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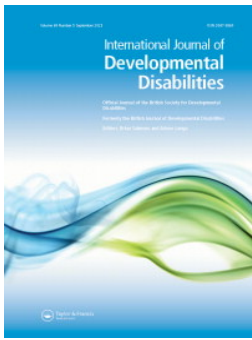
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# Providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic: experiences of direct support workers

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## Abstract

**Background:** Although the current preventive measures relating to COVID-19 can lead to challenges in the daily work of direct support workers (e.g. keeping 1.5 m distance), it remains vital to uphold the principles of person-centred care when working with older people with intellectual disabilities. The current study explores the extent to which direct support workers have been able to apply a specific form of person-centred care (i.e. integrated emotion-oriented care, or IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic.

**Method:** Six direct support workers from five facilities serving older people with intellectual disabilities in the Netherlands participated in this qualitative study. They participated in a two-hour focus group, which was transcribed verbatim, and the transcript was analysed thematically.

**Results:** Three themes emerged: (i) the negative impact of changes due to the COVID-19 measures on service users; (ii) the adaptation of direct support workers to changes due to the COVID-19 measures; and (iii) putting the needs and wishes of service users first.

**Conclusion:** This study provides first impressions into the experiences of direct support workers providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic.

**KEYWORDS:** Person-centred care; integrated emotion-oriented care; COVID-19; coronavirus; older people with intellectual disabilities; direct support workers

## Introduction

Since the start of the COVID-19 crisis, people with intellectual disabilities have been regarded as especially vulnerable to COVID-19 (World Health Organization 2020). For example, the greater prevalence of underlying health conditions in this population (Courtenay and Perera 2020), as well as to the fact that they often depend on daily support from professionals or relatives, which often takes place in close physical proximity (Tummers *et al.* 2020) leads to a greater risk of contracting the COVID-19 virus. To prevent the rapid spread of infection and serious illness, or even death,

many preventive measures have been adopted to daily life, including quarantine and other social distancing. In addition to these general measures, many support services for people with intellectual disabilities introduced strict measures for in-person contact with relatives, while their working and daytime services were closed (World Health Organization 2020). While the preventive measures obviously have had a great impact on the daily lives of many people with intellectual disabilities, including increased experiences of distress, loneliness and agitation (e.g. Courtenay 2020, Drum *et al.* 2021, Embregts *et al.* 2020), they have also had a major emotional, practical, cognitive and professional impact on direct support workers leading, among other things, to challenges and changes in their daily work (Embregts *et al.* 2021).

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Given that older people are at greater risk of more serious illness and death from COVID-19, the preventive measures are particularly restrictive for group homes accommodating older people, including those with intellectual disabilities (Garnier-Crussard *et al.* 2020). Preventive measures such as social distancing could lead to practical difficulties for both older people with intellectual disabilities and their direct support workers, especially in case there is a greater need for physical support. Furthermore, it is not inconceivable that the increased experiences of distress and loneliness of older people with intellectual disabilities due to restrictions on visiting of family members also impacts the dynamics between them and their direct support workers. For this reason, it has been particularly challenging for direct support workers to provide support to older people with intellectual disabilities during the COVID-19 pandemic (Vahia *et al.* 2020). The restrictions and social-isolation measures aimed at containing the virus are often at odds with the principles of person-centred care (Dichter *et al.* 2020). The World Health Organization (2018) defines person-centred care as care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health. Furthermore, person-centred care can be seen as a philosophical framework that guides delivery of healthcare and is based on individuals' values and preferences (Fazio *et al.* 2018). In the Netherlands, person-centred care is operationalised according to an approach known as integrated emotion-oriented care, or IEOC (van der Kooij 2014), which entails five intervention components: focussing on the perspective of service users, adjusting to the current needs of service users, connecting with service users, working in a safe and trusting team culture, and creating room for the informal networks of service users (Thalen *et al.* 2021). Despite the current COVID-19 preventive measures, it remains vital to uphold these principles when working with older people (Dichter *et al.* 2020). It is therefore important to arrive at a careful balance between infection management and person-centred care, in order to maintain the social participation, mental health and quality of life of older people with intellectual disabilities. To date, however, the extent to which direct support workers are able to apply person-centred care under the challenging circumstances resulting from the COVID-19 measures remains unclear. The current study therefore investigates the following research question: To what extent are direct support workers able to apply a specific form of person-centred care (IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic?

## Method

### Participants

A focus group interview was held with six female direct support workers from five geographically distributed residential care facilities for older people with intellectual disabilities operated by one large healthcare organisation in the Netherlands. At all five residential care facilities, IEOC was carried out. The inclusion criteria for the participants were (1) providing direct care to older people with intellectual disabilities and (2) applying IEOC for at least two years. After the focus group interview, demographic information (i.e. gender, age and working experience) and information regarding the level of disability of the service users was obtained from the participants by email. Three of the five residential care facilities had experienced internal outbreaks of COVID-19, and the direct support workers affiliated with these facilities thus had to cope with this situation. All participants were Dutch and their mean age was 37.3 years (SD = 13.7, range: 25–63). The participants had an average working experience of 13.6 years (SD = 9.2; range: 2–24) in the care of older people with intellectual disabilities and had been providing IEOC for an average of 6.9 years (SD = 8.2; range: 2–23). The service users of four of the participants had mild to moderate intellectual disabilities, those of one participant had moderate to severe intellectual disabilities, and the other participant worked with service users having various levels of intellectual disabilities.

The focus group was conducted on 4 February 2021 during the second lockdown period in the Netherlands (15 December 2020 to 5 June 2021). During this second lockdown, public places, schools, shops, and restaurants were closed, as well as working and daytime services for people with an intellectual disability. Moreover, citizens were obliged to wear a face mask outdoors for protection and always keep 1.5 m apart. Residential support services for people with intellectual disabilities only allowed face-to-face contact with relatives under very strict conditions and with a strict maximum of one person a day. The residential facilities included in this study which were affected by an internal COVID-19 outbreak were shut down immediately. Only direct support workers and physicians were allowed to enter and leave the facility when wearing fully protective equipment (e.g. masks and suits). In case an individual was infected with the COVID-19 virus, further restrictions such as room isolation (i.e. quarantine) were used.

### Procedure

Ethics approval was granted by the Ethics Review Board of Tilburg University (EC-2016.29). Participants were recruited using convenience sampling through the managers of five residential care facilities for older people with intellectual disabilities, in which care and

support is provided in accordance with the IEOC approach. The managers selected eligible direct support workers who had provided IEOC for at least two years to take part in an online focus-group meeting. After agreeing to transfer their contact details to the researchers, eligible direct support workers were contacted by the first author and provided with written and oral information about the nature and purpose of the study. They were also notified that their responses would be audio recorded and processed confidentially, and that they could withdraw from the study at any time. All six direct support workers voluntarily agreed to participate and provided written informed consent.

### **Focus group**

To address the current research aim and capture the experiences of direct support workers with respect to COVID-19 and applying IEOC, a qualitative descriptive study design was chosen. Focus groups are group discussions, led by an experienced moderator, supporting people to discuss different aspects of a particular topic in a focussed way (Krueger and Casey 2015). Group dynamics are one of the characteristics of a focus group interview; therefore, the type and extent of data obtained through a focus group is often deeper and richer than data obtained from a one-to-one interview (Rabiee 2004). The two-hour focus group was moderated by an experienced researcher (MT) with an overall understanding of the study to keep the sessions on track (Nassar-McMillan and Borders 2002) following the focus group design of Krueger and Casey (2015).

The focus group started with a brief introduction of the participants and a PowerPoint® presentation explaining the present study. Following this presentation, the researchers explored the extent to which the direct support workers felt that they had been able to provide IEOC to older people with intellectual disabilities in their daily practice during the COVID-19 pandemic. A semi-structured topic list had been developed for this purpose, consisting of topics to explore what the participants had perceived as difficult or infeasible, what they had done differently as compared to before the pandemic and what had gone well with regard to providing IEOC during the pandemic. Questions such as: “How did you continue to explore for the service users’ needs and possibilities? How did you connect with the service users? How did you meet the service users’ changing support needs? How did you manage to take the time to organize your work based on the wishes and needs of service users? All questions were followed by a number of follow-up questions, such as: When concentrating on this topic, what worked well in daily care and support for older people with intellectual disabilities during the COVID-19 pandemic and what did not? Why did it work well and why not? Compared to the period prior to the COVID-19 pandemic, what is

different in daily care and support for older people with intellectual disabilities? What remained the same? The focus group centred primarily on the first three interventions components of the IEOC approach (Thalen et al. 2021), which are directly related to service users.

Due to the COVID-19 pandemic and the corresponding preventive measures, the focus group was conducted using video-conferencing software (i.e. Zoom). Although we would have preferred to conduct this session in person, focus groups and interviews using video-conferencing software have been found to generate data of comparable quality (Braun and Clarke 2013) and have been assessed particularly relevant in the context of COVID-19 (Boland et al. 2021).

### **Data analysis**

The audio-recorded data were transcribed verbatim, and thematic analysis was used to identify themes (Braun and Clarke 2006). Thematic analysis is a method for identifying, analysing, and reporting salient patterns within qualitative data and is considered to be a useful method to examine participants’ perspectives, emphasising similarities and differences and generating unanticipated insights (Braun and Clarke 2006). After reading the transcript of the focus group in detail, three authors (MT, WvO and KV) independently and inductively coded the same 20% of the transcript by assigning codes to relevant data concerning the perspectives of the participants with regard to the provision of person-centred care during the pandemic. The initial coding was followed by a discussion of similarities and differences regarding their interpretations and coding decisions until inter-coder consistency was reached and the procedure was further strengthened (Ritchie et al. 2014, Thomas and Harden 2008). In case of disagreement, a fourth author (PE) was consulted. The remaining part of the transcript was coded independently in two pairs (MT and WvO or MT and KV). Again, the codes were discussed until full consensus was reached. The final set of codes was then grouped according to similarity, collated into potential themes by three authors, and subsequently reviewed jointly by all authors. Finally, the themes were named and defined, and the authors jointly developed a narrative structure with accompanying descriptions.

### **Results**

Three distinct themes were identified in the thematic analysis: (i) the negative impact of changes due to the COVID-19 measures on service users; (ii) the adaptation of direct support workers to changes due to the COVID-19 measures; and (iii) putting the needs and wishes of service users first.

### **Theme I: The negative impact of changes due to the COVID-19 measures on service users**

The direct service workers indicated that the preventive COVID-19 measures had led to a lack of social and physical contact for older people with intellectual disabilities. They also reported that their service users had become tenser and appeared to be more restless than before the pandemic, and that the preventive measures and the lack of exercise and other daytime activities had led them to become short-tempered, as they had to stay at home all day. Although the participants noted that some service users had responded well to the situation, others had experienced it as too hectic and decided to stay in their own rooms more frequently. Although this choice was voluntary, service users were also occasionally forced to stay in their rooms due to room isolation because of an actual or potential COVID-19 infection in the group home. This had a negative impact on the well-being of all older service users with intellectual disabilities, especially due to the restrictions on their freedom. Another consequence of the preventive measures was the fact that direct support workers had to take over certain tasks from service users that they normally do themselves (e.g. making tea and preparing meals). In other words, the preventive measures did not only affect the service user's feelings of independence and autonomy, it also led to situations in which direct support workers were forced to make choices in their caseload due to the increasing number of tasks:

Because they (i.e. service users) need more than they usually do, and you obviously don't have the time for that. It's just very busy, and then, you must make a well-considered decision... because, at that time, you're actually taking things over from them [Direct support worker 5].

According to the participants, older people with intellectual disabilities in general needed clear and repeated explanations and reassurance to understand the current COVID-19 situation. Moreover, the continuously changing COVID-19 measures (i.e. scaling up and down the COVID-19 guidelines) were particularly difficult for these older service users to understand, *let alone* to comply with. This was especially the case when the measures were not communicated clearly. The direct support workers noted that referring to their own experiences was helpful in this respect:

It's usually the case that you make yourself vulnerable in a certain way. [I explained] It's the same with me. And I'm not allowed to visit my mum and dad either. My folks aren't allowed to hug my children or celebrate birthdays either [Direct support worker 2].

### **Theme II: The adaptation of direct support workers to changes due to the COVID-19 measures**

At the beginning of the COVID-19 pandemic, it was necessary for the direct support workers to become accustomed to the new reality. Due to the measures, direct support workers had to keep distance from their service users, in addition to restricting their freedoms. The participants experienced this situation as both difficult and undesirable, as it is diametrically opposed to the philosophy of IEOC. In addition to the need for adjustments and additional effort to maintain contact, the direct support workers noted that it had sometimes been essential to break the rules in order to provide IEOC and meet the needs of the service users. For example, they explained that physical contact (e.g. when assisting with personal care) constitutes a significant part of their work and, as such, it was inevitable. One support worker who also belonged to the at-risk group had initially felt somewhat unsafe, but eventually chose to not maintain the distance of 1.5 m:

No. I did try to keep them away from me in the beginning, didn't I? So really, no, 1.5 metres. But that scared them [service users], because it's not like me at all. That's also very weird [Direct support worker 3].

The direct support workers identified flexibility and creativity as important skills that had helped them to work according to the philosophy of IEOC during the COVID-19 pandemic. For example, they tried to make the atmosphere in the group homes even more pleasant than usual by offering more group activities in the living room, in order to compensate for the preventive measures and create moments of positive contact. Despite the fact that in-person contact with informal network members was limited or not allowed, direct support workers observed an increase in dialogue and coordination with the informal networks of service users (e.g. through telephone and/or video calls). Support workers deliberately tried to involve the members of these networks by working with them to find solutions (e.g. arranging video conferences). In addition, various initiatives were taken to be active in informing and involving the informal network, including issuing a weekly newsletter and sending personal cards and flowers more often. The participants indicated that they would definitely like to continue these initiatives after the COVID-19 crisis has passed:

I don't think it will go away just like that. We've been doing that for months now, so we've sort of gotten used to it as a new way of working. Because the informal networks are so important to our service users, we want to keep those lines open [Direct support worker 6].



### **Theme III: Putting the needs and wishes of service users first**

In the focus group, the direct support workers indicated that care and support services have continued, despite the measures. Some direct support workers indicated that the COVID-19 pandemic has not changed their bond with service users. They recounted that, although service users sometimes seemed to dislike them because of the preventive measures that they had to impose on them, they stressed that this was only temporary. In some cases, they had even experienced that the measures had positive effects (e.g. valuing the positive contact moments even more because of the situation they were in). As described by one direct support worker:

I enjoy the moments of positive contact more intensely. This is because, tomorrow, there might be a contamination and, in three weeks' time, half the location will be gone, in the worst-case scenario. We just live—every day should be a celebration. It might be even more important in light of the COVID-19 pandemic [Direct support worker 2].

The direct support workers participating in the focus group recalled that they had been present for their service users prior to the COVID-19 pandemic, and that they had continued to be present throughout the pandemic as well. In this case, being present meant not only that the direct support workers remained physically present, but they also provided emotional support by listening, reassuring, and explaining the situation to the service users when necessary. They were nevertheless limited in terms of the attention and closeness that they could offer to these older people with intellectual disabilities. Despite the high workload and frustration stemming from the preventive measures, the participants indicated that the needs and wishes of their service users remained paramount. To be able to meet these needs and wishes, they worked in close collaboration with their direct colleagues and others in multidisciplinary teams. Together, they discussed the risk of contamination in relation to the provision of the care and support to older service users with intellectual disabilities. After weighing the risks, they sometimes consciously chose to abandon certain restrictions, even if it resulted in running an increased risk of contamination. As explained by one direct support worker:

You have to dare to take risks ... One of our service users is almost deaf and blind, and her communication consists largely of touching and cuddling. At first, we tried to discourage that a bit. Then she stopped wanting to eat ... And then we decided, you know what? We'll go ahead and cuddle her, and just turn our heads a bit ... And from that time on, she started eating well again. So now she eats very well and we can just keep communicating with her [Direct support worker 4].

### **Discussion**

In the present study, six direct support workers serving older people with intellectual disabilities shared their

experiences concerning the extent to which they had still been able to provide person-centred care (according to the IEOC approach; van der Kooij 2014, Thalen et al. 2021) during the COVID-19 pandemic. Despite the negative impact of the changes resulting from the COVID-19 measures on service users, the support workers followed their natural tendency to adapt to the situation by trying to mitigate these negative effects. More specifically, when necessary, they sometimes broke the rules in order to provide IEOC and meet the needs of service users. They even indicated that they had remained present for their service users in the same way that they had prior to the COVID-19 pandemic, and that they had continuously tried to adjust to their needs in the changing situation. The needs and wishes of the older service users remained paramount. This sense of responsibility for and loyalty to their service users speaks to the vital role that direct support workers play in the lives of older people with intellectual disabilities, as also illustrated in a study by Embregts et al. (2020). In addition, direct support workers continued to search for other ways to continue connecting with service users, as required in order to provide high-quality care and effective support (Hermsen and Embregts 2015). Finally, while putting the needs and wishes of service users first, direct support workers described the importance of coping with the COVID-19 pandemic with the entire team, such that they could discuss how to deal with strict measures and consult other disciplines within their organisations. The support workers also noted that they had continued to encourage the active involvement of members of the informal networks of service users, even though in-person contact was limited. Moreover, given the importance of communication during crises (World Health Organization 2020), it is interesting to note that the direct support workers participating in this study reported having maintained and facilitated communication with members of relevant formal and informal networks.

The present study has several implications for policy and practice. Overall, the direct support workers in this study stated that, despite COVID-19, they were able to apply all five components of IEOC: focussing on the perspective of service users, adjusting to the current needs of service users, connecting with service users, working in a safe and trusting team culture, and creating room for the informal networks of service users. This observation seems to be consistent with the integrative character of the person-centred IEOC approach. More specifically, IEOC is a multicomponent, integrated and holistic approach in which one component is linked to another. A single initiative might therefore be related to multiple components and can cause a chain of events in relation to more than one IEOC component at the same time (Thalen et al. 2021). In other words, IEOC is not a standard procedure that direct support

workers can simply apply. It requires a basic attitude that helps them to adapt to constantly changing measures and, therefore, with the changing support needs of older people with intellectual disabilities throughout the COVID-19 pandemic. Although the support workers referred to the challenges and impact of the pandemic, working according to IEOC apparently offered them tools that helped them to cope adequately with the situation. The findings of this study offer suggestions for how direct support workers might cope with future crises (e.g. a new pandemic or internal crisis in a group home or healthcare organisation), while continuing to guarantee the provision of person-centred care and support for people with intellectual disabilities. For example, in line with previous studies (e.g. Embregts *et al.* 2021), creating space for personal creativity and improvisation to meet the needs and wishes of people with intellectual disabilities is imperative. Flexibility in order to cope with the challenging working environment is also important in this respect. Sharing such experiences by means of, for example, intervision and online webinars might be valuable.

Notwithstanding these implications, it is important to consider several limitations of the present study when interpreting its results. Although the number of participants in our study meets the recommendations of Braun and Clarke (2013), our sample was relatively small and included merely one focus group interview, due to the difficulties of conducting this type of research under the prevailing circumstances. Hence, future research should address the experiences of other direct support workers to gain more knowledge regarding the application of person-centred care during a long-term pandemic and in order to increase the reliability of our findings as this study serves as a first exploration. Second, the current study focussed on the experiences of six direct support workers during the second lockdown period. Although this provides valuable insights for potential future lockdowns, it is important to continue studying their experiences during the ongoing COVID-19 pandemic. As government and societal responses to the COVID-19 pandemic evolve, it is conceivable that the experiences of direct support workers providing person-centred care may change during the COVID-19 pandemic. Third, it would be interesting to add the experiences of service users themselves to our body of knowledge. We were nevertheless able to address a variety of perspectives by including direct support workers from five residential facilities. The design of the study would have been strengthened by numerous focus group interviews, the involvement of a larger number of healthcare organisations and the inclusion of a broader range of perspectives (e.g. service users and their informal networks). Despite these limitations, this study can be seen as a valuable contribution to existing knowledge about the experiences of direct support workers during the

COVID-19 pandemic and offers directions for future research exploring how an integrated, multicomponent approach like IEOC can be beneficial in light of challenges such as those raised by the current situation.

## Conclusion

This study provides relevant first impressions into the experiences of six direct support workers providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic in the Netherlands. Despite the negative impact of changes due to the COVID-19 measures on service users, the direct support workers in this study experienced they were still able to provide person-centred care (i.e. IEOC) by successfully adapting to the COVID-19 measures and continuing to put the needs and wishes of service users first.

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## Disclosure statement

No potential conflict of interest was reported by the authors.

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