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Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: A thematic analysis

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Abstract

Background: The present study aimed to explore the experiences and needs of direct support staff during the initial stage of the COVID-19 lockdown in the Netherlands.

Method: Overall, eleven direct support staff were recruited from five intellectual disability services to participate in this descriptive qualitative study. They recorded 34 audio messages during the considered period. Thematic analysis was used to analyse these audio recordings.

Results: Four themes emerged: (1) Emotional impact, which pertained to various emotions they experienced in their work; (2) Cognitive impact, which referred to challenges and changes they had undergone in their work; (3) Practical impact, which centred on the practical impact of the pandemic on their work; and (4) Professional impact, which concerned their experiences with other professionals.

Conclusions: This study provides valuable insights into the experiences and needs of direct support staff during the COVID-19 pandemic, which, in turn, can help inform practice in preparation for a second wave of COVID-19 or another future pandemic.

KEYWORDS

corona, COVID-19, experiences of direct support staff, intellectual disability

1 | INTRODUCTION

The World Health Organization has labelled the coronavirus disease 2019 (COVID-19) a global pandemic. Subsequent to its initial outbreak in China in December 2019, the virus, which is passed on by human-to-human transmission via either direct contact or small droplets (Lai, Shih, Ko, Tang, & Hsueh, 2020), has now spread worldwide. At the time of writing this article, there were over 13.8 million confirmed cases and over 580,000 deaths (World Health Organization, 2020a).

People in long-term care, including those with an intellectual disability, have been labelled as being especially vulnerable to COVID-19 (World Health Organization, 2020b). Although not everyone with an intellectual disability is more vulnerable, a higher proportion of people with intellectual disabilities also have underlying health conditions (Courtenay & Perera, 2020). Moreover, given that these individuals are both heavily reliant on daily physical support from relatives and professionals and invariably live in group settings, some individuals are at a higher risk of contracting the coronavirus (Tummers, Catal, Tobi, Tekinerdogan, & Leusink, 2020). In an attempt

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to reduce the risk of infections, manifold preventive measures have been adopted by the World Health Organization and countries across the globe, such as enjoining their citizens to stay at home and engage in social distancing in public spaces; closing public places such as restaurants, sport facilities and schools; and significantly reducing the usage of public transport. In addition to these measures, many support services for people with intellectual disabilities have introduced strict measures for face-to-face contact with relatives, while work and day services for people with intellectual disabilities have been closed (World Health Organization, 2020b). While the measures introduced to reduce infection levels have evidently had a profound impact on the daily lives of many people with intellectual disabilities (e.g. increased experiences of distress, agitation and loneliness; Courtenay, 2020), they have also impacted greatly upon the work of direct support staff in this area.

In normal circumstances, direct support staff working with people with intellectual disabilities often encounter various psychological challenges—especially when working with service users who frequently display challenging behaviour—including an increased risk of work-related stress and anxiety, burnout and feelings of depersonalization, irritation and emotional exhaustion (Edwards & Burnard, 2003; Jenkins, Rose, & Lovell, 1997; Mitchell & Hastings, 2001). This derives from challenging client behaviour, interpersonal issues with colleagues and organizational concerns (Mutkins, Brown, & Thorsteinsson, 2011). In a labour market already characterized by the increased scarcity of (qualified) social care professionals (Kroezen, van Hoegaerden, & Batenburg, 2018), understaffing due to COVID-19 poses even more demands. Moreover, increased agitation and distress among people with intellectual disabilities as a result of the current restrictions may raise additional challenges for direct support staff, especially if these service users do not understand the significance of these measures. However, in practice, the picture that is emerging from a variety of intellectual disability services is not a wholly negative one. For instance, although some services for people with intellectual disabilities in the Netherlands have reported increased absence and sickness rates among direct support staff, others have reported a considerable decrease (VGN, 2020). In addition, some intellectual disability services have reported a reduction in challenging behaviour by people with intellectual disabilities, in part, due to greater stability in staff teams due to the closing of work and day services. While some study protocols have been published that explore the impact of the COVID-19 pandemic on individuals with intellectual disabilities as well as their caregivers via an anonymous online survey (Linehan et al., 2020), hitherto no research has been conducted which explores the potential challenges and benefits to direct support staff. In the light of this lacuna in extant research, in their rapid review of studies that examined long-term care staff, Embregts, van Oorsouw, and Nijs (2020) identified potentially useful insights from previous infection outbreaks, which encompassed three themes: emotional responses (i.e. fears and anxieties, stress, tension, confusion and no supplementary challenges); ethical dilemmas (e.g. locking doors to prevent wandering service users infecting others); and work attendance (i.e. refusal

and exclusion of service users). The recommendations identified by the authors to better support and protect long-term care staff centred on housing and materials, policy and guidelines, education and the provision of information (Embregts, van Oorsouw, et al., 2020). Although their rapid review provides valuable insights, the studies they considered solely examined long-term care staff working with the elderly; hence, studies about direct support staff working with people with intellectual disabilities were not included in their review.

Consequently, research into the potential challenges and benefits generated by the COVID-19 pandemic for direct care staff working with people with intellectual disabilities is urgently needed. Indeed, the experiences and needs of direct support staff simply cannot remain unexamined in relation to either current or future infection outbreaks. Therefore, the aim of the present descriptive qualitative study is to identify the experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic. More specifically, the study focuses on their experiences and needs during the initial stage of the lockdown in the Netherlands, which covered the period between 15 March and 11 May 2020. The study is underpinned by the following research question: “What are the experiences and needs of direct support staff working with people with intellectual disabilities during the initial COVID-19 lockdown in the Netherlands?”

2 | METHOD

2.1 | Design

A descriptive qualitative study design was used to capture the experiences of direct support staff with respect to COVID-19. To capture these experiences, direct support staff were invited to record weekly audio messages.

2.2 | Participants

Fourteen intellectual disability services in the Netherlands, which are all members of the Academic Collaborative Centre Living with an intellectual disability at [Tilburg University], were invited to participate in this study. In the relatively short space of time in which the study was conducted, five services responded promptly to express their interest in participating. Hence, direct support staff were recruited from these five intellectual disability services. All direct support staff who were working with people with intellectual disabilities, irrespective of their level of intellectual functioning, in any of these five intellectual disability services were eligible to take part in the study. Participants were recruited using convenience sampling via the managers of the respective intellectual disability services, who subsequently invited eligible direct support staff to take part by email or telephone. Eligible direct support staff were provided with an information sheet that explained the nature and purpose of the study, before being asked to indicate whether they were interested

in participating. Those who expressed an interest in doing so were contacted by the third author (NF) to provide written informed consent and to make arrangements about data collection.

In total, eleven participants (eight women; three men) recorded audio messages for the study. They had a mean age of 41.7 years ($SD = 12.5$, range: 22–59). On average, they had worked within the field of intellectual disabilities for 19.8 years ($SD = 11.8$, range: 4–41), with 7.7 years ($SD = 9.3$, range: 1–25) of experience in their current job. Two of them worked with people with mild intellectual disabilities, one with people with moderate intellectual disabilities, and seven worked with people with severe intellectual disabilities to profound intellectual and multiple disabilities, while one participant worked with people with various levels of intellectual disabilities. All direct support staff worked in residential support service settings, which housed up to 16 service users per unit. They ordinarily worked day and evenings shifts; however, based on anecdotal information, the direct support staff indicated that they were working longer hours during the COVID-19 pandemic and, in some cases, had more shifts due to the closure of work and day services usually attended by people with intellectual disabilities. The extent to which this occurred differed across both the week and the direct support staff.

2.3 | Materials and procedure

Given that the aim of this study was to identify the experiences and needs of direct support staff during the initial COVID-19 lockdown in the Netherlands (which lasted from 15 March to 11 May 2020), participants were invited to record weekly audio messages during this period. The present authors decided to use audio messages, which are comparable to self-recorded diaries whereby direct support staff self-recorded their experiences with respect to the lockdown period, as the method of data collection rather than conducting semi-structured interviews towards the end of the lockdown, because the latter rely on the retrospective capacities of the participants, which may be subject to recall bias. The risk of potential recall bias has been found to increase in crisis situations (Singh & Wilkes, 1996), such as the COVID-19 pandemic, and hence, for the purposes of this study, audio messages were deemed to constitute the most reliable data. Moreover, various healthcare professionals and managers indicated that this method was the most convenient for the participating direct support staff, who were already exceptionally busy during pandemic, insofar as they were able to determine for themselves when they wanted to record the audio messages. Although the use of audio recordings prevented us from posing follow-up questions, the participants were clearly instructed in advance to describe as many details and feelings as possible in their audio recordings. Furthermore, in the third week of data collection, the authors also engaged in brief telephone conversations with all of the participants to reiterate these instructions.

In addition to the four brief questions that served as a guideline for their reflections in each of the audio messages (How was your day today? What have you been through today? What did you

encounter today? What went well today?), the participants were asked to explicitly reference the period immediately prior to the COVID-19 pandemic when reflecting on how they were experiencing the current situation. The audio messages were recorded at the end of the working day at times which were convenient for the participants. All the audio messages were transcribed verbatim, and the participants were anonymized. Overall, there were 34 recorded audio messages for all of the participants, with a mean duration of 4.9 min (range: 2–17). The amount of recorded audio messages for each participant ranged from 1 to 7 (mean: 3.3).

The audio messages were recorded during the initial lockdown period in the Netherlands, which lasted from 15 March to 11 May. This phase of the lockdown was relatively relaxed insofar as it was only the most fertile locations for COVID-19 to spread that were closed or shut-off to the general public, namely schools, sports clubs and public places, such as cafes, restaurants, hotels, cinemas and museums. Contact professions, such as hairdressers, nail studios and physiotherapists, were also closed. Furthermore, public transport ran on a scaled-down timetable with night trains and most intercity services being cancelled. Although some shops decided to close temporarily, they were allowed to open provided they followed strict instructions and restricted the maximum number of visitors. In addition, people could go out for a walk or visit others—provided they did so with no more than two persons together and retained a 1.5-metre distance at all times. Fines were introduced of up to €400 for individuals and €4,000 for companies who failed to comply with these measures.

2.4 | Analyses

In accordance with a constructivist approach, the analyses tapped into the sense that direct support staff made of their experiences of COVID-19. The audio messages were amalgamated into one transcript per individual and analysed using thematic analysis (Braun & Clarke, 2006), which is a method for identifying, analysing and reporting patterns in data. The thematic analysis used to analyse the audio messages in this study comprised a six-phase process (Braun & Clarke, 2006). First, two authors (TT and NF) carefully read through the verbatim transcriptions of the audio messages in detail to familiarize themselves with the data. Second, initial codes were inductively generated based on phrases that were of clear importance for the study (i.e. related to the experiences of direct support staff working during the COVID-19 pandemic). That is to say, there were no prior assumptions or particular theories that were guiding this initial coding phase, which was conducted by the second and third authors (TT and NF). The inter-rater reliability between these two sets of initial coding was calculated, resulting in an 85.5 per cent level of agreement. Any disagreements were discussed with the first author (PE), before an agreed version of the final set of codes was established. Third, all of the codes ($N = 484$) were grouped together by similarity and then subsequently collated into potential themes. Codes that were wholly unrelated to the aims and objectives of the study were discarded into a miscellaneous category (e.g. staff

comments on the butcher's delivery to the service). This procedure was performed by both the second and third authors (TT and NF). Fourth, all authors (PE, TT and NF) jointly reviewed the themes for internal homogeneity (i.e. the degree to which the codes in one theme cohered in a meaningful way) and external homogeneity (i.e. the degree to which the codes in different themes could be clearly distinguished from one another). Fifth, the themes were defined and named by the second and third authors (TT and NF), before a narrative structure with accompanying descriptions was subsequently established in close collaboration with all of the authors (PE, TT and NF). Finally, a scholarly report of the thematic analysis was jointly produced by all the authors, in conjunction with vivid and compelling extracts from the participants.

2.5 | Ethical considerations

Ethical approval for this study was granted by the Ethics Review Board of [Tilburg University, the Netherlands] (RP149). In consultation with the Ethics Review Board and the data representative of [Tilburg University], all audio messages were sent by email to the third author, before then being safely stored on a secure server of [Tilburg University]. The anonymity of the participants was retained by concealing their names in the data via the use of pseudonyms.

3 | RESULTS

The thematic analysis identified four distinct overarching themes: *Emotional impact*, *Cognitive impact*, *Practical impact* and *Professional impact*. The overarching themes were divided into twelve subthemes, which are displayed in Table 1. In addition to this, Table 1 also provides the number of codes for each theme/subtheme and indicates how many participants contributed to each theme/subtheme.

3.1 | Overarching theme 1: Emotional impact

This first theme reflects the various emotions that the direct support staff experienced in their daily work during the COVID-19 pandemic.

3.1.1 | Subtheme 1.1: The fear of becoming infected

Direct support staff described at great length their profound fear of becoming infected with COVID-19. Although this fear was present during the entire period of data collection, the direct support staff primarily mentioned it at the beginning of the COVID-19 pandemic. At that time, protective equipment was only available for those working with people with intellectual disabilities who

Theme	Subtheme	Number of codes	Number of participants that contributed to the subtheme
Emotional impact	The fear of infection	63	9
	Frustration and disappointment	13	5
	Sense of responsibility	10	5
	Overwhelmed with emotions	55	10
	Total	145	10
Cognitive impact	Coping	19	7
	Reflection	18	7
	Problem-solving attitude	27	7
	Perseverance	13	6
	Total	77	11
Practical impact	Impact of preventive measures	90	11
	Experiencing time pressure	79	9
	A lack of face-to-face team meetings and increased use of digital consultation	25	4
	Total	194	11
Professional impact	Cooperation and connectedness between support staff and other professionals	68	9

TABLE 1 Distribution of the 484 codes across the themes and subthemes

were officially diagnosed with COVID-19. Given the long incubation time of the virus, however, direct support staff worried that they, in fact, may have unknowingly been working with people who were infected with COVID-19, and, hence, had done so without adequate protective equipment. This manifested in a fear that they themselves would become infected, but they were also scared that they would infect their own family and friends when working without any protective measures against COVID-19. To reduce the risk of infection, direct support staff sometimes went to great lengths at home, by, among other things, retaining their distance from partners and children. In some cases, both the direct support staff and their partners worked with people with intellectual disabilities. In the following extract, one direct support staff member shared his fear that both he and his partner would get infected with COVID-19:

My biggest fear is that my partner and I will both become infected with the coronavirus. In that case, I don't know what to do with our children.

[Direct support staff 9]

One particularly complicated situation for direct support staff was the contrast between the “inside world” (i.e. the healthcare organization) and the “outside world” (i.e. the world outside the healthcare organization). More specifically, they were struck by the fact that, on the one hand, they had close contact with potentially infected people with an intellectual disability without wearing any protection, while, on the other hand, still having to function with the outside world and introduce very strict measures to avoid any contamination. In this respect, direct support staff were afraid to act as a bridge between these two worlds, in which one could infect the other, which sometimes made them feel angry and misunderstood:

I find it difficult to relate myself between that inner world [of the healthcare organisation] that is actually open during work, and the open world [outside the healthcare organisation] that is actually closed, but this is the case in the whole world – the whole world is closed. That's tricky and difficult. How does that make me feel? Sometimes it makes me sad, sometimes it makes me angry, it makes me desperate, and I often feel misunderstood. People [not working in healthcare] live ‘safely’ and the present authors have to get out every day.

[Direct support staff 6]

3.1.2 | Subtheme 1.2: Frustration and disappointment

Some direct support staff were frustrated about the risk they were forced to take every day by working without protective equipment

with a population who did not always understand the severity of the situation, and, hence, did not always comply with the preventive measures. Furthermore, the fact that their well-established fear was not being recognized by the government, such as, for example, during the weekly COVID-19 press conferences by the Dutch government, frustrated the direct support staff. Indeed, they were deeply disappointed that the intellectual disability field was largely overlooked by the media. For example, as one direct support staff described, staff in hospitals received many gifts from business communities, whereas staff in the intellectual disability field were simply invisible:

Talking about appreciation, ha, funny to mention. My wife who works in the hospital comes home almost every day after work with flowers, mugs, plants, chocolates, and more of those things – gifts. All donated by the business community to our heroes in healthcare. The present authors in the intellectual disability field do not see generous donors waiting to shower us with praise.

[Direct support staff 1]

3.1.3 | Subtheme 1.3: Sense of responsibility

Direct support staff described feeling a great sense of responsibility towards the vulnerable people that they were supporting during the COVID-19 pandemic. This sense of responsibility pertained to both the physical and mental well-being of the people with intellectual disabilities that they support. More specifically, the direct support staff indicated that they did not want to have it on their conscience that people with intellectual disabilities could become infected as a result of their actions. Indeed, when people with intellectual disabilities did get infected, direct support staff invariably found it hard to let go of the situation when they were at home. As one direct support staff member noted:

They promised to let me know if the situation with the service user deteriorated or anything. Maybe I shouldn't ask, but well – if I don't ask, they won't inform me. But in my head, I will keep thinking about it anyway.

[Direct support staff 4]

As well as this, the direct support staff's sense of responsibility also extended to the possibility of preventive measures with regard to COVID-19 being relaxed. For example, they worried about potential new and unanticipated risks for people with intellectual disabilities when the lockdown measures were lessened. According to one direct support staff member:

The morning didn't start too bright for me, actually. That's not me, actually. But yes, the news [on the

easing of COVID-19 measures] again, thinking about my beloved work. Yes, the easing of the measures does not make me very happy.

[Direct support staff 6]

Finally, despite their expressed fear of becoming infected, the direct support staff clearly stated that when an individual with an intellectual disability was infected with COVID-19, they felt responsible to support that person as best as they possibly could. They also tried to involve the stricken individual's family members as much as possible by calling them regularly for an update or by, for example, facilitating a video call between the infected person and their family.

3.1.4 | Subtheme 1.4: Overwhelmed with emotions

As well as the fear of becoming infected, frustration and disappointment, and the profound sense of responsibility they felt to service users, direct support staff also experienced emotions that could fluctuate sharply across the course of the day. For instance, on the one hand they described being excited when a service user or colleague was cured of COVID-19 or when management showed their appreciation to them for their efforts. Direct support staff also reported being enthused when family members of individuals with intellectual disabilities made small, heart-warming and loving gestures:

A service user's sister has sent post cards. Super sweet. Yes, to every service user in the group home. The warmth, love, and creativity that comes with it at the moment, yes, that's very touching to see.

[Direct support staff 4]

On the other hand, however, direct support staff also described feelings of sorrow and suffering when they saw that people with intellectual disabilities missed their parents, or, alternatively, worried that direct support staff, other people with an intellectual disability or family members might become infected and, as a result, pass away. When an individual with an intellectual disability had become infected with COVID-19, other service users worried immensely about them, despite direct support staff trying to put them at ease:

... and with another service user, you could just see in her eyes that she was concerned. You can keep it so small, but the service users are extra sensitive to that, and they can tell from your face that it's serious, and you really can't hide it. That was very difficult, yes.

[Direct support staff 4]

3.2 | Overarching theme 2: Cognitive impact

The second overarching theme pertains to the challenges and changes direct support staff underwent in their daily work as a result

of the COVID-19 pandemic. This required direct support staff to display a wide repertoire of skills to handle new and often complex situations, namely coping, reflection, problem-solving and perseverance. The present authors describe each of these in turn below.

3.2.1 | Subtheme 2.1: Coping

Direct support staff described various coping strategies for handling stress during the COVID-19 pandemic. Specifically, some direct support staff reported seeking to neither talk nor think too much about COVID-19 during their daily work, and instead just simply focused on "doing their job." As one direct support staff member noted:

Yes, you start to think differently, like 'oh, a service user is coughing, what if he's infected with the coronavirus?' You should just not think about it because otherwise I think you're going to go crazy.

[Direct support staff 3]

In addition, direct support staff described using their common sense and talking about the situation with colleagues or people they felt comfortable with as alternative coping strategies. In this way, the direct support staff tried to gain perspective and avoid panicking.

3.2.2 | Subtheme 2.2: Reflection

Direct support staff described reflecting on the new situation and life in general during the COVID-19 pandemic, by, among other things, asking themselves what is truly essential in their lives. Furthermore, direct support staff reflected on positive things, such as the things they were still able to do or how lucky they were that no one with intellectual disabilities in their group home was infected or passed away of COVID-19. Finally, direct support staff reflected upon how they would uphold the recent positive developments and new-found knowledge when life returned to normal, such as the stronger degree of collaboration between group homes and day care facilities.

... I am asking myself, and I just don't know, like, okay, what if everything goes back to normal, can the present authors keep that sense of a 'we-feeling' and the extra activities that are being offered to the service users now? Can the present authors continue with this, or does it really depend on the corona mindset? That's an issue I'm dealing with right now.

[Direct support staff 7]

3.2.3 | Subtheme 2.3: Creativity

Working during the COVID-19 pandemic has necessitated direct support staff to come up with creative solutions and develop

alternative ways of meeting and arranging day programmes for people with intellectual disabilities who are unable to attend their regular day care facilities. As the COVID-19 measures were on the verge of being eased, support staff had to come up with innovative solutions to adhere to this new reality within the group home. For example, one group home turned their bicycle shed into a visiting area: two tables, separated by Plexiglas, which were decorated with plants and craftwork made by the service users themselves.

Now the present authors are discussing with the managers how the present authors can possibly arrange the family visiting. So we're asking our whole team for tips on how the present authors can have contact with family and people with intellectual disabilities at a safe, appropriate distance.

[Direct support staff 3]

3.2.4 | Subtheme 2.4: Perseverance

Direct support staff showed immense perseverance during this COVID-19 pandemic; indeed, they carried out their job despite the very real fear of contamination, considerable adaptation in the aftermath of COVID-19 measures and sometimes extra shifts as a result of staff shortages.

Some colleagues are ill for a long time already, so yes, the present authors don't know when they'll return. As a result, many shifts are still open, and the present authors try to fill them with the fixed support staff. But I've been working on a contract for 36 hr, so I sometimes have to work more.

[Direct support staff 3]

3.3 | Overarching theme 3: Practical impact

The third theme centres on the practical impact that COVID-19 had on the daily work of direct support staff. Although direct support staff reported a wide range of effects, such as people with intellectual disabilities not being able to attend their day care facilities anymore and having to use protective equipment, some of them also recounted that their job continued as normal and that they were able to provide support in much the same way that they usually did.

3.3.1 | Subtheme 3.1: Impact of preventive measures

Direct support staff described a wide range of additional procedures that they had to carry out when people with an intellectual disability became infected with COVID-19, namely that they had to wear protective equipment and provide extra medical care (e.g. measure

temperature and blood saturation). In addition, direct support staff had to retain a 1.5-metre distance from service users at all times. However, they stressed that doing so was almost impossible when working with people with intellectual disabilities. This was because, although direct support staff tried to keep their distance whenever possible, physical contact constitutes a significant part of their work and, as such, was inevitable. This was particularly the case for those direct support staff who were working with people with severe to profound intellectual disabilities, who require extensive support with eating/drinking and self-care.

And what keeps challenging me at work is the fact that the present authors cannot keep a 1.5-metre distance to others. Both in terms of care towards people with an intellectual disability, but also among colleagues if the present authors have to support or care for a person with intellectual disabilities together. Physical contact is simply inevitable then.

[Direct support staff 1]

Another impact of the COVID-19 measures on direct support staff working with people with mild-to-moderate intellectual disabilities concerned the difficulties they faced explaining the COVID-19 measures and the multiple iterations of these measures in the pandemic to these specific service users. One consequence of these difficulties was that direct support staff had to regularly encourage people with moderate-to-mild intellectual disabilities to adhere to the rules.

Slowly, by making many agreements with them, by speaking to them one-on-one, the present authors were able to explain what the present authors want to do if..., what the present authors should do if..., in order to limit or prevent coronavirus contamination as much as possible.

[Direct support staff 10]

3.3.2 | Subtheme 3.2: Experiencing time pressure

Direct support staff reported experiencing more time pressure during the COVID-19 pandemic for a variety of reasons, which, in turn, resulted in direct support staff working in their own time:

Days are often hectic these days. Because of the many gaps in the schedule, I worked with temporary direct support staff today. I knew that in advance, which is why I started 20 min earlier – voluntarily, in my spare time. This is to be able to read the reports properly, and to be able to start the day on time.

[Direct support staff 1]

As well as this, the additional time required for both extra medical procedures for people with intellectual disabilities who were infected

with COVID-19 and for applying the COVID-19 measures generally caused notable challenges for direct support staff, as time was already sparse due to the staff shortages:

Because the present authors only had four contact moments a day with the infected service users, and you still want to give them the attention they need. This meant that you spent a lot of time taking care of one service user. Where you normally have the service users in a group, you now had to sit one-one-one with the service user in their bedroom. When you're done, after 45/60 min, you first have to disinfect everything as well.

[Direct support staff 5]

Furthermore, people with intellectual disabilities were not permitted to go to their day care facilities due to the COVID-19 measures, so direct support staff who worked at the group homes also had to provide day care activities. At the same time, day care facility staff were seconded to group homes, but this did not result in there being enough staff to cover all the daily shifts. In combination with the staff shortages, the direct support staff in the group home worked both longer (extra) shifts and in their own time. Conversely, people with intellectual disabilities did not have to be transferred to their day care facilities, which, in turn, resulted in more time for the direct support staff to engage in other activities.

To ease the pressure on the daily schedule of the support staff, service providers decided to postpone most of the overarching coordination tasks of key support staff to a later date. However, precisely when this later date would be remained unclear. Although key support staff understood this decision, most of them were also concerned about how they maintain good quality care in the long term, when the focus was solely on providing daily support. Therefore, some key support staff once again used their own time to continue to complete the most important coordination tasks:

And now that my work is under pressure, I often answer my email from home, in my spare time. This is far from ideal, but it gives me a bit of peace that the most necessary communication continues.

[Direct support staff 1]

3.3.3 | Subtheme 3.3: A lack of face-to-face team meetings and increased use of digital consultation

In accordance with the COVID-19 measures, all team meetings were either cancelled or took place digitally. When the meetings were cancelled, direct support staff noticed that they missed being able to coordinate with their colleagues on how best to support service users. Nevertheless, they were also hesitant about digital team meetings, on the grounds that they were often ineffectual due to

the fact that people either talked at the same time or failed to add anything of substance to the meeting:

These [team meetings] will probably take place digitally in small groups, because Skyping with 20 colleagues at the same time, that will probably end up with everyone constantly talking and shouting over each other.

[Direct support staff 1]

On the other hand, digital modes of communication (e.g. Skype, Zoom and Microsoft Teams) were widely used by direct support staff for consultation with colleagues, conversations with people with intellectual disabilities and their relatives, as well as to carry out administrative tasks from their own home. Their experiences of digitally communicating with people with intellectual disabilities varied greatly. As one direct support staff member put it:

What is interesting is that some people with an intellectual disability with whom I have video calls experience it as very unrestricted and less intimidating than face-to-face conversations. That is, some service users consider it to be convenient not to have direct eye contact. On the other hand, other people [service users and staff] miss the physical contact, me included.

[Direct support staff 2]

3.4 | Overarching theme 4: Professional impact

Direct support staff worked together with many different groups of people during the COVID-19 pandemic, reporting both positive and negative experiences of doing so.

3.4.1 | Subtheme 4.1: Collaboration and connectedness between support staff and other professionals

Despite the reported fear, time pressure and frustrations, direct support staff described that they were satisfied with the level of collaboration in their team. Indeed, a positive atmosphere and feelings of connectedness with their colleagues were cited. However, there were some preconditions for this strong collaboration to function: no COVID-19 infections in the group home, not too many gaps in the work schedule and working with familiar colleagues (no temporary support staff):

Well, tonight the present authors were lucky to work with four permanent and trusted team members, and it's nice to work like this. The present authors are well

attuned to each other, so the evening programme went smoothly.

[Direct support staff 1]

The collaboration between direct support staff from group homes and day care facilities was mostly reported as having been positive. A significant precondition for effective collaboration between these professionals was not to have too many direct support staff in one group home, especially in situations in which the communication between the two groups of direct support staff was suboptimal.

The contact between direct support staff and other professionals (e.g. psychologists, managers and doctors), was less frequent than prior to the COVID-19 pandemic. Direct support staff noticed that they had less time to deliberate with other disciplines, because they had to spend most of their time engaging in the direct care and support for people with intellectual disabilities. However, in those instances in which direct support staff noticed that professionals from other disciplines showed concern regarding their situation, they appreciated it very much:

It is very much appreciated that psychologists call. They [psychologists] shouldn't worry that their calls are inconvenient, because when that's the case the present authors [direct support staff] simply don't answer the phone. And uhm... the present authors always try to call the psychologists back if the present authors see that they have called.

[Direct support staff 2]

4 | DISCUSSION

In the present study, eleven direct support staff working with people with intellectual disabilities recorded weekly audio messages for the purposes of gaining insight into their experiences and needs during the initial phase of the COVID-19 lockdown in the Netherlands. The thematic analysis of the data identified four emergent overarching themes: *Emotional impact*, *Cognitive impact*, *Practical impact* and *Professional impact*.

In the audio recordings, the direct support staff discussed at considerable length how fearful they were of being infected with COVID-19. Most notably, in light of the long incubation time of the coronavirus, they were worried that they had unknowingly worked with people with intellectual disabilities who were infected with COVID-19 without adequate protective equipment, resulting in the dual fear of infecting both themselves and their family and friends. However, this fear appears to not be specific to COVID-19, but rather is a common feature of all epidemics/pandemics. In their rapid review of studies that focused on the psychological impact of epidemics and pandemics on the mental health of healthcare professionals, Stuijtzand et al. (2020) reported that healthcare professionals not only fear for the safety of those that they support, but rather also for their own health and that of their family members. The

direct support staff that took part in the present study described that this fear sometimes manifested itself in feelings of anger and frustration, which, in turn, deleteriously impacted upon their mental health. Previous studies lend support to this finding, insofar as they have shown that supporting service users during an epidemic or pandemic may negatively affect the mental health of care professionals themselves (Brooks, Dunn, Amlôt, Rubin, & Greenberg, 2018; Vyas, Delaney, Webb-Murphy, & Johnston, 2016). In particular, healthcare professionals are at an increased risk of psychological distress, alcohol/drug misuse, insomnia and symptoms of anxiety, anger, burnout, post-traumatic stress disorder (PTSD) and higher perceived stress (Embregts, van Oorsouw, et al., 2020; Stuijtzand et al., 2020). These mental health problems appear to be related to organizational, social, psychological and personal factors, which, in turn, potentially impede the quality of care and support provided to service users (Stuijtzand et al., 2020). It should be noted, however, that although the rapid reviews by both Stuijtzand et al. (2020) and Embregts, van Oorsouw, et al. (2020) provide relevant insights with respect to the explanatory factors behind the mental health problems of healthcare professionals in both general health care and long-term elderly care, there are hitherto no studies examining the direct support staff working with people with intellectual disabilities.

Notwithstanding the fears expressed by direct support staff of being infected with COVID-19, they also noted that they felt a sense of responsibility to continue the support they provide to people with intellectual disabilities. In order to continue to provide good support in challenging circumstances, they sometimes worked from home in their own time and/or began their shifts early to have more time to prepare and read all the reports carefully. At other times, based on anecdotal newspaper reports in the Netherlands, they have even gone so far as to "lock" themselves in the group homes to support service users 24/7, in order to reduce the risk of contamination for the people they support. This sense of responsibility for and loyalty to their service users speaks to the vital role that direct support staff play in the lives of people with intellectual disabilities. A high-quality interpersonal relationship between staff and service users, of which compassion and considerate involvement are two key components, is obligatory for good quality care and effective support (Hermesen & Embregts, 2015), which, in turn, helps to prevent lonesomeness and (mental) health problems (Bigby, Clement, Mansell, & Beadle-Brown, 2009) and to positively impact upon the quality of life of the service users (Schallock, 2004). It would be interesting for future studies to address this issue in greater detail, as part of the challenge for direct support staff is the increased professional demands placed upon them at a juncture when both personal threats (to their health) and family stress are also eminent (Stuijtzand et al., 2020).

In addition to this, the direct support staff involved in the present study also stressed the importance of appreciation and communication. Specifically, they greatly appreciated it when other professionals, such as their manager or a psychologist, for example, expressed concern with their situation and contacted them to ask how they were doing. Moreover, clear communication from the healthcare organization was also noted to be of paramount

importance, specifically with respect to internal policy regarding visits and the use of protective equipment. Indeed, while communication is always important, this is especially the case in crisis situations (World Health Organization, 2020c). In many countries, healthcare organizations have organized COVID-19 crisis teams (World Health Organization, 2020c), to which employees can pose questions with respect to the COVID-19 pandemic and receive guidance about how to act in particular situations. These crisis teams are often also given the assignment to communicate the internal policy of their healthcare organization. To support these crisis teams in the Netherlands with any queries that were raised in this unique situation, researchers affiliated with the Dutch Association of Academic Collaborative Centres for Intellectual Disabilities jointly researched scientific knowledge on this subject and made this information available to healthcare practitioners. Initially, the questions from the crisis teams were answered using a standard scientific template, but in order to also make the results accessible and available to direct support staff, service users and their relatives, accessible summaries and easy-to-read summaries were also subsequently created (Embregts, Leusink, et al., 2020).

The present study has various implications for policy and practice. First, it is important to recognize the emotional impact of the COVID-19 pandemic on direct support staff working with people with intellectual disabilities. Paying attention to and acknowledging their fear of being infected is vital for both (local) governments and healthcare organizations, insofar as it is likely that this would have a positive effect on the continuity of the teams of direct support workers. Moreover, in accordance with Embregts, van Oorsouw, et al. (2020) recommendation, the provision of clear information from healthcare organizations and COVID-19 crisis teams is of paramount importance for assuaging these fears. For example, direct support staff need clear information so as to be able to work more effectively with preventive measures (e.g. face masks, gloves and aprons) and cope with families that disagree with the visitor ban, but also in order to help eradicate unsubstantiated rumours about the lack of preventive measures. Second, the present research also has implications for aiding direct support staff in their transformed work environment. Specifically, this study has shown that working within the confines of the new preventive measures has had an enormous impact on their work, namely in terms of enhancing the time pressure they experience. To reduce this pressure, healthcare organizations decided to postpone most of the overarching coordination tasks performed by key support staff to an unspecified date. This decision led to concern among key direct support workers about how they could maintain good quality care in the long term. It is essential that healthcare organizations emphasize that direct support staff are not alone responsible for this endeavour and that they can count on the healthcare organization in general and on managers and psychologists in particular. Finally, given that the collaboration between direct support staff from group homes and day care facilities were mostly cited as being positive during the COVID-19 pandemic, it is important to jointly discuss how this positive change could be maintained in the near

future as and when service users return to their day care facilities. Establishing clear agreement and being receptive to each other's perspectives are important aspects in this respect.

Notwithstanding these implications, the present study should be interpreted with some limitations in mind. First, audio messages were used to collect the data. These audio messages are comparable to self-recorded diaries, whereby direct support staff self-recorded their experiences with respect to the COVID-19 pandemic on the basis of some brief questions that served as a guide for their reflections. This method of data collection was deemed to provide reliable data as a result of the reduced risk of recall bias, as well as being convenient for the participating direct support staff who were already exceptionally busy during this period, insofar as they were able to decide when to record the audio messages. While this prevented us from posing follow-up questions, the participants were nevertheless clearly instructed in advance to describe as many details and feelings as possible in their audio recordings. Moreover, in the third week of data collection, the authors briefly talked with all the participants over the phone to repeat these instructions. Second, although the findings of this study did not reveal differences between the participants based on age, gender or their current job experiences, this study had a small sample size, and, as such, it would be interesting for future research to study these potential demographic differences on a larger scale. Third, as with all qualitative studies, possible researcher bias could have occurred. To mitigate the effects of this bias, the analysis and interpretation of the research were subject to review by the research team. That is, the research team collectively reflected on and challenged the decisions and conclusions that were drawn from the data. Fourth, in line with the purpose of conducting qualitative research, the small sample size in the study raises the question of whether the current findings can be generalized. Moreover, it would have been interesting to explore the effect of confounding factors, such as the impact of COVID-19 on the personal and domestic lives of the direct support staff, on the findings of the present study. Hence, future research should seek to take these aspects into account. Finally, this study focused on the experiences and needs of direct support staff during the initial phase of the COVID-19 lockdown in the Netherlands. While the study provides useful insights for potential future lockdowns, it is safe to assume that the current pandemic will continue until a vaccine is found. Therefore, as a follow-up to the audio messages used in this study, direct support staff who took part in this study will be interviewed at various points in the next year to further inquire into some of the topics that emerged in the audio messages.

Despite these limitations, this study provides relevant insights into the experiences and needs of direct support staff working with people with intellectual disabilities during the initial phase of lockdown in response to the COVID-19 pandemic in the Netherlands. It would be valuable to develop an online survey, based on the findings outlined in this paper, and administer it to a large group of professionals, which, in turn, would result in more generalizable insights into the effects of the pandemic. This information would help governments and healthcare organizations prepare for and rapidly

intervene in the event of either a potential second wave of COVID-19 or a new infection outbreak.

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CONFLICT OF INTEREST

The authors declare not to have any conflict of interest.

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REFERENCES

- Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 363–376. <https://doi.org/10.1111/j.1365-2788.2009.01154.x>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brooks, S. K., Dunn, R., Amlöt, R., Rubin, G. J., & Greenberg, N. (2018). A systematic, thematic review of social and occupational factors associated with psychological outcomes in healthcare employees during an infectious disease outbreak. *Journal of Occupational and Environmental Medicine*, 60, 248–257. <https://doi.org/10.1097/JOM.0000000000001235>
- Courtenay, K. (2020). Covid-19: Challenges for people with intellectual disability. *British Medical Journal*, 369, m1609.
- Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of Psychological Medicine*, 1–6. <https://doi.org/10.1017/ipm.2020.45>
- Edwards, D., & Burnard, P. (2003). A systematic review of stress and stress management interventions for mental health nurses. *Journal of Advanced Nursing*, 42, 169–200. <https://doi.org/10.1046/j.1365-2648.2003.02600.x>
- Embregts, P. J. C. M., Leusink, G., Maes-Festen, D., Putten, A., Schuengel, C., & Sterkenburg, P. (2020). COVID-19 en de zorg en ondersteuning aan mensen met verstandelijke beperkingen: alleen samen krijgen de academische werkplaatsen de kennisvragen beantwoord [COVID-19 and the care and support for people with intellectual disabilities: only together can the academic workshops answer the knowledge questions]. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen*.
- Embregts, P. J. C. M., van Oorsouw, W. M. W. J., & Nijs, S. (2020). Impact of infection outbreak on long-term care staff: A rapid review on psychological well-being. *Journal of Long-Term Care*. 70–79. <https://doi.org/10.31389/jltc.40>
- Hermesen, M., & Embregts, P. J. C. M. (2015). An explorative study of the place of the ethics of care and reflective practice in social work education and practice. *Social Work Education*, 34, 815–828. <https://doi.org/10.1080/02615479.2015.1059804>
- Jenkins, R., Rose, J., & Lovell, C. (1997). Psychological well-being of staff working with people who have challenging behaviour. *Journal of Intellectual Disability Research*, 41, 502–511. <https://doi.org/10.1111/j.1365-2788.1997.tb00743.x>
- Kroezen, M., Van Hoegaerden, M., & Batenburg, R. (2018). The joint action on health workforce planning and forecasting: Results of a European programme to improve health workforce policies. *Health Policy*, 122, 87–93.
- Lai, C. C., Shih, T. P., Ko, W. C., Tang, H. J., & Hsueh, P. R. (2020). Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and corona virus disease-2019 (COVID-19): The epidemic and the challenges. *International Journal of Antimicrobial Agents*, 55, 105924.
- Linehan, C., Aranten-Bergman, T., Beadle-Brown, J., Bigby, C., Birkbeck, G., Bradley, V., ... Tossebro, J. (2020). COVID-19 IDD: A global survey exploring the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers. *HRB Open Research*, 3, 39. <https://doi.org/10.12688/hrbopenres.13077.1>
- Mitchell, G., & Hastings, R. P. (2001). Coping, burnout, and emotion in staff working in community services for people with challenging behaviors. *American Journal on Mental Retardation*, 106, 448–459.
- Mutkins, E., Brown, R. F., & Thorsteinsson, E. B. (2011). Stress, depression, workplace and social supports and burnout in intellectual disability support staff. *Journal of Intellectual Disability Research*, 55, 500–510.
- Schallock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48, 203–216.
- Singh, J., & Wilkes, R. E. (1996). When consumers complain: A path analysis of the key antecedents of consumer complaint response estimates. *Journal of the Academy of Marketing Science*, 24, 350.
- Stuijzand, S., Deforges, C., Sandoz, V., Sajin, C. T. C. T., Jaques, C., Elmers, J., & Horsch, A. (2020). Psychological Impact of an epidemic/pandemic on the Mental Health of Healthcare Professionals: A Rapid Review. *BMC Public Health*, 20, 1230. <https://doi.org/10.21203/rs.3.rs-30156/v1>
- Tummers, J., Catal, C., Tobi, H., Tekinerdogan, B., & Leusink, G. (2020). Coronaviruses and people with intellectual disability: An exploratory data analysis. *Journal of Intellectual Disability Research*, 64, 475–481.
- VGN (2020). *The effects of COVID-19 on direct support staff*. Retrieved from <https://www.vgn.nl/nieuws/laatste-nieuws-over-het-coronavirus>
- Vyas, K. J., Delaney, E. M., Webb-Murphy, J. A., & Johnston, S. L. (2016). Psychological impact of deploying in support of the US response to Ebola: A systematic review and meta-analysis of past outbreaks. *Military Medicine*, 181, e1515–e1531.
- World Health Organization (2020). *Guidance on COVID-19 for the care of older people and people living in long-term care facilities, other non-acute care facilities and home care*. Retrieved from <https://iris.wpro.who.int/bitstream/handle/10665.1/14500/COVID-19-emergency-guidance-ageing-eng.pdf>
- World Health Organization (2020). *Infection prevention and control guidance for long-term care facilities in the context of COVID-19*. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/331508/WHO-2019-nCoV-IPC_long_term_care-2020.1-eng.pdf?sequence=1&isAllowed=y
- World Health Organization (2020). *Risk communication and community engagement readiness and response to coronavirus disease (COVID-19): Interim guidance*. Retrieved from <https://apps.who.int/iris/bitstream/handle/10665/331513/WHO-2019-nCoV-RCCE-2020.2-eng.pdf>

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