Deaf Residents With Intellectual Disabilities During the First Covid-19 Associated Lockdown

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Abstract

Two indicators for stress (mood and aggressive behavior) were evaluated in order to investigate the effect of the restrictions taken against the spread of the coronavirus on people who are deaf and hard of hearing (DHH) and have intellectual disabilities (ID). In three therapeutic living communities, specifically designed for the visual communication needs of people who are DHH and have ID, the mood of the residents is routinely assessed by staff members and every aggressive incident is recorded with the Staff Observation of Aggressions Scale-Revised (SOAS-R). For the 38 residents who were present 8 weeks before the first lockdown (t1) and the following 8 weeks (t2), mood ratings and ratings of aggressive behavior were compared between the two time periods. In contrast to our hypothesis the mood ratings of the residents had a slight significant improvement, whereas the incidents and severity of aggressive behavior did not change significantly. These results suggest that with proper communicative support, individuals who are DHH and have ID can cope effectively with significant restrictions imposed by a pandemic-caused lockdown.

Background

Courtenay (2020), in his letter to the British Medical Journal, called attention to the specific challenges that people with intellectual disabilities (ID) face due to the restrictions associated with the current Covid-19 pandemic. Additionally, he mentions the risk of an increase of challenging behaviors due to difficulties in tolerating change as well as difficulties that arise in the care situation. Multiple studies have been published, showing the demanding situation for people with ID and people caring for them. Factors that are repeatedly mentioned in these studies are stress, stress-related symptoms, and anxiety due to the fear of contracting the coronavirus as well as a response to changes in daily routines (Buono et al., 2021; Courtenay & Perera, 2020; Scheffers, Moonen, & van Vugt, 2021). As a matter of fact, people with ID are at higher risk for contracting Covid-19 due to physical health problems and difficulties in understanding the underlying reasons for guidelines (Courtenay & Perera, 2020). There might be a potential increase in problem behaviors in people with ID, due to various reasons such as the before mentioned stress levels, changes in routines, changes in care people due to infections or quarantine (Courtenay & Perera, 2020).

Those who are deaf and hard of hearing (DHH) in addition to ID are often faced with communicative difficulties as they frequently live in environments that do not adequately meet their needs for visual communication. Communication barriers can in turn provoke increased rates of aggressive behavior (McClintock, Hall, & Oliver, 2003).
The Lebenswelt (LW) is a therapeutic living community program in Austria for people who are DHH and have intellectual and multiple disabilities including neurodevelopmental and psychiatric disorders. The LW is characterized by its developmentally sensitive milieu therapy program, focusing on the needs of this specific deaf population, particularly regarding communication and social relationships. The LW is characterized by constant use of sign language, adapted to the participants’ communication levels and needs. About a quarter of the staff members are DHH. All staff members are trained to communicate in sign language at least at level A2 according to the Common European Framework of Reference for Languages (CEFR, Council of Europe, 2001) and are constantly trained in weekly sign language classes. The use of additional visual communication such as pictograms and visual schedules supports understanding (Fellinger et al., 2020). The staff-resident relationship is an essential element of the therapeutic community process and can be characterized by partnership and elements of friendship. Each resident has a staff member as a primary contact person for personal matters, with regularly scheduled times exclusively for the two to spend together. It is the task of this key person to explore the resident’s concerns and wishes, so that they can be addressed in his/her development plan.

There are three separate sites with this kind of program. They all include both living and supported working facilities. The majority of the participants live in one of the three LW (n = 48), whereas some (n = 12) attend only the working facilities. All three sites are located in the center of the villages, offering the participants inclusion into the community. Sign language classes are provided in the local communities to create a welcoming atmosphere toward the participants of the LW.

The first lockdown in Austria was introduced by the government on March 16, 2020, in reaction to the start of the global pandemic with measures against the spread of the coronavirus. This first lockdown allowed people to leave their homes for essential activities only such as grocery shopping, medical consultations, and walks. All nonessential shops were closed. Also, to protect vulnerable groups no visitors were allowed at special needs facilities. Consequently, the residents of the LW had no social contact beyond the therapeutic community setting, since many of the residents’ usual activities (e.g., shopping, visiting restaurants, bowling, swimming) and home visits on the weekend had to be cancelled. Additionally, all participants who attended the day program only had to stay at home during the lockdown period. Furthermore, 10 residents of the LW were also staying at home with their relatives. It was possible to keep the staff-resident ratio stable at all three sites during the corona measures. However, there was a change in the constellation of the teams. At one of the three sites, three teams were formed, and worked for three consecutive days in 1 week. They then had a 7 day break, worked four consecutive days the following week, and worked for three consecutive days in 1 week. They then had a 7 day break, worked four consecutive days the following week, followed by 1 week off. The other two sites had two teams who changed weekly.

From the beginning of the lockdown, staff members thoroughly explained in sign language the transmission paths of the coronavirus, the concept of physical distancing as well as the measurements that were taken by the government. Additionally, symbols from the Metacom website (Kitzinger, 2020) were used to explain the situation through pictures. The daily evening TV news was watched together and afterwards discussed and explained in easy-to-understand sign language. One particular change was the use of face masks. Even though the situation was new and unfamiliar, the reactions were not as negative as expected. Some of the participants were even eager to use face masks themselves to protect them from an infection. When face masks were produced in their own workshops, they gained particular popularity. As communication with people who are DHH relies to a high degree on seeing the interlocutor’s face for lipreading and understanding emotions and linguistic facial expressions, the masks also had a negative influence on communication. It became even more important for staff to use their eyes, eyebrows, body language and gestures, and other alternative means of communication such as written language, picture symbols, or drawings. The need to express emotions by signs grew bigger. If there was a risk for communication breakdown for various reasons such as ambiguous signs, there was an agreement that the mask could be taken off, if the distance between the two communication partners was big enough. Caregivers were encouraged to particularly monitor the comprehension of their signed messages by the participants and to assure their understanding of what the participants were trying to convey. Nevertheless, the beginning of the Covid-19 pandemic was a time where misunderstandings occurred more frequently than before, as reported by various staff members.

For organizational reasons associated with the coronavirus one of the three sites had to close their working facilities. As a consequence, considerable effort was made by the caregivers at this site to provide a clear daily structure in order to compensate for this. Activities included walks, group activities indoors, and some handcrafting.

So far, no study has been published on the effects the measures against the spread of the coronavirus had on people who are DHH and have ID. The primary aim of this study is to investigate changes in mood and frequency and severity of aggressive behavior of people who are DHH and have ID living in therapeutic communities 8 weeks before the first lockdown and the first 8 weeks of the lockdown.

It is hypothesized that the measures taken to avoid the spread of the coronavirus have a negative effect on the stress and anxiety levels of people who are DHH and have ID, which in turn could lead to a decrease in mood ratings, and an increase in incidence rates and severity of aggressive behavior.

Methods

Participants

This study includes 38 residents who are DHH and have ID, who were present at the therapeutic living communities during the 8 weeks before the introduction of the measures (t1: January 20–March 15, 2020) and the following 8 weeks (t2: March 16–May 10, 2020). Their sign language abilities range from using single sign utterances to some fluency in sign language. Participant characteristics for the sample are presented in Table 1.

Table 1 shows the descriptive results for the total sample. There were 38 residents present at the LW during the first lockdown, of which 37% were female. The average age was 50.5 years (SD = 18.69). The average IQ reference age was 72.5 months (SD = 21.51). Regarding additional diagnoses, 55% were diagnosed with ID and significant impairment of behavior (ICD-10; F70.1-F79.1), 24% with epilepsy, 37% with cerebral palsy, 5% with autism spectrum disorder, and 8% were deafblind. Five residents were in psychiatric inpatient treatment within the last 6 years.

Measures

Staff members at the LW routinely assess the mood of the residents three times a day on a five-point-scale, where 1
Table 1 Participants’ characteristics

| Characteristic                                      | Value       |
|----------------------------------------------------|-------------|
| Residents present                                  | 38          |
| Male n (%)                                         | 24 (68%)    |
| Age in years M (SD)                                | 56.22 (18.69) |
| Intelligence reference age in months M (SD)        | 72.49 (21.51) |
| ID with significant impairment of behavior n (%)    | 21 (55%)    |
| History of psychiatric inpatient treatment in the last 6 years n (%) | 9 (24%) |
| Epilepsy n (%)                                     | 9 (24%)     |
| Cerebral Palsy n (%)                               | 7 (18%)     |
| Autism Spectrum Disorder n (%)                     | 3 (8%)      |
| Deafblind n (%)                                     | 3 (8%)      |
| Staff-residents ratio                              | 1:4.25      |

Table 2 Change of outcome variables between t1 and t2 (n = 38)

| Variable                              | t1 M (SD) | t1 Min-Max | t2 M (SD) | t2 Min-Max | Difference t2-t1 M | d | p value | p value WW |
|---------------------------------------|-----------|------------|-----------|------------|-------------------|---|---------|-----------|
| Mood                                  | 3.56 (.26) | 3.03–4.39 | 3.61 (.22) | 3.18–4.12 | .05 .19 .095 .040 |
| Aggressive behavior - Incidence       | 5.58 (11.08) | 0–49 | 4.95 (10.40) | 0–44 | -.63 .06 .166 .116 |
| Physical aggression toward others - Incidence | 2.37 (5.24) | 0–28 | 2.29 (5.67) | 0–24 | -.08 -.02 .845 .482 |
| Threatening of physical aggression - Incidence | .63 (1.79) | 0–9 | .66 (1.58) | 0–6 | .03 .02 .861 .809 |
| Verbal aggression - Incidence         | .95 (2.70) | 0–12 | 1.32 (3.66) | 0–18 | .37 .14 .181 .298 |
| Aggression toward objects - Incidence | .71 (1.58) | 0–6 | .92 (2.11) | 0–10 | .21 .13 .282 .233 |
| Auto-aggression - Incidence           | 1.95 (7.15) | 0–38 | 1.55 (6.25) | 0–36 | -.40 -.06 .181 .246 |
| Aggressive behavior - Severity        | 5.19 (5.55) | 0–15 | 3.84 (5.15) | 0–17 | -1.35 -.24 .117 .064 |

Notes. d = standardized mean difference (i.e., mean differences between t1 and t2 divided by the standard deviations at t1).

Statistical Analysis

The changes in the outcome variables are reported. Due to small sample size and largely non-normally distributed incidence variables, nonparametric analysis was also used to back up the results.

Results

Table 2 shows the means and standard deviations for the outcome variables at t1 and t2. The analyses show a small significant improvement in the mood ratings (d = .19, p < .10, PWilcoxon-W-Test < .05) between t1 and t2. None of the measures of incidents and the severity of aggressive behavior changed significantly between the two time periods. Physical aggression toward others showed the highest incidence rate both at t1 (M = 2.37) and t2 (M = 2.29). The incidence rate of auto-aggression was quite high compared to the other dimensions in both time periods (t1: M = 1.95; t2: M = 1.55); this is almost exclusively due...
to one resident. Threatening of physical aggression showed the lowest incidence rate in both time periods ($t_1: M = .63$; $t_2: M = .66$).

**Discussion**

In this study, we investigated the effects of measures taken during the first lockdown due to the Covid-19 pandemic in spring 2020 on the mood, incidents, and severity of aggressive behavior of people who are DHH and have ID and live in therapeutic living communities specifically designed for their communication needs. In contrast to our hypothesis, the group showed no significant increase in incidents and severity of aggressive behavior during the time of the restrictions. Unexpectedly, the results even indicate a small improvement of the mood ratings between the two time periods. It is important to note that no one at the therapeutic living communities was infected with the coronavirus during the study period. Due to the reduced number of activities and contacts with people from outside, staff members were able to spend more time in direct interactions with the residents. This led to a calmer atmosphere, which gave more space to uninterruptedly respond to the residents’ mental states and interests, which seemed to reduce the residents’ levels of arousal. Daily efforts to reduce anxiety by explaining the situation around Covid-19 in sign language and other means of visual communication created additional opportunities for meaningful communication. Thanks to the great efforts of staff members, it was possible to maintain the positive atmosphere in the LW. The constant access to information appeared to be of utmost importance. Preparing news and information in a way that is accessible and understandable for the people who are DHH and have ID was crucial. The preparation and passing on of information provided an opportunity for residents and staff members to start conversations and spend a more intense time together. Due to the cancelation of outside activities, there was more time for direct interactions with games and inside activities.

Additionally, the reduced number of people present at the LW and the different shift schedules of the staff members might have had a positive influence on the mood of the residents. We suspect with caution that less activities, but continued meaningful engagement and targeted attention and care from staff members, not only levels out the restrictions but might even have a mood-uplifting effect. It was not possible to investigate whether this positive effect was only temporary or sustained over a longer period of time.

The findings cannot be generalized to people who are DHH and have ID living in settings not adapted to their visual communication needs. At all three sites particular attention is paid to meaningful engagement and targeted attention and care from staff members, it was possible to maintain the positive atmosphere in the LW. The constant access to information appeared to be of utmost importance. Preparing news and information in a way that is accessible and understandable for the people who are DHH and have ID was crucial. The preparation and passing on of information provided an opportunity for residents and staff members to start conversations and spend a more intense time together. Due to the cancelation of outside activities, there was more time for direct interactions with games and inside activities.

**Conclusion**

Restrictions due to measures taken during the beginning of the Covid-19 pandemic do not necessarily lead to a decrease in mood or an increase in aggressive behavior, if people who are DHH and have ID are embedded in an environment where visual communication is in constant use and can therefore be used to explain and discuss the situation in an accessible way. Time with less activities combined with more intense attention of caregivers and stable daily routines could even be perceived as a protective factor.

**Conflicts Of Interest**

All authors declare no conflicts of interest.

The study was approved by the ethical committee of the Hospital of St. John of God in Linz.

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