*. The overarching themes were divided into eight subthemes, which are displayed in Table 2, including verbatim examples of each subtheme.

Theme 1: We need to stay healthy

The first theme focused on the mothers' concern about their children's vulnerability and their efforts to support their well-being. In their efforts to protect their child, the mothers tried to implement safety measures that suited their personal family situation. To address these issues, two interconnected subthemes emerged: *A constant health threat* and *Struggling with the balance of infection risk and a manageable family life*.

Subtheme 1.1: A constant health threat

Perhaps unsurprisingly, all participants spoke about the fear of their child getting infected and getting

Table 2 Overarching themes and subthemes

Overarching theme	Subtheme	Verbatim examples
<i>We need to stay healthy</i>	<i>A constant health threat</i>	Our son has been at the intensive care multiple times due to airway infections. Therefore, for us, it was a big fear that he would get COVID-19 because he can get very sick from every flue with a higher infection risk than a regular child. This made us very fearful. (Diona)
	<i>Struggling with the balance of infection risk and a manageable family life</i>	We are very strictly following the safety measures because our number one priority is that our son cannot get sick. Therefore, we only go shopping by ourselves and if we ride our bikes, we only ride them towards nature where you will not encounter other people and if you encounter them, you can pass them by with a lot of space in between. (Amy)
<i>We made it work</i>	<i>My child with an intellectual disability should have a good day</i>	I always try to find activities that give my daughter joy but also enable her to give meaning. Last week we painted cards that I can send to old, lonely people. (Bernadette)
	<i>We are in this together</i>	If I have to teach my class I cannot watch my daughter. My family always discuss with each other who can take over and support her. This way, we make this work together. (Christine)
	<i>Space to breathe</i>	We live in a nice place. We have a front yard where we have social contact with the neighbours and a lovely backyard. Inside the house, we have enough space to sit together but also go our separate ways. (Bernadette)
<i>My child's and family's place in the world</i>	<i>Is my child worth saving?</i>	My son is extra vulnerable to pneumonia so I was really scared he would get infected. I heard all these stories that people with an intellectual disability were not allowed into hospitals. Therefore I thought: This will not happen to me, if my child cannot go to the hospital, I will do anything to prevent him from getting sick. (Eveline)
	<i>Feeling the same but different</i>	People around me start to go out and do nice things again. I am very strict in this and even though my daughter understands the situation, I know she does not like it. Behind our house is a soccer field where more and more kids are playing again. My daughter cannot go there and play with the others. (Eveline)
	<i>Fewer expectations</i>	Because I have more peace, I have even more peace in my household because I am no longer obliged to do things for the outside. I can do the things that I find important and have peace of mind. (Diona)

seriously ill. This was a major concern for all five mothers. They were worried about their child being more vulnerable once infected because of underlying medical issues. Therefore, even ordinary daily activities were considered to be potentially hazardous by some. As one of the mothers explained at the time:

I already notice that I find grocery shopping really scary. If people come to close in line, I go ahhrgh! I just do not want to go shopping anymore because I am afraid my son will get ill. (Amy)

Moreover, the COVID-19 pandemic seemed to bring up underlying trauma related to the medical history of their child and the fears that came with it. For example, Christine and Diona talked about living with the real possibility that their child might die. Diona felt a constant sense of threat that her son Peter could die at any time. The invisible and unpredictable nature of the coronavirus intensified their fears for their children's health. This fear became so intense for Diona that she even wondered, at times, if she would have been a lot more relaxed and carefree during the pandemic if her son had already passed away. Their children's medical history meant that Diona and Eveline were sceptical when physicians told them not to worry too much. As Diona explained:

What if he gets infected? That is our biggest fear, because from a common cold virus he also gets critically sick. We believe he would not survive a COVID-19 infection. The doctors tell us we should not think this way, but I think that when you look at the reality, there is real chance he will not survive. (Diona)

To protect the health of their child and reduce their fears, the mothers have tried to take as many preventive measures as possible for them to reduce the risk of infection. All mothers stated that the safety of their child was their main priority. This meant that the mothers wanted to take as much control of the situation as possible, even if that meant stopping all paid support.

In 1.5 weeks my feelings changed from no fear to extreme fear. So then we made that decision [cancelling all professional care], and I have not

regret it for a second. I cannot bear to think that he would get infected now, or any other time. (Diona)

Subtheme 1.2: Struggling with the balance of infection risk and a manageable family life

All mothers took precautions to protect their families. This entailed taking full-time care over their family with minimal or no physical contact with the outside world. However, the different approaches taken by the five mothers need to be understood in the broader context of their family lives.

Even though Amy and Eveline would have preferred self-quarantine for their family to control the risk of infection, in the longer term, this was not a realistic option for them. Amy talked about the challenges of caring for her very active and energetic child and admitted that, by lunchtime, she was feeling exhausted. She knew that she could not sustain this and had accepted help from a neighbour and had started making occasional use of private day care. This allowed her to have time to herself and relieved some of the stress and tension. Eveline accepted support workers back into her house after her husband admitted that he could not manage without help any longer. The fact that there was no clear end date added to the uncertainty and stress for these parents:

... my husband says that we cannot tell how long this will take. It is not as if we can set our minds to a 2 month-period and power through it knowing it will be calm again. (Eveline)

Even though Diona's family was in self-quarantine at the time of the interview, she also acknowledged that the quarantine could not last forever and was concerned about what the future held:

When do we allow the nurses back in our home and when do we decide to go out for groceries and stuff like that, or go to birthdays again? I do not know. We live day by day and when I start thinking about it ... it frightens me. (Diona)

Finding a balance between protecting of their child and maintaining daily life for their family presented different challenges to the mothers. However, the

mothers all struggled to create a balance in their lives and the lives of their family. For example, Amy and Christine choose to let their children have a limited form of physical contact with friends in order to lift their spirits. For example, Christine had a large garden where she let her daughter play netball with her friend (keeping the 1.5-m distance) while she drank coffee with the friend's mother. For Christine, this helped to sustain a healthy family life without taking undue risks.

Theme 2: We make it work

The second theme provides insight into how the mothers managed the drastic changes to family life. Different strategies worked for different families: providing daily structure for the child with intellectual disabilities or adjusting the day according to their needs. Strong family bonds, teamwork and building in personal time formed the key to 'success'. To address these issues, three subthemes emerged: *My child should have a good day*, *We are in this together* and *Space to breathe*.

My child with an intellectual disability should have a good day

Most mothers thought that school helped to create a daily routine for their child. The mothers believed a daily schedule offered their child meaningful activities, structure and experiences of success. Whereas most mothers praised the teachers for being involved and supportive, Christine felt that her daughter's school failed to meet her needs.

It was very frustrating [that they offered only limited tools to the parents]. Until, at some point, I've had enough of it. So I'd sent an email to the teacher and well, it turned out they could offer a lot more. Coming to school and picking up a bag [filled with school materials], a schedule, and stuff like that. Then I am thinking, geez, why could not they have offered that to everyone? (Christine)

Amy and Bernadette also experienced difficulties in implementing a daily schedule at times. In order to maintain a calm atmosphere, they seemed to try and avoid any form of confrontation with their child that could cause upset or behavioural difficulties.

Therefore I prefer doing the things from his schedule that he likes to do because than we will have a nice time. That does mean that I have to run and dance and jump and catch and yeah, haha. (Amy) However, having the energy to keep their child occupied and happy could be very draining for the mothers, in addition to the other stressful impacts of lockdown.

We are in this together

Even though the full-time care for their family placed increased demands on the mothers, most mothers felt that their strong family bonds helped them to cope. In particular, they felt that they and their partners were good teams. The mothers were also pleased to see the positive interactions between their children with an intellectual disability and their brothers and sisters:

I have to say I'm very proud of our boys. And our family. It has actually already been like this. Sometimes they tease her [sister with an intellectual disability], but I think that is normal. And when she needs help, they help her. Their girlfriends too. They go for a bike ride and eat some pancakes or strawberries along the way. They really try to make to best out of the situation. I think she is lucky having her brothers. (Christine)

On the contrary, Eveline, mother of two young children with an intellectual disability, felt she had to take most responsibility to maintain family life. The sudden reductions to care at home, due to the pandemic, proved very difficult for her husband. He was at home full time and needed moments to rest because of his autism. Therefore, Eveline felt that the family would be unable to cope if she became ill with COVID-19.

Well, if I will get sick it will not go well here in the family, because there is nobody who can keep things going. (Eveline)

Space to breathe

Providing 24-h care to their child, which was usually shared with teachers and other professionals, and having few, if any, opportunities to leave the house (e.g. for sports or visiting friends), left little space for the mothers themselves. They frequently mentioned

that having time for themselves was important to relieve stress and renew their energy. Consequently, they tried to build short breaks into their daily routines. For example, Bernadette started each day by walking the dog, and Amy got up earlier than the rest of the family and introduced smartphone time for her sons after lunch. As Amy explained:

We are now constantly living in each other's pockets. No bad words, but sometimes you just need some space for yourself (...) For me that is literally being alone, a moment of not needing to help someone or caring for someone else. (Amy) The physical space available for their families in and around their house was also an important factor. Four mothers reported feeling lucky to have a house and a garden, with private space for everyone. However, Eveline felt that the lack of space in their apartment caused friction within her family.

Theme 3: My child's and family's place in the world

The third theme is about the societal experience of being a mother of a child with an intellectual disability. The dramatic situation of the pandemic forced the mothers to reflect on the societal, ethical value of the life of their child with an intellectual disability. Even though mothers claimed to experience the same struggles as any other family during the pandemic, they sometimes felt misunderstood by others. However, due to the intelligent lockdown, the mothers experienced fewer outside demands, allowing them and their children to experience a certain calmness. To address these issues, three subthemes emerged: *Is my child worth saving?*, *Feeling the same but different*, and *Fewer expectations*.

Is my child worth saving?

The mothers did not only express major concerns about their child's health but also felt in a vulnerable position when it came to medical care for their child. At the time when the interviews were carried out, the intensive care units almost fully occupied in the Netherlands. Bernadette, Diona and Eveline were anxious that their child would not qualify for a bed in an intensive care unit. For example, Bernadette

feared that her daughter, who has profound intellectual and multiple disabilities, a complex medical history and a shorter life expectancy, would not be afforded the same access to treatment as a typical 18-year-old. Due to her son's history of hospitalisation, Diona has always felt that the fate of her child was in the hands of medical staff. She was acutely aware that physicians value her son's life differently to her and her and husband.

We already know how it is like when our child is in the intensive care unit. We would really want to fight, but the doctors only see a little child that is not capable of doing much. For us, he means the world, but doctors have a different view. Now during the corona crisis I think to myself: would this, eventually, be the end? (Diona) Diona and her husband have learned how to fight for their son's life. However, the constant fear that physicians will eventually decide to let their son die was brought into sharp relief due to the limited intensive care capacity during the pandemic.

Feeling the same but different

All mothers knew that their family's situation was not unique and that everybody in society was more or less affected by the COVID-19 pandemic. They felt relatively fortunate about the way their children were handling the lockdown period and talked about people who were worse off. Bernadette, for example, even sent away the nurses that usually took care of her daughter because she felt they could be of more to others.

We just think it important that the nurses can be at use at places where they are needed the most. And in the current situation, that is not in our home. They are currently working at an intensive care unit and in terminal care. Well, really at places where they are more urgently needed than here. (Bernadette)

However, mothers' views were contradictory at times. While stating that their situation was not unique, some of them also talked about the ways in which the COVID-19 pandemic had affected them differently from other families. For example, Diona and Eveline felt their family had needed to take more stringent preventive measures than families without

a child with an intellectual disability. As a result, Eveline expressed feelings of guilt that her daughter could not play outside like other children. Diona believed that other people had little understanding of her situation:

You just learn to form your own opinion and do your own thing. Because people do not understand your decisions. They are not in a similar situation, so they have no idea. They do not have the responsibility for a child with multiple disabilities. (Diona)

Christine had tried to ensure that her daughter with an intellectual disability had the same opportunities for schooling and social inclusion as her other two sons. However, due to the homeschooling during the pandemic, she became aware that the special education school did not offer her daughter the level of teaching that would allow her to achieve her full potential. Christine also felt deeply disappointed that the school only offered limited online education. She was frustrated when she saw that regular schools, with larger numbers of pupils in each class, offered considerably more opportunities for learning.

Why is not online education possible for her every day? I hear that in regular primary schools, with 30 children in one class, the children have to take a one-hour class each day, and the teacher will give feedback to the ones that need it afterwards. Here at the special education school we have 15 children in one class who will need a one-hour class and a daily schedule. That should be easy, right? (Christine)

Fewer expectations

Some mothers explained how the lack of stimuli and (social) expectations during the COVID-19 pandemic brought a certain calmness to family life. This seemed to make them aware of the busy and rather intense schedules that they and their children normally have. Diona observed that her son felt more calm and peaceful, and Eveline realised that her daughter's temper tantrums had stopped occurring during the pandemic. They both believed that this difference was due to their child's difficulty dealing with the large number of demands in their normal daily routine.

Well, when my daughter is exposed to a lot of stimuli, after school she can get tantrums; kicking, beating, yelling, a lot of crying. And currently she does not have these tantrums. (Eveline)

The parents also thought that their other children, without an intellectual disability, had benefitted from having fewer demands and expectations placed on them. In turn, the mothers felt that this reduced the demands on themselves. For example, because there were no appointments with physicians and therapists, Diona she felt a sense of calmness for the first time in years.

Since our son was born, my husband and I, maybe that sounds strange, but we never have peace. That week that we went on vacation, we had to relax because after that week it all started again. Now we are forced to relax, and that is what we have been doing for five weeks now (...) Nobody expects us to visit, not to a hospital, not to an appointment, nowhere. (Diona)

Discussion

This study reported on the experiences and needs of five mothers caring for a child with an intellectual disability during the COVID-19 lockdown period in the Netherlands. Three overarching themes were identified: *We need to stay healthy*, *We make it work* and *My child's and family's place in the world*.

The findings of this study provide various valuable insights with respect to the experiences of mothers during the first COVID-19 lockdown. Firstly, participants reported that fewer social expectations and the absence of daily pressures during the COVID-19 pandemic had a positive impact on their child with an intellectual disability and their family as a whole. Their accounts echo those reported by Rogers *et al.* (2021). Although this is a noteworthy and constructive observation, engagement in meaningful daily activities remain important for achieving personal development, physical well-being, social relationships, social integration and other domains of quality of life (Mansell & Beadle-Brown 2012). Therefore, it may be helpful to explore how a better attunement between the school or day service and home situation can be achieved to

promote the child's development while preventing overstimulation.

Secondly, providing care for family members under COVID-19 lockdown restrictions also meant that mothers had little, if any, time for themselves. In general, parents caring for children with an intellectual disability are already more at risk of mental health problems, yet the risk of serious mental health problems for these parents increased even further during the COVID-19 lockdown restrictions (Willner *et al.* 2020). Thus, mothers' self-care is even more important under COVID-19 lockdown restrictions. Therefore, it remains vital for mothers to continue to have short breaks to offer personal space and time out from the daily demands of life at home. These breaks may also give mothers an opportunity to re-energise in order to provide a safe and loving environment for each family member.

Thirdly, although all mothers in the current study experienced drastic changes in their daily life during lockdown, different coping strategies worked for different families. For example, some mothers introduced a daily structure for the family and the child with an intellectual disability, whereas others flexibly adjusted the day according to their child's needs. When re-establishing services, professionals (e.g. direct support staff, teachers and day-care staff) could learn from the families they are supporting and try to adjust their input to the personal needs of the individuals and their families (Alexander *et al.* 2020). Expecting families to fit back into rigid systems, without any adjustment, may prove difficult and discouraging.

Finally, the pandemic heightened the mothers' fears for their children. Participants described the fear of their child getting infected and getting seriously ill. Their worries were intensified due to their child's underlying medical issues. These experiences are consistent with past research concerning parents' experiences of obtaining medical care for their child. For example, in their cross-sectional study of 117 parents with a child with an intellectual disability, Seliner *et al.* (2016) reported that most parents worried about their children's well-being and safety when hospitalised. Moreover, the parents in the current study felt in a vulnerable position when it came to qualifying for critical care for their child, due to limited capacity in intensive care units. These fears are likely to persist as long as the pandemic and the

shortage of intensive care units continue. Participants felt that medical practitioners placed less value on the quality of life of their child with an intellectual disability than on the lives of other children, which would make it more likely that their child would not qualify for critical care. It was reported that parents and physicians may differ in how they value the quality of life of a child with multiple disabilities and in how much value they attach to the different factors that contribute to a person's quality of life; however, physicians' impressions of the lives of people with multiple disabilities are merely based on their experiences with these children in a hospital setting (Zaal-Schuller *et al.* 2018). Parents who care for their child in a daily setting could contribute important information concerning their child's quality of life (Morrow *et al.* 2008). This information may result in medical professionals having a better understanding of the actual quality of life of a child with multiple disabilities, which in turn may improve decision-making about access to intensive care for these children. Furthermore, work needs to be done to make medical practitioners more aware of and sensitive to concerns of families with a child with an intellectual disability in general. In the future, one possibility would be to include family members and people with an intellectual disability themselves in the education of medical practitioners (Tracy & Iacono 2008).

The results of the current study should be interpreted in light of several limitations. First, due to the difficulties of conducting this type of research during the first wave of COVID with mothers caring for a child with an intellectual disability, the sample size of the current study was relatively small, limiting the interpretation of the findings. Moreover, given the small number of participants, it is possible that other themes or subthemes might have emerged if there had been additional participants. Nevertheless, as this study was the first to explore these experiences during the COVID-19 pandemic, the findings remain informative and relevant. It would be important for future research to include a larger number of participants, while also focusing on other families, such as families whose child lives at a residential facility or whose child was brought home due to the pandemic (Vereijken *et al.* submitted). Second, this study only focused on the experiences of mothers. Although theoretical frameworks, such as the family

systems theory, acknowledge that fathers are an integral part of the family (Seligman & Darling 2007), relatively few studies have investigated the perspectives of fathers (e.g. MacDonald & Hastings 2010; Taylor *et al.* 2016). Likewise, no mothers from culturally diverse backgrounds were included in the study, and therefore, we are unable to comment on whether they might have had other experiences and needs during the lockdown period in the Netherlands. Hence, it would be interesting for future research to address the experiences and needs of fathers as well as well mothers, from culturally diverse backgrounds, in various countries. Third, the current study focused on the experiences and needs of mothers during the first lockdown period. Although this provides valuable insights for potential future lockdowns, it is expected that the COVID-19 pandemic will continue for as long as no vaccine is available. As government and societal responses to the COVID-19 pandemic evolve, mothers' experiences may change during the COVID-19 pandemic. Therefore, it is important to continue studying experiences of parents caring for a child with an intellectual disability during the ongoing COVID-19 pandemic.

Despite these limitations, the current study provides valuable insights into the experiences and needs of mothers caring for a child with an intellectual disability during the COVID-19 pandemic in the Netherlands. These insights include the importance of balancing the child's development with the risk of overstimulation, the need for of breaks and mother self-care and the potential benefits of adjusting support for individual families based on their experiences during the first lockdown. Insights from this study are likely to remain relevant, particularly with regard to providing remote care and support, which is likely to continue for the foreseeable future (Wind *et al.* 2020).

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Conflict of interest

The authors declare not to have any conflict of interest.

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