A thematic analysis into the experiences of people with a mild intellectual disability during the COVID-19 lockdown period

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Background. The COVID-19 pandemic is expected to have a substantial impact on people with an intellectual disability. The goal of the current study was to explore the experiences and needs of people with a mild intellectual disability during the COVID-19 lockdown period in the Netherlands.
Method. A descriptive qualitative methodology was conducted, using semi-structured individual interviews with six people with a mild intellectual disability. Data were analysed thematically.
Results. Three overarching themes were found: (i) Missing social contact and having people close; (ii) Being housebound has changed my daily life; and (iii) Hard to understand the preventive measures.
Conclusions. Important insights into the experiences and needs of people with a mild intellectual disability during the COVID-19 lockdown period were gained. These insights are valuable with respect to a potential second COVID-19 wave or a future infection-outbreak.

KEYWORDS: intellectual disability, COVID-19, corona, pandemic, experiences of people with a mild intellectual disability

The present COVID-19 pandemic is a severe health threat to millions of people around the world and has a huge impact on their lives. In an attempt to control this pandemic, countries worldwide have taken measures to protect their citizens from COVID-19, such as the closure of public places (e.g. cafes, cinemas, schools and museums), instructions to stay at home and keep social distance, and quarantine in the case of infection (World Health Organization 2020). These measures have had considerable impact on people with an intellectual disability (Courtenay 2020). The loss of work or day time activity may have had a particularly significant impact on them, due to the lack of other purposeful activities in their lives (Lysaght *et al.* 2009, 2017). It is assumed that further distress may have been caused because people with an intellectual disability failed to understand the measures or what their purpose was (Courtenay 2020).

Nevertheless, based on anecdotal information, the picture that is emerging is not simply a negative one (Hughes and Anderson 2020). For example, several

intellectual disability organisations have reported a decrease in challenging behaviour displayed by people with an intellectual disability, possibly due to more stability in staff teams (Rose et al. 2020; VGN 2020). In addition, several organisations have reported that people with an intellectual disability are more settled and relaxed than they were before the COVID-19 pandemic (Hughes and Anderson 2020). Despite assumptions and anecdotal observations about the potential challenges and gains experienced by people with an intellectual disability, with regards to the COVID-19 pandemic, empirical research is lacking. Research is needed to gain insight into the impact of COVID-19 on the lives of people with an intellectual disability and to explore their needs. Therefore, the aim of this paper is to explore the experiences and needs of people with an intellectual disability with respect to the COVID-19 pandemic. In this study, we will focus on the experiences and needs of people with a mild intellectual disability with a (paid) job during the initial stage of the lockdown in the Netherlands, which took place between March 15 and May 11.

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Table 1 Demographic Information of the participants

Pseudonym	Gender	Age	Marital status	Living arrangements	Work situation
Adam	Male	58	Widower	Individual apartment in supported accommodation in community	Part-time volunteer work (3 days a week)
Bobbi	Female	49	Single	Independent in community	Part-time volunteer work (4 days a week)
Chloe	Female	51	Single	Individual apartment in supported accommodation in community	Full-time volunteer work
Daisy	Female	42	Single	Independent in community	Part-time volunteer work (3.5 days a week)
Emily	Female	26	Partner	Individual apartment in supported accommodation in community with partner	Part-time volunteer work (4 days a week)
Freddie	Male	26	Single	Independent in community	Part-time volunteer work (3 days a week)

Method
Participants
A sample of six people with an intellectual disability were interviewed. The inclusion criteria were: (a) aged $\geq$ 18 years, (b) having a mild intellectual disability, (c) receiving community supported living arrangements, (d) having a (paid) job and (e) being able to talk about their feelings and experiences. Demographic information, provided by the participants themselves after the interview, are presented in Table 1, with pseudonyms used for all participants to protect confidentiality.

Procedure
Ethical approval was provided by the Ethics Review Board of Tilburg University (RP149). A purposive sampling procedure was used; recruitment was carried out amongst the employees of the Dutch advocacy group for people with an intellectual disability. The coaches of this advocacy group identified six individuals that met the inclusion criteria. The second author (KvB) contacted these potential participants by phone and gave them further details about the study. She also sent them the study information sheet. All six individuals voluntarily agreed to take part in this qualitative study and provided informed consent.

Interview
A semi-structured interview guide was developed to explore the participants' experiences and needs during the lockdown period. This guide consisted of three main topics: (1) the impact of the measures to prevent the spread of COVID-19; (2) perceptions of family and professional support; and (3) the fear of the disease itself, and themselves or loved ones catching it. Interviews lasted between 16 and 36 min. These topics were introduced by four brief questions: How was your day today? Can you tell me about what you have been doing today? Can you tell me about any problems you have had to deal with today? What went well today?. The entire interview guide can be requested from the authors.

All participants were interviewed during the lockdown period in the Netherlands, which took place from March 15 to May 11. During this period, schools and public places were closed, as well as work and day services for people with an intellectual disability. In addition, professions that require physical contact, such as hairdressers, beauticians, and dentists, were forced to close. Moreover, people were instructed to stay at home and maintain social distance from other people when outside their home. Compared to other countries, the lockdown period in the Netherlands was relatively mild. That is, most other European countries introduced stricter measures, such as the severe limitations of movement in Italy and Spain, only allowing vital, certifiable work situations and emergencies or health reasons.

Due to the COVID-19 pandemic, the interviews were conducted via video conferencing facilities. Although the researchers would have preferred to carry out face-to-face interviews, telephone interviews have been found to generate data of comparable quality (Braun and Clarke 2013).

Data analysis
In accordance with a constructivist approach, the analyses tapped into the sense that the participants made of their experiences of COVID-19. Inductive thematic analysis was used to identify themes (Braun and Clarke 2006). After reading the transcripts from all interviews in detail, two authors (MV and MT) independently coded the data that were deemed to be relevant to the current study. Disagreements were discussed with the first author (PE). The next step was to group related codes into potential themes (MV and MT). Subsequently, five authors (PE, NF, MV, MT and AJ) jointly reviewed the themes in order to ensure that (i) the codes in each theme were coherent, and that (ii) the codes in different themes could be clearly distinguished. Finally, the themes were defined and named by two authors (MV and MT) and a narrative structure with accompanying descriptions was produced by all authors.

Results
After analysing the interviews, three overarching themes emerged: (i) Missing social contact and having

people close; (ii) Being housebound has changed my daily life; and (iii) Hard to understand the preventive measures.

Overarching theme I: Missing social contact and having people close

Participants said that they missed social contact and being able to see their family, friends and colleagues in person. As a result, they started using video conferencing as an alternative way of maintaining contact. However, the experiences with this technology differed across participants. Although Emily and Daisy found video conferencing impersonal, they still felt that it was a good way to keep in touch with family and colleagues during the COVID-19 pandemic. Daisy, for example, used to make vlogs along with a colleague, a peer with an intellectual disability she was friendly with, and they started doing this via video conferencing facilities instead of face-to-face. Daisy said that she still had a lot of fun making the vlogs with her colleague. In contrast, Freddie and Chloe found it difficult to maintain their social contacts remotely. Freddie greatly missed physical contact, cuddling people and giving them a pat on the back. He found social distancing to be odd and unpleasant. When face-to face contact was not possible, Freddie preferred texting to video conferencing, which made him feel insecure. As Freddie explained:

> "When you're making video calls you can only see someone on a screen, but when you're talking to each other you see the person in front of you and that feels much more comfortable and then you can understand each other much better."

Chloe also missed seeing her colleagues and felt a lack of engagement or sense of connectedness with them. Although remote communication made her feel less lonely, it heightened her feeling of distance from other people. She wanted to have more contact with her friends and colleagues from work but struggled to make this happen and felt her efforts were not reciprocated:

> "I do miss a little commitment and a little connectedness. At a distance from each other then it's more distant and I don't know, I don't like that, I just want to see them in person. (…) I therefore feel a little underprivileged, I don't feel comfortable with that. (…) Yes, I do call my colleagues, but I don't really get feedback. Maybe they're also searching, that they find it hard themselves. I'm just very open and honest with myself and I try to involve people in my life, but I just find that difficult, it doesn't work out'.

Theme II: How being housebound has changed my daily life

Being housebound had a major impact on the lives of the participants. The participants missed the opportunity to go outside to take part in activities and found it difficult being at home most of the time. Adam, for example, normally liked to go outside and meet people. He became bored:

> "Yes, I do know how to fill in my time. Playing video games for example and watching the television. But you know, at some point, yet get a little tired of just sitting at home."

Moreover, participants noticed that they had to adjust their daily routine, which was easier for some participants than it was for others. Bobbi, for example, found it difficult to be housebound and felt as if the walls were closing in on her. She indicated that she needed daily structure to get her out of bed in the morning and worried about how the COVID-19 pandemic would evolve. Freddie did not like working from home. He found it confusing and admitted he would rather be watching videos. In contrast, Daisy found working from home beneficial because she could organise her working day in her own way. As she explained:

> "Well, I have some physical health issues. It is good for me to lie down a couple of times a day. When I have to work at the office, I cannot do this. But now, when I'm working from home, I can, which is good for my physical health."

Theme III: Hard to understand the preventive measures

The changes in public life and the new rules associated with the COVID-19 pandemic provided challenges for participants. They talked about practical issues, for example, how to manage their daily food shopping and how to keep a safe distance when visiting family, to prevent them from becoming infected. In addition, participants had a hard time understanding all the rules imposed by the government and dealing with the changes in acceptable public behaviour, and experienced anxiety and stress as a result. For example, Bobbi sometimes found it difficult to properly understand and apply the new rules. Although she wanted to keep herself informed about the situation by regularly watching the news reports, she experienced a lot of confusion and stress due to the large amount of information and the use of difficult language. For instance, when she visited the pharmacy to pick up her medication, Bobbi was unaware of the specific rules that were in place at the time:

> "I was then publicly confronted by another customer. He became angry as I was not following the rules. This made me feel very bad. I feel anxious that I might have to experience it again."

Participants also felt very responsible for their own health and that of others. For example, although Adam was disappointed about the fact that he could not do his own shopping because he belongs to the high-risk group, he let his family do his shopping for him to keep safe. Freddie thought carefully about whether or not it was necessary to go outside or use public transport. He chose to avoid travelling on public transport in order to leave the space for people working in key professions. Moreover, he stopped inviting friends to his house:

> "I don't invite other people to my house anymore, because you don't know where others have been. I do not want to infect others, especially my parents. I sometimes go to my parents, I will soon install a TV at my father's house. I want to be able to keep doing that, and inviting friends over only increases the risk that I might infect my parents."

Discussion

In the interviews, the participants talked about missing the company and being close to loved ones and people they had close relationships with. They also talked about how their lives had changed because they were housebound due to the COVID-19 restrictions. Their experiences are comparable to people without intellectual disabilities. For example, in their study with older adults, van Tilburg *et al.* (2020) reported increased levels of loneliness and reports of worry about the pandemic. Similar findings were obtained by Tull *et al.* (2020), from their nationwide community adult sample. They also reported increased loneliness and greater health anxiety. Due to the preventive measures, the participants of the current study were no longer able to go to their work and undertake activities with their family, friends, or colleagues. As a result, there was a loss of structure and daily routine. In addition, there were the added difficulties of understanding and applying the new rules. One immediate action would be to make more accessible information available to people with an intellectual disability (Chinn and Homeyard 2017). For example, it would be beneficial for people with an intellectual disability to have an easy read and accessible website with up-to-date information about COVID-19, using both text and images.

All participants in the current study were engaged in voluntary work roles. Employment can provide an important opportunity for social inclusion for people with an intellectual disability (Lysaght *et al.* 2017) and is associated with improved physical and mental health, increased quality of life, and provides structure and routine to daily life (Jahoda *et al.* 2008; Lysaght *et al.* 2009). The sudden loss of a job due to the COVID-19 pandemic may have had a significant impact, especially for people with an intellectual disability who are known to have relative small social networks (van Asselt-Goverts *et al.* 2013). Therefore, it should be considered how they could be supported to work from home, as persons without intellectual disabilities have had the opportunity to do. This would be especially important in the case of a potential second COVID-19 wave or another future outbreak of infection.

A limitation of the current study is that participants all had a mild intellectual disability and had voluntary work roles. It is likely that participants in this study were therefore better connected and supported than many of their peers with intellectual disabilities. In addition, although the number of participants of our study meets the recommendation of Braun and Clarke (2013), our sample was relatively small due to the difficulties of conducting this type of research in the current circumstances. It would be important to try to recruit a larger number of participants in future studies. Moreover, the participants in this study were probably also more technically skilled and more capable to use the Internet and video conferencing facilities than many people with intellectual disabilities. It would be important for future research to try to capture the experience of a wider group of people with intellectual disabilities as the situation with the pandemic unfolds. Although worthwhile insights were obtained that could be helpful for future potential lockdowns, it is likely that some preventive measures (e.g. keeping 1.5 m distance from each other) will remain in place for as long as there is no vaccine. Therefore, the present authors will follow-up the current participants throughout the upcoming year to explore whether their experiences change as Government and societal responses to the COVID-19 pandemic evolve.

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