Concerns and needs of people with intellectual disabilities and their caregivers during the COVID-19 pandemic in Japan

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Abstract
Background: People with intellectual disabilities (IDs) and their caregivers face difficulties during the COVID-19 pandemic. However, limited studies have comprehensively investigated their challenges, especially in Japan. We aimed to clarify the concerns and needs of people with IDs and their caregivers during the COVID-19 pandemic in Japan. Method: From March to August 2021, 27 in-depth interviews were conducted with principal caregivers of people with moderate to profound IDs in Japan. We then transcribed the interviews and conducted deductive coding using predetermined codes focused on their daily life difficulties. Inductive coding was used to ensure that no important themes were overlooked. Results: We found four concerns and four needs among people with IDs and their caregivers as significant themes. Conclusions: Our results provide useful information for supporting people with IDs and their caregivers, especially among those who need medical or social care in accordance with the infection control and social-distancing policies.

Introduction
People with intellectual disabilities (IDs) often have more health care needs than those without IDs (Cooper et al., 2015). However, several barriers toward achieving...
appropriate health care access or hospital experiences have been identified. A previous study revealed that people with IDs find it challenging to describe their medical needs appropriately given their limited communication skills (Gibbs et al., 2008). A study in the UK reported that people with IDs and their caregivers were severely burdened by long waiting times at hospitals (Ward et al., 2010). A study in Japan highlighted the lack of positive experiences among parents of people with IDs due to the medical staff’s negative attitudes toward them and their families and the limited access to appropriate care (Nodaka and Arakida, 2017).

The COVID-19 pandemic has emerged as a global problem. Notably, people with IDs are particularly vulnerable under the current pandemic given that they often have co-morbidities, such as respiratory and cardiac diseases and diabetes, that could increase the severity of COVID-19 symptoms (Turk et al., 2020). Some studies have described how people with IDs and their caregivers had challenging experiences during the pandemic (Embregts et al., 2021; Navas et al., 2021; Neece et al., 2020; Willner et al., 2020). For instance, limited understanding regarding the importance of hygiene and quarantine makes it difficult for people with IDs to protect themselves from infection (Courtenay and Perera, 2020). Moreover, schools, day services, and respite care no longer provided their usual support due to the pandemic (Courtenay and Perera, 2020; Navas et al., 2021; Neece et al., 2020). Furthermore, the impact on caregivers has increased significantly (Courtenay and Perera, 2020), with a study reporting greater levels of caregivers’ objective stress scores compared to pre-pandemic levels (Willner et al., 2020). A study also reported that parents experienced difficulties being stuck at home with children with IDs (Neece et al., 2020).

Furthermore, the country’s welfare and health care systems and policies also influence the impact of COVID-19 on people with IDs. In Japan, outbreaks in residential care facilities for people with IDs occurred at the beginning of the COVID-19 pandemic (Asahi Shinbun, 2021a). Moreover, in Japan, only patients with severe medical conditions can be hospitalized, requiring those with mild to moderate symptoms to stay at home or in hotels (Ministry of Health and Labor and Welfare, 2021). People with severe IDs and their caregivers will be under considerable strain if they need to be hospitalized or admitted to a care facility. Likewise, organizations for IDs have expressed concerns regarding the health care of people with IDs during the pandemic, such as “What should I (parents) do when contracted by the virus? Who can take care of my child?” (Japan Federation of Inclusion Associations For Hand in Hand, 2020). One Japanese study investigated the quality of life of children with neurodevelopmental disorders and their parents during the pandemic, subsequently revealing limited working styles among mothers and deterioration in children’s sleep rhythms due to parental stress (Ueda et al., 2021). However, the aforementioned studies have primarily focused on children without IDs and with mild IDs. Little information has been available regarding what people with severe IDs and their caregivers experience during the pandemic. In order to fill this gap in the literature, the current study aimed to clarify the concerns and needs of people with moderate to profound IDs and their caregivers during the COVID-19 pandemic and obtain the information needed to provide appropriate support from a public health perspective.
Materials and methods

Sample

We interviewed 23 mothers and 4 fathers of 24 people with moderate to profound IDs, among whom 2 were siblings. The Japanese government classifies the degree of IDs based on IQ and activities of daily living to determine the need for various social welfare benefits and programs before issuing a Certificate of Intellectual Disability (Bureau of Social, 2021). Our classification of the degree of IDs was based on the official classification listed in the disability certificate. The disability certificate is issued by each municipality and enables people with disabilities to receive disability welfare services based on the law and services provided by private businesses. The classification of IDs is mainly based on IQ in the Japanese welfare system (Table 1). Some municipalities lump severe and profound together, and moderate and mild together, and issue a classification on the disability certificate. However, the IQ range for the severity classification remains the same. The municipalities of the people recruited for this study had a system in which the severity of profound, severe, moderate and mild was described in the disability classification. We excluded people who lived in group homes given our focus on the needs within the home environment.

We purposefully sampled “information-rich” participants (Patton, 1990) from various sources. Firstly, the first author has a family member with a profound ID. Therefore, snowball sampling was conducted through the first author’s personal connections, from which 15 mothers and 4 fathers participated. Secondly, we approached three caregiver groups, the first two of which had personal connections with the first author (i.e., the first author and her friend were volunteers). The first author contacted the third group for this study through their website. We sent out invitations to participate in the study via e-mail through these caregiver groups and received e-mail responses from eight mothers expressing interest. The first author revealed that she was a junior resident physician working in a hospital and had a family member with an ID during the sampling process.

Data collection

After obtaining written informed consent, in-depth interviews were conducted using the interview guide (see Supplementary material) via telephone or Zoom® (without using the video function) between March 2021 and July 2021. The topics asked included age, sex, medical histories, family structures, accessibility of social services for caregivers and people with IDs (see Table 2). Thereafter, we inquired regarding lifestyle changes during the COVID-19 pandemic and their challenges. The first (SF) and second (NN) authors reviewed the data after the first author conducted the initial interview. Afterwards, SF, NN, and the third author (YY) engaged in discussions after the first author completed all interviews. SF and NN received formal training in qualitative

| Table 1. The Classification of IDs in the Japanese welfare system. |
|----------------------|------------------|
| **The range of IQ**  |
| Mild                 | 50-69            |
| Moderate             | 35-49            |
| Severe               | 20-34            |
| Profound             | under 20         |
Table 2. Demographics of the caregivers and people with IDs included in this study.

| Variables                        | Mean (SD) or N (%)                      |
|----------------------------------|----------------------------------------|
| **Caregivers (N = 27)**          |                                        |
| Age                              | 54.2 (4.6); min: 10, max: 35           |
| Mother                           | 23 (85.2)                              |
| Father                           | 4 (14.8)                               |
| Marital status                   |                                        |
| Married                          | 25 (92.6)                              |
| Bereaved                         | 2 (7.41)                               |
| Job                              |                                        |
| Full-time jobs                   | 4 (14.8)                               |
| Part-time jobs                   | 5 (18.5)                               |
| Self-employed                    | 5 (18.5)                               |
| Not working                      | 13 (48.1)                              |
| Chronic illnesses                |                                        |
| Present                          | 13 (48.1)                              |
| Absent                           | 14 (51.9)                              |
| **People with IDs (N = 24)**     |                                        |
| Age                              | 21.6 (5.5)                             |
| Sex of people with IDs           |                                        |
| Male                             | 18 (75.0)                              |
| Female                           | 6 (25.0)                               |
| Severity of IDs                  |                                        |
| Profound                         | 8 (33.3)                               |
| Severe                           | 10 (41.7)                              |
| Moderate                         | 6 (25.0)                               |
| Comorbidity<sup>a</sup>          |                                        |
| Autism Spectrum Disorder         | 12 (50.0)                              |
| Epilepsy                         | 8 (33.3)                               |
| Down syndrome                    | 4 (16.6)                               |
| Cerebral palsy                   | 3 (12.5)                               |
| Bipolar disorder                 | 3 (12.5)                               |
| Post encephalitis                | 2 (8.33)                               |
| Sleep disorder                   | 2 (8.33)                               |
| Other                            | 3 (12.5)                               |
| Coexisting Physical Disability   | 4 (16.6)                               |
| Welfare, education, and employment support used in daily life | Welfare support related to care for daily life 14 (58.3) |
| Special-needs schools/ Special-needs classes in local schools | 6 (25.0) |
| Support for employment           | 4 (16.6)                               |
| Welfare service<sup>b</sup>      |                                        |
| Care for daily life              | 14 (58.3)                              |
| Daytime support                  | 11 (45.8)                              |
| Mobility support                 | 11 (45.8)                              |
| Short-stay service               | 8 (33.3)                               |
| After-school daycare             | 4 (16.6)                               |
| Activity support                 | 4 (16.6)                               |
| Support for continuous employment type B | 2 (8.33) |
| Others                           | 4 (16.6)                               |

(continued)
interviewing in graduate programs. Additionally, NN had multiple experiences in the supervision of qualitative research.

The interviews lasted approximately 40 min (mean: 39.9 min, range: 26-68 min) and were conducted in Japanese. All the participants supported the author’s desire to report on the current situation of people with IDs in the COVID-19 pandemic, shared the importance of the report, and were enthusiastic and willing to discuss the topic. Thus, we determined that the information in our samples was rich enough. Interviews were audio-recorded and transcribed verbatim. Ethics approval for this study was granted by the Research Ethics Committee of Tokyo Medical and Dental University granted ethical approval for the study [M2020-272-01]. The Research Ethics Committee has approved the research plan, which states that the author will conduct the interviews, anonymize them using a correspondence table so that the identity of the interviewee will not be known after transcription, and that the author of the interview will code the interviews and publish them with no personal information so that the identity of the interviewee will not be known at the time of publication. We also explained to participants that participation in the interviews was voluntary and that they could refuse consent or withdraw consent later.

**Data analysis**

Reflective thematic analysis was used to analyze the interview transcripts (Braun and Clarke, 2021). Reflective TA was chosen as the research method for the following reasons: 1) In reflective TA, the research question, the authors’ knowledge, perspective, and experience, and the data content are combined by the researchers to develop themes with rigorous validation (Braun and Clarke, 2021); 2) In particular, the first author is an insider familiar with the research topic and its context, and an aspiring child psychiatrist with the mindset of a public health researcher. Thus, reflective TA was chosen because those factors allowed for a more in-depth examination of the issue and clarification of the difficult experiences of people with IDs and their caregivers. The first author directed the coding and developed the initial code lists with NN. The final list of themes was established through a process of merging, evolving, and refining the initial codes over and over again, and through discussions among SF, NN, and YY. Data were then coded using deductive coding with predetermined codes focused on lifestyles characteristics (i.e., codes related to how people with IDs...

| Variables       | Only parents | 8 (33.3) |
|-----------------|--------------|----------|
| Family members  | With parents and grandparents | 5 (20.8) |
|                 | With parents and sibling       | 13 (54.2)|
|                 | Other                      | 1 (4.17) |
| Medication      | (+)                        | 12 (50.0)|
|                 | Anti-epileptics          | 7 (29.2) |
|                 | Anti-psychotics          | 6 (25.0) |
|                 | Mood stabilizer          | 2 (8.33) |
|                 | Others                   | 4 (16.6) |

aTotal exceeds 24 due to multiple comorbidities
bTotal exceeds 24 due to multiple welfare support
cTotal exceeds 24 due to multiple combination of family types
dTotal exceeds 24 due to multiple medication
live and how caregivers deal with children with IDs, especially during the COVID-19 pandemic). Inductive coding was also used to ensure that no important themes were overlooked. A social-ecological model was then used to organize the themes (CDC, 2020). This model assumes that people’s behavior is influenced by a complex interplay of individual, relationship, community, and societal factors (CDC, 2020). Finally, our results were presented to the participants for member checking to check whether our understanding accurately reflected their experiences and perspectives (Birt et al., 2016; Harvey, 2015). Data were managed using ATLAS.ti.

We considered reflexivity throughout the research process (Jootun et al., 2009). SF has a family member with a profound ID. Thus, before starting this project, SF had personal connections with caregiver groups and families of people with IDs, which made it easier to recruit participants for this study. SF revealed to the participants that she has a family member with an ID and has been familiar with IDs, which might encourage participants to more freely express their thoughts. Additionally, the researchers held close briefings and discussions with each other when creating the interview guide, coding, and interpreting the results to avoid overlooking anything evident to those familiar with IDs and not to those who were not.

**Results**

A total of 27 caregivers (average age, 54.2 years) caring for 24 people with IDs were recruited. Table 2 summarizes the demographic characteristics of the people with IDs and their caregivers who participated in this study. Among the 27 interviewed caregivers, 23 (85.2%) were mothers, whereas 14 (51.9%) were employed. The severity of IDs ranged from moderate to profound. People with IDs had various comorbidities, such as autism spectrum disorder, epilepsy, and Down syndromes.

Eight significant themes related to the concerns and needs of people with IDs and their caregivers were identified (see Table 3). Four of these themes were concerns: (1) “what if we get infected the COVID-19!,” (2) “fostering understanding on the COVID-19 pandemic,” (3) “lack of pastime activities,” and (4) “when the parents are gone.” The remaining four were needs: (1) “need for a place where caregivers can share information and concerns,” (2) “government and welfare services, please be more flexible!,” (3) “more support for care workers,” (4) “reasonable modifications in health care.”

**Concerns**

*What if we get infected the COVID-19!* Caregivers believed that contracting COVID-19 would cause problems for themselves or people with IDs. Some participants mentioned; “I have no idea what to do” [Caregivers who are mothers (CGM) 3, 5, 14, 16, 19]. Initially, caregivers believed that they would need to care for people with IDs who contracted COVID-19 at home for as long as possible and that problems would arise should people with IDs need to be hospitalized or quarantined in a designated hotel. Considering that leaving people with IDs alone is challenging, caregivers perceived that their children with IDs needed constant, uninterrupted, intimate care. Some caregivers mentioned, “He needs care at all times, 24 hours!” [CGM 11, 14]. “Tearing off the intravenous drip” [CGM 4, 6], “wandering around the room” [CGM 1, 15], or “shouting in a loud voice” [CGM 1] were the main concerns for some caregivers. Caregivers were worried about sedation and physical restraint. Notably, one caregiver stated, “I am worried because I do not know if they are going to give him a sedative or some other kind of injection to put him to sleep” [Caregivers who are fathers (CGF) 1]. Caregivers were readily willing to accompany people with IDs to the hospital or be infected with COVID-19 given their close proximity with them. One caregiver stated, “[People with...
### Table 3. Main themes and sub-themes around lifestyles of people with IDs.

| Themes | Corresponding factor from the Social-Ecological Model | Representative quotes |
|--------|-------------------------------------------------------|-----------------------|
| **Concerns** | | |
| What if we get infected the COVID-19! | Individual | “I have no idea what to do” [CGM 3, 5, 14, 19] |
| | | “He needs care at all times, 24 hours!” [CGM 1, 11, 14] |
| | | “tearing off the intravenous drip” [CGM 4, 6] |
| | | “wandering around the room” [CGM 1, 15] |
| | | “shouting in a loud voice” [CGM 1] |
| | Relationship | “I am worried because I do not know if they are going to give him a sedative or some kind of injection to put him to sleep” [CGM 1] |
| | | “Our children have immune system disease other than IDs, so they are at high risk for serious illness” [CGM 2] |
| | | “she [the person with an ID] has a cardiac and lung trouble, I’m really worried about her being infected” [CGM 23] |
| | | “People with IDs will be hospitalized with parents [i.e. caregiver], and I don’t care if I get infected by caring for the people with IDs closely” [CGM 2] |
| | | “I don’t even know if I can be with him in the hospital” [CGM 4] |
| | | “If I catch a virus, she [a person with an ID] catches it, too. When she [a person with an ID] catches it, I will catch it, too” [CGM 3] |
| | | “I’m afraid my husband bringing home the virus” [CGM 5] |
| | | “Not everyone can be her caregiver… because the mother-daughter bond is strong” [CGM 3] |
| | | “I don’t think it’s fair to ask his sister to do it” [CGM 17] |
| | Community | “If pandemic occurred in care facilities, leading to their closure, there would be a severe burden on the caregivers [because caregivers have to take care of the people with IDs all day long in their home]” [CGM 2] |
| | | “There should be a short-stay place or a short-stay place that can accept such a person if the person or the family member becomes infected or becomes a close contact” [CGM 3] |
| | | “If a person with an ID is infected with the COVID, I would like to make sure that he or she be hospitalized, but in reality, many hospitals refuse to admit him or her, and it might be difficult for the hospital to admit him or her unless it has a psychiatric department” [CGM 3] |
| | | “The first thing we had to do was to figure out how to tell him [a person with an ID] about the COVID-19 in a simple way since he couldn’t see it and therefore it was difficult for him to understand” [CGM 8] |
| | | “I had to tell him that it was full of germs” [CGM 22] |
| | | “Why, why can’t I go outside?” [CGM 17] |
| | | “He cannot wear masks properly” [CGM 3] |
| | | “After wearing it for a long time, he takes it off and plays with the string” [CGM 19] |
| | | “If I can’t wear a mask properly, we will still be looked down upon.” [CGM 12] |
| | | “It’s the COVID-19, so people are definitely on edge” [CGM 3] |
| | | “Make sure they [people with IDs] wash their hands and gargle when they get home” [CGM 13] |
| | | “He can’t act like to avoid passing on the virus to others” [CGM 19] |
| | Fostering understanding on the COVID-19 pandemic | Individual | “The first thing we had to do was to figure out how to tell him [a person with an ID] about the COVID-19 in a simple way since he couldn’t see it and therefore it was difficult for him to understand” [CGM 8] |
| | | “I had to tell him that it was full of germs” [CGM 22] |
| | | “Why, why can’t I go outside?” [CGM 17] |
| | | “He cannot wear masks properly” [CGM 3] |
| | | “After wearing it for a long time, he takes it off and plays with the string” [CGM 19] |
| | | “If I can’t wear a mask properly, we will still be looked down upon.” [CGM 12] |
| | | “It’s the COVID-19, so people are definitely on edge” [CGM 3] |
| | | “Make sure they [people with IDs] wash their hands and gargle when they get home” [CGM 13] |
| | | “He can’t act like to avoid passing on the virus to others” [CGM 19] |
| | | “Of course he took off the mask at first when he [a person with an ID] went to the office, but as we put it on him again and again, now he can keep it on for a while without much reluctance” [CGM 2] |
| | | “For him [a person with an ID], patience was something he could not see [and therefore could not understand], but he was able to develop patience and perseverance [by experiencing the COVID-19 pandemic]” [CGM 8] |
| | Lack of pastime activities | Individual | “They can’t pass the time on their own” [CGM 19] |
| | | “There is not much that a child with a disability can do [to pass the time]” [CGM 4] |
| | | “She stayed in a small space at home all the time, so she is stressed out and she starts to hold a towel in her hand all the time” [CGM 4] |
| | | “When the office said they were going to be closed, all the weekdays would be empty. We were really troubled” [CGM 23] |
| | | “I wonder if it was an opportunity to reevaluate a life that was kind of too messed up” [CGM 15] |
| | | “He might not want to go out” [CGM 18] |
| | | “He might like a monotonous life against my expectation” [CGM 12] |
| | When the parents are gone | Individual | “I’ve been in a situation where I can’t take a break even though I’m getting older, and I’m worried that it will last forever” [CGM 11] |
| | | “I wonder they [someone who care the people with IDs in the future] will ever notice when he is sick” [CGM 18] |
| | | “How does she [a person with an ID] get to the clinic?” [CGM 4] |
| | Community | “I’ve been in a situation where I can’t take a break even though I’m getting older, and I’m worried that it will last forever” [CGM 11] |
| | | “I wonder they [someone who care the people with IDs in the future] will ever notice when he is sick” [CGM 18] |
| | | “How does she [a person with an ID] get to the clinic?” [CGM 4] |
| | Societal | “I think it would be very helpful if there was a place where people with IDs could stay after work, even after they reach adulthood, like a day service” [CGM 12] |

(continued)
Table 3. (continued)

| Themes                                      | Corresponding factor from the Social-Ecological Model | Representative quotes                                                                                                                                                                                                 |
|--------------------------------------------|-------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Needs                                      | Social                                                | “If parents don’t move around, there is no place to get information about it. If there had been such a contact point, I would have been able to deal with it sooner” [CGM 3] |
|                                            |                                                       | “It would be nice to have a chance to talk about the difficulties with other caregivers a little more... to let off steam” [CGM 15]                                                                                     |
|                                            |                                                       | “It’s like, “I shouldn’t say this because everyone is having a hard time”, and I think everyone is already holding back, so, um, it would be better if there was a place where people could escape the pain a little more” [CGM 15] |
|                                            |                                                       | “I often wonder individually if this child [a child with an ID] needs this [service], or that this child [a child with an ID] needs this [services], or that this child [a child with an ID] can develop this [skill] more. So I wonder if there is something I can do to choose the appropriate welfare services for each person” [CGM 3] |
|                                            |                                                       | “I would like to see more services for people with severe and profound IDs, as there are limited facilities available for them” [CGM 10]                                                                              |
|                                            |                                                       | “After experiencing the hospitalization of my daughter with an ID (due to bone fracture), I felt the need for assistance services during hospitalization” “The same goes for short stays, including respite hospitalization” [CGM 10] |
|                                            |                                                       | “There were really only a few workers [in the facilities], and they really had to stay awake to deal with them [people with IDs]” [CGM 7]                                                                            |
|                                            |                                                       | “Vaccinations for staff working in the care facilities could be given a little more priority” [CGF 3]                                                                                                                                 |
|                                            |                                                       | “There is always a shortage of labor, especially for care workers, so I would like to see their wages raised a bit more... I think the world should be more aware of the position of those who work in the welfare sector, like those who work in medical institutions. I think it would be good for the world to know more about them, or rather, to know them as a profession with more status” [CGM 12] |
| Government and welfare services, please be more flexible! | Social                                                | “I would like to see more services for people with severe and profound IDs, as there are limited facilities available for them” [CGM 10]                                                                              |
|                                            |                                                       | “After experiencing the hospitalization of my daughter with an ID (due to bone fracture), I felt the need for assistance services during hospitalization” “The same goes for short stays, including respite hospitalization.” [CGM 10] |
|                                            |                                                       | “There were really only a few workers [in the facilities], and they really had to stay awake to deal with them [people with IDs]” [CGM 7]                                                                            |
|                                            |                                                       | “Vaccinations for staff working in the care facilities could be given a little more priority” [CGF 3]                                                                                                                                 |
|                                            |                                                       | “There is always a shortage of labor, especially for care workers, so I would like to see their wages raised a bit more... I think the world should be more aware of the position of those who work in the welfare sector, like those who work in medical institutions. I think it would be good for the world to know more about them, or rather, to know them as a profession with more status” [CGM 12] |
| More support for care workers                | Social                                                | “I would like to see more services for people with severe and profound IDs, as there are limited facilities available for them” [CGM 10]                                                                              |
|                                            |                                                       | “After experiencing the hospitalization of my daughter with an ID (due to bone fracture), I felt the need for assistance services during hospitalization” “The same goes for short stays, including respite hospitalization.” [CGM 10] |
|                                            |                                                       | “There were really only a few workers [in the facilities], and they really had to stay awake to deal with them [people with IDs]” [CGM 7]                                                                            |
|                                            |                                                       | “Vaccinations for staff working in the care facilities could be given a little more priority” [CGF 3]                                                                                                                                 |
|                                            |                                                       | “There is always a shortage of labor, especially for care workers, so I would like to see their wages raised a bit more... I think the world should be more aware of the position of those who work in the welfare sector, like those who work in medical institutions. I think it would be good for the world to know more about them, or rather, to know them as a profession with more status” [CGM 12] |
| Reasonable modifications in health care      | Social                                                | “I would like to see more services for people with severe and profound IDs, as there are limited facilities available for them” [CGM 10]                                                                              |
|                                            |                                                       | “After experiencing the hospitalization of my daughter with an ID (due to bone fracture), I felt the need for assistance services during hospitalization” “The same goes for short stays, including respite hospitalization.” [CGM 10] |
|                                            |                                                       | “There were really only a few workers [in the facilities], and they really had to stay awake to deal with them [people with IDs]” [CGM 7]                                                                            |
|                                            |                                                       | “Vaccinations for staff working in the care facilities could be given a little more priority” [CGF 3]                                                                                                                                 |
|                                            |                                                       | “There is always a shortage of labor, especially for care workers, so I would like to see their wages raised a bit more... I think the world should be more aware of the position of those who work in the welfare sector, like those who work in medical institutions. I think it would be good for the world to know more about them, or rather, to know them as a profession with more status” [CGM 12] |

"I hope hospitals create a [waiting] space for us [the caregiver and a person with an ID] to be together" [CGM 18]
IDs will be] hospitalized with parents [i.e., caregivers], and I do not care if I get infected [by caring for the people with IDs closely]” [CGM 2]. However, caregivers were concerned that people with IDs could be quarantined after hospitalization to prevent the spread of infection and were unsure whether they could attend to them upon hospitalization. One caregiver said, “I do not even know if I can be with him in the hospital” [CGM 4]. The caregivers who assumed that they were infected were also concerned about infecting people with IDs given the close proximity between them. Simultaneously, caregivers believed that once people with IDs became infected, their caregivers would also become infected. One caregiver stated, “If I catch a virus, she [a person with an ID] catches it, too. When she [a person with an ID] catches it, I will catch it, too” [CGM 3]. Caregivers were also anxious about other family members bringing home the virus. One caregiver mentioned, “I am afraid my husband bringing home the virus” [CGM 5]. Caregivers also believed that not everyone could be a caregiver. One caregiver mentioned, “Not everyone can be her caregiver … because the mother-daughter bond is strong” [CGF 3]. Furthermore, parents perceived that the worst situation for care giving would be when both parents were to contract COVID-19. A caregiver expressed that she was unwilling to ask the siblings of people with IDs to provide care. She said, “I do not think it is fair to ask his sister to do it” [CGM 17].

Caregivers were afraid of the pandemic affecting facilities or schools. One caregiver mentioned, “[If pandemic occurred in care facilities, leading to their closure], there would be a severe burden on the caregivers [because caregivers have to take care of the people with IDs all day long in their home]” [CGM 2]. Moreover, some people with IDs are vulnerable to infections because of the underlying disease. One caregiver said, “Our children have immune system disease other than IDs, so they are at high risk for serious illness” [CGF 2]. Another caregiver said, “she [the person with an ID] has a cardiac and lung trouble, I am really worried about her being infected” [CGM 23].

Parents mentioned the need for care services when the primary caregiver is sick, particularly when the caregivers tested positive for COVID-19. One caregiver stated, “There should be a short-stay place or a short-stay place that can accept such a person if the person or the family member becomes infected or becomes a close contact” [CGM 5]. They also noted experiencing difficulty in accessing medical services when people with IDs tested positive for COVID-19 and required hospitalization. A caregiver mentioned, “If a person with an ID is infected with the COVID, I would like to make sure that he or she can be hospitalized, but in reality, many hospitals refuse to admit him or her, and it might be difficult for the hospital to admit him or her unless it has a psychiatric department” [CGM 5].

**Fostering understanding on the COVID-19 pandemic.** Given the limited comprehension of people with IDs, caregivers found it challenging to foster understanding on the virus itself and the necessity for continuous lifestyles changes. One caregiver claimed, “The first thing we had to do was to figure out how to tell him [a person with an ID] about the COVID-19 in a simple way since he could not see it [and therefore it was difficult for him to understand]” [CGM 8]. Another stated, “I had to tell him that it was full of germs” [CGM 22]. According to caregivers, people with IDs who used to go out a lot asked loudly and repeatedly, “Why, why can’t I go outside?” [CGM 17].

The limited understanding of people with IDs regarding COVID-19 is also related to their limited understanding on sanitary/hygiene issues, of which mask wearing are one of the main concerns. Several people with IDs were reluctant to wear masks and attempt to keep their nose out of the mask. In Japan, where 90% of the population wears masks (Market Research Center Japan (NRC), 2021), people with IDs and their caregivers seemed to receive unpleasant gazes from people around them in public places when people with IDs do not cover their noses with their masks. One caregiver stated, “He cannot wear masks properly” [CGM 5], whereas another stated, “After wearing it for a long
time, he takes it off and plays with the string” [CGM 19]. Moreover, one caregiver stated, “If we cannot wear a mask properly, we will still be looked down upon” [CGM 12]. According to the caregivers’ view, all people, not only those with IDs and their families, experienced stress due to COVID-19-related lifestyle changes. One caregiver indicated, “It is the COVID-19, so people are definitely on edge” [CGM 3]. Caregivers also strongly attempted to keep their children and themselves clean. One caregiver insisted, “Make sure they [people with IDs] wash their hands and gargle when they get home” [CGM 13]. Given their limited understanding, people with IDs are also unable to performed actions that mitigate the spread of the virus. A caregiver stated, “He cannot act like to avoid passing on the virus to others” [CGM 19].

However, it is worth noting that the COVID-19 epidemic promoted not only fear or anxiety but also positive aspects in some of the study participants. Some caregivers claimed that their children with IDs were gradually adapting to their new lifestyles, including wearing masks or washing their hands. One caregiver mentioned, “Of course he took off the mask at first when he [a person with an ID] went to the office, but as we put it on him again and again, now he can keep it on for a while without much reluctance” [CGM 2]. Caregivers also indicated that people with IDs developed patience as the COVID-19 pandemic progressed. One caregiver stated, “For him [a person with an ID], patience was something he could not see [and therefore could not understand], but he was able to develop patience and perseverance [by experiencing the COVID-19 pandemic]” [CGM8].

Lack of pastime activities. During the first wave of the pandemic in Japan in April and May 2020, most schools and several care facilities had closed. Numerous daycare centers and swimming pools had also closed. Parents mentioned that people with IDs had been forced to stay home those days. The participants understood that people with IDs had few hobbies they found fulfilling, thereby making it challenging for them to pass long hours each day. A caregiver indicated, “They [people with IDs] cannot pass the time on their own” [CGM 19]. Another stated, “There is not much that a child with a disability can do [to pass the time]” [CGM 4]. Furthermore, closure of schools or facilities, which reduces the number of pastime activities, could even lead to problematic behaviors. One caregiver reflected, “She [a person with an ID] stayed in a small space at home all the time, so she is stressed out and she started to hold a towel in her hand all the time” [CGM 4]. Another caregiver mentioned, “When the office said they were going to be closed, all the weekdays would be empty. We were really troubled” [CGM 23].

Interestingly, however, as people experienced the new normal under the COVID-19 pandemic, some participants began to question whether the pre-pandemic routine of running errands incessantly was too much for people with IDs. One caregiver realized, “I wonder if it was an opportunity to reevaluate a life that was kind of too messed up” [CGM 15]. Meanwhile, another said, “He [a person with an ID] might not want to go out” [CGM 18]. “He [a person with an ID] might like a monotonous life against my expectation” [CGM 12].

When the parents are gone. Some caregivers felt exhausted because of continues care. One caregiver said, “I have been in a situation where I cannot take a break even though I am getting older, and I am worried that it will last forever” [CGM 11]. Caregivers can age further or die in the future. As such, they were worried about the availability of medical services for their children with IDs should they become ill in the future. One caregiver stated, “I wonder they [someone who care the people with IDs in the future] will ever notice when he is sick” [CGM 18]. Another caregiver mentioned, “How does she [a person with an ID] get to the clinic?” [CGF 4]. Caregivers strongly desired a temporary care facility that people with IDs could use after work, even when they become adults. One
caregiver stated, “I think it would be very helpful if there was a place where people with IDs could stay after work, even after they reach adulthood, like a day service” [CGM 12].

**Needs**

**Need for a place where caregivers can share information and concerns.** Caregivers perceived the need for a place where caregivers could discuss and share their information and concerns. Most parents indicated that they experienced difficulty collecting appropriate information for their care or services. Parents wanted government services that could provide information related to people with IDs, such as what kind of welfare services are suitable for their children with IDs or when to start procedures to receive disability pensions. One caregiver stated, “If parents do not move around, there is no place to get information about it. If there had been such a contact point, I would have been able to deal with it sooner” [CGM 3]. Another caregiver also stated, “It would be nice to have a chance to talk about the difficulties with other caregivers a little more… to let off steam?” [CGM 15]. Caregivers also desired counseling services to help calm those who care for people with IDs. The same caregiver stated, “It is like, I should not say this because everyone is having a hard time, and I think everyone is already holding back, so, um, it would be better if there was a place where people could escape the pain a little more” [CGM 15].

**Government and welfare services, please be more flexible!** Caregivers mentioned that they needed more flexible government and welfare services. For instance, they wanted governments to provide mobility support services that satisfied the needs of the individuals. One caregiver stated, “I often wonder individually if this child [a child with an ID] needs this [service], or that this child [a child with an ID] needs this [services], or that this child [a child with an ID] can develop this [skill] more. So, I wonder if there is something I can do [to choose the appropriate welfare services for each person]” [CGM 3]. Moreover, one mother claimed, “I would like to see more services for people with severe and profound IDs, as there are limited facilities available for them” [CGM 10]. The same caregiver also mentioned, “After experiencing the hospitalization of my daughter with an ID (due to bone fracture), I felt he need for assistance services during hospitalization” [CGM 10]. The same mother also said, “The same goes for short stays, including respite hospitalization.”

**More support for care workers.** Several parents expressed their gratitude to the care workers. When the first episode of the COVID-19 pandemic occurred, many care facilities decided to continue conventional care as much as possible. Caregivers recognized that their efforts saved many caregivers. One caregiver stated, “There were really only a few workers [in the facilities], and they really had to stay awake to deal with them [people with IDs]” [CGM 7]. Furthermore, people with IDs find it difficult to prevent the spread of the virus by wearing masks or other means, placing care workers at risk for infection. Therefore, caregivers felt an urgent need to prioritize the vaccination of care workers. One caregiver mentioned, “Vaccinations for staff working in the care facilities could be given a little more priority” [CGF 3]. The parents also perceived the necessity of improving labor conditions for care workers, such as salaries or social status. Another caregiver emphasized, “There is always a shortage of labor, especially for care workers, so I would like to see their wages raised a bit more… I think the world should be more aware of the position of those who work in the welfare sector, like those who work in medical institutions. I think it would be good for the world to know more about them, or rather, to know them as a profession with more status” [CGM 12].
Reasonable modifications in health care. The Americans with Disability Act defines reasonable modifications in health care as “the adjustment of policies, practices, and procedures, if needed, to provide goods, services, facilities, privileges, advantages, or accommodations” (Nadeau, 2020). Most of the caregivers highlighted the need for reasonable accommodations in hospitals for people with IDs. Moreover, the caregivers felt that many people with IDs had a problem with staying or waiting for a long time. One caregiver stated, “There are many people [with IDs] who have hard time waiting” [CGM 9]. Another caregiver mentioned, “He [a person with an ID] does not sit still, he is wandering around” [CGM 18]. The caregivers believed that this problem also affected their access to health care considering that long waiting times in hospitals are a serious problem. Particularly in the COVID-19 pandemic, taking people with IDs to a large vaccination site was the new emerging concern. One caregiver stated, “It is impossible for her [a person with an ID] to be asked to wait somewhere [at a large vaccination site]” [CGM 3]. Hence, many caregivers perceived the need to develop a medical service system for people with IDs, such as priority appointments or waiting in a private room with a caregiver. One caregiver stated, “I would like to see a hospital that gives priority to people who have difficulty waiting, so that they can make appointments at a time when they do not have to wait” [CGM 19]. Moreover, as described earlier, caregivers perceived that they could not leave people with IDs alone in hospitals. One caregiver stated, “I hope hospitals create a [waiting] space for us [the caregiver and a person with an ID] to be together” [CGM 18].

Discussion

The present study identified eight significant themes related to their concerns and needs of people with IDs and their caregivers. Four of them are concerns: “what if we get infected with the COVID-19!,” “fostering understanding on the COVID-19 pandemic,” “lack of pastime activities,” and “when the parents are gone.” Meanwhile, the other four are their needs: “need for a place where caregivers can share information and concerns,” “government and welfare services, please be more flexible!,” “more support for care workers,” and “reasonable modifications in health care.”

Concerns

What if we get infected with the COVID-19!. This theme is the principal concern of caregivers during the pandemic. The majority of families in Japan, to which most people with IDs and their parent caregivers belong, are nuclear families (Statistics Bureau, Ministry of Internal Affairs and Communications, 2010). Therefore, the principal caregivers (mainly mothers) faced the challenge of finding another caregiver in the family should they become infected or a close contact and are unable to care for their children with IDs. In this situation, the principal caregivers may also have trouble finding social support for their children with IDs.

The COVID-19 pandemic has presented an unpredictable and urgent situation. Prior studies have reported that people with IDs were vulnerable to environmental changes during disasters and have increased challenging behaviors due to strong anxiety and fear (Kondo and Shiose, 2019; Takahashi et al., 1997; Taki and Tojo, 2013). Increased stress in disaster situations had also been observed in caregivers of people with IDs (Kondo and Shiose, 2019; Sawa et al., 2013). Indeed, Kondo et al. highlighted the importance of the presence of someone who the caregivers of people with IDs can rely on. Investigating the needs and concerns of people with IDs and their caregivers during the COVID-19 pandemic will provide useful information regarding the preparation of future emergency responses.
Fostering understanding on the COVID-19 pandemic. Reports have found that young children find it difficult to adapt their behavior to daily life during the COVID-19 pandemic (Mitchell, 2020). Our study found that because people with IDs also had limited intellectual capacity, understanding COVID-19 and its preventive measures were challenging for people with IDs. Several publishers have attempted to produce books that use stories and direct descriptions to illustrate the difficulties of life during the COVID-19 pandemic (Mitchell, 2020). Some of these books are aimed at children with developmental problems, including children with IDs. Considering the expected usefulness of these methods, they are also expected to become more widespread to assist in explaining the pandemic to people with IDs.

Caregivers also mentioned the difficulty in getting people with IDs to understand the need for masks and wear them. A survey of medical professionals reported that 78.4% of them felt uncomfortable wearing masks (mostly disposable surgical masks) (Cheok et al., 2021). Even medical personnel who understand the importance of masks feel uncomfortable wearing them (Cheok et al., 2021). This can explain why people with IDs are understandably reluctant to wear them. Additionally, some people with IDs may also have comorbid ASD, which presents with the symptoms of hypersensitivity (American Psychiatric Association, 2013). In fact, studies have reported sensory problems associated with mask wearing and hand washing in children with ASDs (Mutluer et al., 2020). Therefore, comorbid ASD may have influenced the refusal of some people with IDs, who had difficulty wearing a mask and lacked understanding regarding COVID-19, to wear a mask.

Lack of pastime activities. People with IDs tend to lead passive lives (i.e., they tend to live with little autonomy), with few opportunities to choose leisure activities (Rogers et al., 1998; Verdonschot et al., 2009). Given that schools, care services, and activities had closed owing to the pandemic, people with IDs had to spend their “free” time elsewhere. Both people with IDs and caregivers had a stressful time. According to our results, “the lack of pastime activities” led to challenging behaviors among people with IDs. A previous study argued that challenging behaviors represented a communication mismatch between people with IDs and surrounding people (Kevan, 2003). The same study suggested that the challenging behaviors of people with IDs might indicate the “desire for escape.” Another study reported that language impairments were associated with severe aberrant behaviors (Disabilities, 2000). A systematic review and meta-analysis reported that stress, anxiety, and depression occurred in the general population during the COVID-19 pandemic (Salari et al., 2020). People with IDs had little leisure time, led stressful lives, and had no method of communicating their feelings to others, which may lead to challenging behaviors.

Furthermore, some participants began to wonder whether the pre-pandemic routine of running errands incessantly was too much for people with IDs. An apparent difference exists between the state of daring to do nothing and the state of having nothing to do (Kundera, 1997). Although people today tend to dislike not having anything to do (Kundera, 1997), the pandemic appears to have made some participants realize that even having nothing to do can actually be taken positively rather than negatively.

When the parents are gone. In Japan’s super-aging society, the “8050 problem,” which describes a situation wherein a family with parents in their 80s have adult children who need care in their 50s, has been discussed in recent decades (Koyama et al., 2010). The aging parents often face financial hardships associated with raising their children in their 50s (KHJ All Japan Federation of Hikikomori Family Associations, 2019). This is also true in ID families (Hirai, 2017). Given the limited capacity of welfare facilities, parents are worried about the care their children would receive when they are no longer able to do so. Despite the movement in Japan to keep people with
IDs out of institutions, parents did not seem confident that their children with IDs would be able to live in the community as they do. Therefore, the biggest concern for caregivers was to make sure that the people with IDs could live peacefully.

Needs

Need for a place where caregivers can share information and concerns. While Japan’s social security system uses an application-based system, there are four major barriers to using the system (Goto, 2017). First, people may not be able to access the system given the occasional insufficient information from the government and other sources (Goto, 2017). Second, although the data is delivered properly, people may not be able to access the system because they do not know what it is (Goto, 2017). Third, despite being aware of the system, people are discouraged from using it due to the stigma and unfriendly responses from the government (Goto, 2017). Fourth, the system is too complicated, or the hurdles to exercising one’s rights are too high, placing a heavy burden on applications (Goto, 2017). Considering these facts, it is not surprising that caregivers struggled to receive adequate services.

There are many family groups around the world that share information and help each other (American Association on Intellectual and Developmental Disabilities (AAIDD, 2021; Japan Federation of Inclusion Associations For Hand in Hand, 2021; The Arc For people with intellectual and developmental disabilities, 2021). For instance, a Japanese family group of IDs was quick to express in May 2020 that people with IDs are vulnerable to the COVID-19 pandemic and associated environmental changes (Japan Federation of Inclusion Associations For Hand in Hand, 2020). However, opportunities for sharing feelings among those who are even closer to them would be more desirable, suggesting the need to increase opportunities for such grassroots exchanges.

Medical workers, such as doctors or nurses, generally do not seem to provide enough information to people with IDs and their caregivers regarding lifestyles and useful services for people with IDs. Ideally, social workers provide such information toward people with IDs and their caregivers. However, it is possible that not enough social worker systems had been established when the participants’ children with IDs were diagnosed. Additionally, caregivers might not have been conscious about social workers and expect doctors or nurses to provide such information. It is also possible that caregivers just desired more empathy from medical professionals. In fact, previous studies have reported a lack of education and knowledge regarding people with IDs among health care providers (Breau et al., 2018; Trollor et al., 2016; Ward et al., 2010), which could lead to negative attitudes and discrimination (Gibbs et al., 2008). Therefore, education for not only pediatricians and psychiatrists but also general healthcare professionals is crucial for promoting familiarization with people with IDs and their surrounding environments.

Government and welfare services, please be more flexible! & More support for care workers. There have been reports of burnout among care workers in facilities for people with IDs (Hasebe and Nakamura, 2005; Mutkins et al., 2011). Moreover, a study that interviewed staff working in facilities for people with IDs in Japan found that they were not satisfied with their treatment, particularly with their low salary, short holidays, and physically demanding work (Hiromitsu, 2008). Burnouts and dissatisfaction among staff working in facilities could lead to inappropriate care and increased risk of abuse. Therefore, society needs to improve the social status of staff working in facilities for people with IDs and attract more people into this field.
Considering Japan’s aging society, raising financial aid would be challenging. In fact, Japan’s public welfare expense amounted to 26,533,700,000,000 yen (i.e., 231,117,813,795 USD) in 2021—a 3.4% increase from the previous year (Ministry of Internal Affairs and Communications, 2021). This expense included children, the elderly, and those with disabilities (physical, intellectual, and mental). The government has worked on these issues as evidenced by their supplementary budget for the fiscal year 2021, which included funds to raise the monthly wages of nursing care workers, childcare workers, and nurses by next February. Moreover, 260 billion yen has been allocated to raise wages by about 3% (9,000 yen or 78 USD) per month (Yomiuri Shinbun, 2021b). Government-led efforts to promote projects to convey the appeal of nursing care to young people have also begun, and 360 million yen (i.e., 3,135,028 USD) has been allocated in budget for the fiscal year 2022 (Ministry of Health, Labor and Welfare, 2021; Yomiuri Shinbun, 2021a). However, some have suggested that increasing wages is not enough to improve the working environment of social staff employed in the disability field (Asahi Shinbun, 2021b). The current situation requires one person to care for a large number of patients, suggesting the need to review staffing standards. Furthermore, in the field of disability welfare, the characteristics of disabilities are diverse and highly individualized, making it harder than caring for the elderly or children, with a high possibility for serious manpower shortage (Asahi Shinbun, 2021b). Therefore, it is important to understand the needs of people with IDs and advocate for them.

Caregivers mentioned that social services, such as mobility support, are not flexibly provided. Another caregiver stated that support for those with severe and profound IDs was lacking. As mentioned above, diverse and highly individualized characteristics of disabilities require considerable manpower (Asahi Shinbun, 2021b). Ensuring adequate number of supporting staff should be the first approach toward improving the lives of people with IDs.

Reasonable modifications in health care. The current study revealed the importance of reasonable modifications (accommodations) in hospitals that help people with IDs receive adequate health care. A survey in NHS acute care hospitals across the UK suggested the importance of “communication adjustments that take into account the patient’s receptive and expressive language skills,” “accommodations for the patient’s ability to cope with different environments, changes in routine, unfamiliar procedures, and unfamiliar staff,” “accommodations for the need to change ways in which care and treatment are provided,” “participation and support of the patient’s caregivers as expert care partners,” “advocacy and support for mental capacity [i.e., mental capacity of people with IDs],” and “providing access to expertise in the care of intellectual disabilities” (Tuffrey-Wijne et al., 2014). These are important points that can also be applied in Japan.

Regardless of the COVID-19 pandemic, people with IDs find it challenging to access appropriate medical care due to problems associated with the inability to wait, dependency, and preventing the spread of the virus, etc. These problems are related to the individual level in the social-ecological model. Moreover, considering these problems from the viewpoint of health care access, these issues are related to the “ability to engage” in the Levesque model of health care access (Levesque et al., 2013). From one perspective, the limited ability of people with IDs to engage makes their access to health care more complicated than that for the general population. Furthermore, many other issues can inhibit access to health care for people with IDs, such as the lack of reasonable modifications.

Our study has several limitations worth noting. First, the combination of neurodevelopmental disorders, such as autism spectrum disorder, could very likely make life more challenging compared to having IDs alone. Although the sample size was not large enough to allow analysis according to disease group, future studies are warranted to explore the needs of each disease group. Second, only subjects with moderate, severe, and profound IDs were enrolled in this study, excluding those with
mild IDs. Thus, our results may not reflect those with mild IDs and their caregivers. Third, caregivers who participated in this study were likely to be highly conscious given that they belonged to parents’ community groups and participated in research. Therefore, the findings may not cover the perspectives of those who are socially disadvantaged and do not receive adequate social support.

Nonetheless, the current study has some implications warranting discussion. Given the limited number of people aware of the concerns and needs of people with IDs and their caregivers during the COVID-19 pandemic, the findings of this study would certainly provide medical professionals with valuable information for emergency assistance during disasters and other emergency situations and help policy makers establish relevant legislation. Our study found that caregivers were anxious about the hospitalization of people with IDs, especially in this critical situation. In the UK, the ID liaison nurse (IDLN) facilitates the provision of reasonable accommodation in health care settings (Gibbs et al., 2008; Tuffrey-Wijne et al., 2014). Introducing a certification system for IDLNs in Japan providing training may useful measures for reducing barriers toward accessing medical care among people with IDs and their caregivers. We also recognized that making people with IDs understand the COVID-19 pandemic is challenging. There are several initiatives that can help provide ID-friendly information using illustrations related to COVID-19, such as vaccination or wearing masks (National Rehabilitation Centers for Persons with Disabilities, 2021). We hope that these efforts would spread to various aspects of daily life and make life easier for people with IDs and their caregivers.

Furthermore, the results of the current study may be applicable when considering measures that would help people with IDs in developing countries face the COVID-19 pandemic. In Africa, people with IDs have been marginalized such that they “are excluded from normal daily activities” (Samboma, 2021) and “are shunned from society” (Samboma, 2021). A report from Botswana argued that the benefits of protection and control measures from COVID-19 should be made available to all (Samboma, 2021). Moreover, a study in Saudi Arabia focused on the impact of COVID-19 on children with ASDs and IDs and recommended enhanced rehabilitation sessions (Athbah, 2021). However, studies on people with IDs have generally been limited to Western countries. The current research conducted in Japan, a non-Western country, will provide valuable information for a broader perspective on the care for people with IDs and their caregivers. We also hope that the results of this study will help raise people’s awareness of the unique difficulties faced by people with IDs and their caregivers.

Conclusions

The current study identified the concerns and needs of people with IDs and their caregivers during the COVID-19 pandemic in Japan. The results of this study will certainly provide useful information that would help support people with IDs and their caregivers, especially when they need medical or social care under infection control and social-distancing policies.

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