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Disinfection behavior for COVID-19 in individuals with Down syndrome and caregivers' distress in Japan: A cross-sectional retrospective study

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Competing interests

The authors declared no potential conflicts with respect to the research, authorship, and/or publication of this article.

Availability of data and material

The datasets analyzed during the current study are not publicly available but are available from the corresponding author on reasonable request.

Authors' contributions

HF and MI contributed to the study conceptualization, development of methodology, investigation. HF conducted formal analysis and wrote the manuscript. MI contributed on previous version of the manuscript. All authors read and approved the final manuscript.

Ethics approval

This study was carried out in accordance with the ethical standards set forth in the 1964 Declaration of Helsinki and its later amendments, with consent from the participant. The protocol was approved by the Oita University Faculty of Education Research Ethics Review Board (R2-015).

Consent to participate

After explaining the details of the study to the participants and assured about the protection of their privacy, they were requested to complete the consent form and questionnaire. The response data of those who completed the consent form were included in the analysis.

Disinfection behavior for COVID-19 in individuals with Down syndrome and caregivers' distress in Japan: A cross-sectional retrospective study

Abstract

The COVID-19 outbreak affected the daily lives of individuals with Down syndrome, who were considered to have a higher risk of severe infection. While several studies have reported mental health issues in children and/or parents in the general population, no study has focused on people with Down syndrome and their caregivers. This study investigated the disinfection behaviors of individuals with Down syndrome and their caregivers' stress. A cross-sectional retrospective survey was conducted in October 2020. Caregivers of children and adults with Down syndrome were administered questionnaires including measures for practiced disinfection behavior in children, caregiver's child-related stress, and psychological distress. About half of the respondents' children practiced hand hygiene and mask-wearing behaviors, while physical distancing was performed less frequently. Habitual practices in physical distancing are affected by intellectual function. Logistic regression showed that caregivers' stress was associated with the irritability of individuals with the disorder (adjusted odds ratio [OR] = 8.44, 95% confidence interval [CI] 1.69–42.09) and the burden of infection-prevention behaviors for people with Down syndrome (adjusted OR = 4.26, 95% CI 1.88–9.65). This study showed the characteristics of disinfection behaviors in individuals with Down syndrome and associated factors for serious caregiver stress.

Keywords: caregiver, COVID-19, Down syndrome, health behaviors, infection prevention, psychological distress

Introduction

Coronavirus disease (COVID-19) is a major public health issue in international society (World Health Organization, 2021). Although vaccines are currently available, non-pharmaceutical preventive measures were the essential tools to control transmission and outbreak of the disease in countries in the beginning (El Guerche-Seblain et al., 2021). In response to the spread of COVID-19 in February 2020, the Japanese government requested that all schools nationwide be temporarily closed from March 2nd, and many special needs schools were subsequently closed as well. On April 7th, a state of emergency was proclaimed. This was extended to the Tokyo metropolitan area and then to all other prefectures in the country on April 16th. The state of emergency was lifted in 39 of the 47 prefectures, followed by the rest of the prefectures on May 14th and May 25th, respectively (Ministry of Health, Labour and Welfare, 2020). During the period between the request for temporary school closures and the lifting of the state of emergency, most people spent most of their time at home, which meant that the COVID-19 countermeasures had to be implemented at home without any prior preparation.

In the Oita Prefecture (the region examined in this study), schools were also closed during April; however, educational activities resumed from May 11th. Children and educators were expected to follow the infection prevention measures established by the government as much as possible in their activities (Ministry of Education, Culture, Sports, Science and Technology, 2020). This included hand washing, physical distancing, and wearing a face mask. The per capita infection rate of the Oita Prefecture was 2.53 in March 2020 and 2.71 in April 2020, indicating that the spread of infection was not critical but that infections were occurring at a steady level.

As a COVID-19 infection countermeasure, self-health management (e.g., recording body temperature and signs of infection) was promoted in Japan along with hand hygiene, physical distancing, wearing a mask in public settings, and ensuring adequate ventilation (Ministry of Health, Labour and Welfare, 2020). Previous reports suggested that parents experienced a significant amount of parental

stress during school closures in Japan (Hiraoka & Tomoda, 2020; Yamamura & Tsutsui, 2021). Even in other countries, including the United States, Czech, and Germany, parents felt great distress during the school closure, which caused parental difficulties in managing the learning activities of children without educational resources or time to teach children (Brom et al., 2020; Davis et al., 2020; Dhiman et al., 2020; May et al., 2021; Teslya et al., 2020). In addition, behavioral problems in children, which were prevalent during the stay-home period (Nakachi et al., 2021), could affect the mental health of caregivers (Christner et al., 2021; Kim et al., 2021; Stavridou et al., 2020). Particularly, caregivers of children with intellectual and developmental disabilities, including Down syndrome, may experience more challenges during this pandemic (Courtenay, 2020).

Recent research suggests a higher risk of COVID-19 infection in individuals with Down syndrome (Clift et al., 2020; Emami et al., 2021; Emes et al., 2021; Gleason et al., in press; Huls et al., 2021; Illouz et al., 2021; Semenzato et al., 2021). Down syndrome is a chromosomal abnormality caused by chromosome 21 trisomy. It is frequently associated with diseases such as congenital heart disease, endocrine disorders, and autoimmune diseases, as well as developmental delays and moderate or severe intellectual disability in most cases (Ram & Chinen, 2011; Weijerman & de Winter, 2010). According to a survey conducted in Japan, 93% of children with Down syndrome also suffer from other health complications, with 64% having a cardiac disease, 19% with thyroid disease, 4% with epilepsy, and 14% having other diseases (Namatame et al., 2019). Therefore, infection countermeasures are more important for those with Down syndrome, who are at an increased risk for severe illness, than for those who are not (Malle et al., 2020). Since Down syndrome is associated with moderate or severe intellectual disability, those affected by it are considered to have difficulty in complying with the behavioral changes required by COVID-19 countermeasures, which have become the “new normal” (Courtenay & Perera, 2020). Since individuals with Down syndrome also have a higher risk of infection and have difficulty changing their behaviors (Illouz et al., 2021), surveys of their caregivers are necessary to understand the difficulties and impact of the pandemic on the mental health of caregivers (Dhiman et al., 2020). Despite some expert

argued cognitive ability may hinder adherence to public infection countermeasures (Courtenay & Perera, 2020) and the need to improve infection protection measures for people with intellectual disabilities during the outbreak (Doody & Keenan, 2021), no published studies are currently available on the disinfection behaviors of people with Down syndrome for COVID-19.

The purposes of this study were to examine 1) the infection countermeasure behaviors of individuals with Down syndrome, 2) the caregivers' distress during April 2020 as a result of the COVID-19 pandemic, and 3) to identify the factors affecting the implemented infection countermeasures and caregivers' distress.

Methods

Participants

The study participants are the primary caregivers of children and adults with Down syndrome who were members of the Oita Prefecture Family Support Group for Down Syndrome (104 families). The group offered monthly group therapy and parent sessions and recreation for children with Down syndrome before the COVID-19 pandemic period. At the time of this study, these activities were not available to the families. Caregivers of children and adults with Down syndrome were eligible.

Procedure

This is a retrospective study of the caregivers of children with Down syndrome, conducted in October and November 2020, in light of the situation in April 2020. Problems such as infection countermeasures for children and an increased burden on caregivers during the school closure period were believed to have

emerged because of the state of emergency in April 2020. Therefore, in addition to the items related to the attributes of their children, respondents were asked to recall the period.

In October 2020, the members of the Oita Prefecture Family Support Group for Down Syndrome were asked to participate in the study via a mailing list, and 104 registered families were subsequently asked to respond to either an online (Google form) or printed questionnaire. A reminder was sent one week after the request for participation in the study, and data from those who responded by the end of November 2020 were included in the analysis.

Questionnaire

The demographic information obtained were a) child's age, gender, school attendance, major comorbid diseases, level of intellectual disability, and b) parental age, gender, and employment status. The questionnaires were developed by the authors for the current survey, except for the K6 for psychological distress. The items of the measures were developed based on the countermeasures provided by the government (Ministry of Education, Culture, Sports, Science and Technology, 2020; Ministry of Health, Labour and Welfare, 2020), common behavioral issues in children, and a report describing caregivers' stress in the period (Okuyama, 2021). The questionnaire items included the demographic information of children with Down syndrome and their caregivers (e.g., age, gender, comorbidities), the frequency of infection countermeasures implemented by the children, their understanding of infection countermeasures, techniques used for countermeasures and their effectiveness, children's stress responses, caregiver stress regarding infection countermeasures and daily life in the situations (i.e., with restrictions in daily life), and psychological distress of the caregiver.

Frequency of Infection Countermeasure Implementation

Respondents were asked how frequently their children observed infection countermeasures, including hand hygiene (e.g., hand washing and alcohol sanitizing), wearing masks, and physical distancing. Each item was scored using a 3-point scale comprising scores of 0 (*never*), 1 (*sometimes or partially*), and 2 (*usually or habitually*). The item scores in each of the three areas were then averaged to obtain an area score. Three area subscales had high internal consistency in the current sample (Cronbach's $\alpha = 0.87$, 0.91, and 0.78, respectively). The higher the score, the more likely the child was to implement infection countermeasures on their own.

Understanding of Infection Countermeasures

Respondents were asked to indicate how much they thought their children understood the infection countermeasures. The questionnaire consisted of four items: the necessity of hand hygiene, the importance of wearing masks, the importance of physical distancing, and the importance of COVID-19 countermeasures in general. They were asked to respond to these four items using a 5-point scale ranging from 0 (*did not understand*) to 4 (*understood well*). Cronbach's alpha for the scale was high ($\alpha = 0.96$). A higher score indicated that the caregivers believed that their child had a better understanding of the infection countermeasures.

Techniques Used for Infection Countermeasures and Their Effectiveness

Respondents were asked to share the techniques they used for personal infection countermeasures and their respective effectiveness. The countermeasures were divided into five categories: verbal instructions, showing videos as examples, showing pictures and illustrations, caregivers demonstrating the examples, and using a checklist. For each of these five items, caregivers were asked to select "did not implement"

for the techniques they did not implement, and to answer using a 3-point scale comprising scores of 1 (*not very effective*), 2 (*somewhat effective*), and 3 (*very effective*) for those that they did implement.

Behavioral Issues in Children

Respondents evaluated the behavior issues (e.g., decreased interest in play, increased irritability, difficulty concentrating, sleep problems, and self-harm or other harm) during the period of school closure and stay-home based on the state of emergency in Japan. Each respondent answered using a 5-point scale ranging from 0 (*never*) to 4 (*almost always* [i.e., almost daily]). The scores were dichotomized as “0” (absence) for scores 0 and 1, and “1” (presence) for scores of 2 or more.

Parental Burden of Infection Countermeasures

Respondents were asked to indicate the extent to which they felt burdened by infection countermeasures for their children. They were asked to respond to three items: hand washing, mask wearing, and physical distancing for their children. The scores for the three items were then averaged, and the higher the score, the more caregivers felt burdened by the infection countermeasures for their children. This scale showed adequate internal consistency (Cronbach’s $\alpha = 0.77$).

Child-related stress

Respondents were asked to answer 11 questions about their child-related stress as caregivers while living in a state of emergency. They were asked to respond using a 5-point scale ranging from 0 (*not at all*) to 4 (*extreme*). The total score of the 11 items was then calculated, and the higher the score, the more the caregivers felt child-related stress during this period. The scale showed high internal consistency

(Cronbach's $\alpha = 0.88$). The respondents were divided into those with serious stress ("1") and those without ("0") based on the 75% interquartile of the sample (≥ 18).

Psychological Distress

The 6-item version of the Kessler Psychological Distress Scale (K6) was used to assess the psychological distress of caregivers as of April 2020. It has been used in various epidemiological studies to assess the degree of psychological distress (Kessler et al., 2002). It is also used to screen for depression and anxiety disorders, and a score of five or higher has been used as a cutoff value in the Japanese population (Sakurai et al., 2011). The K6 showed high internal consistency in the current sample (Cronbach's $\alpha = 0.86$). A K6 score of five or more was used to classify respondents with psychological distress.

Statistical analysis

Statistical analysis was performed using SPSS 22.0 and R 4.0.4 (IBM Corp, 2013; R Core Team, 2021). The characteristics of the sample and measures related to COVID-19 disinfection behavior were reported as counts and percentages. To compare the differences by intellectual function, we used the Mann-Whitney U-test for disinfection behaviors and caregiver burden for disinfection countermeasures for children. We used Spearman correlation coefficients to examine the association between the number of medical comorbidities in children, child-related stress, and psychological distress.

Because we had missing values in the variables used in the following logistic regression models, we applied multiple imputation with chained equations algorithm (MICE) to impute the missing data to reduce the bias in estimation caused by the missing data. An incomplete response was observed in the severity of intellectual disability ($n = 7$; 9.6%). Missing data were considered to be missing at random based on the pattern of the original dataset. The imputation procedure was performed using the *mice*

package (van Buuren & Groothuis-Oudshoorn, 2011). In the procedure, multiple datasets were imputed, and the estimates obtained for each dataset were combined to account for uncertainty in the imputed data. Logistic regression (logreg) was used for the estimates because the item was a binary variable. We generated 300 imputed datasets using the demographic variables and variables used in the logistic regression models.

We then investigated the independent effects of children's behavior issues and the caregiver burden of disinfection for children on caregiver burden and psychological distress using logistic regression analyses. Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated. Multivariable models were limited to only two factors because of the number of events and respondents in this study. We entered a variable of interest (i.e., behavior issues and burden of disinfection for the child) as an explanatory variable and intellectual disability as covariates to estimate the risk of caregivers' psychological distress and child-related stress in each model. Statistical significance was set at $p < 0.05$.

Ethical Considerations

After explaining the details of the study to the participants and assured about the protection of their privacy, they were requested to complete the consent form and questionnaire. The response data of those who completed the consent form were included in the analysis. This study was approved by the institutional review board (R2-015). This study was conducted in accordance with the ethical standards set forth in the 1964 Declaration of Helsinki and its later amendments.

Results

The respondents were 73 caregivers of individuals with Down syndrome (response rate: 70.2%). Most of the respondents were mothers (89%). The mean child age was 12.6 (SD = 10.5) and 23.3% were 18 years

of age or older. The mean respondent age was 46.2 (SD = 10.9). Table 1 shows the demographic characteristics of the individuals with Down syndrome and their caregivers. None of the respondents were infected with COVID-19 during this period.

As per the caregivers' responses, the children with Down syndrome undertook various infection countermeasures (Table 2). Approximately more than half of the children usually perform hand washing (76.7%), the use of alcohol sanitizer (58.9%), and the wearing of masks (57.5%), although the rate varies depending on each behavior. A relatively smaller number of children habitually maintained physical distance from others (17.8%). With regard to appropriate hand hygiene or wearing a mask, about 60% or more understood well or to a certain degree (68% and 59%, respectively) the necessity of following these measures; whereas, 42% did not adequately understand the need for distancing from others (Table 3). The Mann-Whitney U-test showed that children with severe intellectual disabilities performed fewer countermeasures related to physical distancing ($U = 348, p = 0.045$). Other measures did not differ statistically significantly by intellectual function (hand washing, wearing a mask, and caregiver burden). The Spearman's correlation test did not find statistically significant associations between the number of health comorbidities and caregiver burden and psychological distress ($p > 0.05$).

Caregivers used several techniques to teach infection-prevention behaviors to their children. The major methods employed at home were communicating instructions orally (68%, somewhat or very effective) and by setting examples (65%, somewhat or very effective). Other techniques were used less frequently (less than 30%). Although no severe behavioral issues manifested during the period, about 10% of children with Down syndrome lacked motivation to participate in activities, exhibited irritability, and had difficulty concentrating (Table 4). Twenty respondents (27.4%) answered that they had serious child-related stress. Of the total respondents, 26 (35.6%) scored above the cutoff (5 or more) for psychological distress, whereas 4% had a severe range of distress ($K6 \geq 13$).

Table 5 shows the ORs and 95% CIs of the possible risks for psychological distress and caregiver stress. Since self-harm or violence among family members was rare in the current sample, this measure was not included in the logistic regression analyses. Psychological distress of the caregivers was not significantly associated with behavioral issues or the burden of disinfection for their children, although irritability had slightly a higher OR (4.21, 95% CI 0.92 to 19.18, $p = 0.063$). Child-related stress was significantly associated with irritability issues in children (adjusted OR 8.44, 95% CI 1.69 to 42.09, $p = 0.010$), and the burden of infection prevention for children (adjusted OR 4.26, 95% CI 1.88 to 9.65, $p = 0.001$).

Discussion

This was a retrospective survey of the caregivers of people with Down syndrome with regard to their children's infection countermeasure behaviors and the respondents' child-related stress in light of the COVID-19 pandemic. While hand hygiene and mask wearing were widely practiced as infection countermeasures, physical distancing was relatively less practiced. This study identified the burden of children's infection countermeasures and irritability during the period of social restrictions (e.g., school closure and stay-home request) as factors affecting child-related stress. More than half of the respondents' children usually practiced hand washing, hand sanitizing, and mask wearing, and caregivers implemented oral instructions and set examples to teach these behaviors.

Contrary to concerns that intellectual function may hinder the adherence to public health measures (Courtenay & Perera, 2020), hand hygiene and mask wearing were habitually used in people with Down syndrome. The development of such behaviors in people with Down syndrome may have been attributed to adequate support from the family members and care practitioners (del Carmen Ortega et al., 2020). Infection countermeasures that were relatively infrequently implemented were those related to physical distancing. Maintaining physical distance is difficult for individuals with severe intellectual

disabilities as it involves the abstract concept of interpersonal distance, which results in irregular implementation. Prior to the COVID-19 outbreak, schoolteachers in special education schools managed such routine behaviors in Japan; however, caregivers were required to teach disinfection behaviors to their children during this period. Such factors may affect the relative difficulties in physical distancing. Because the participants of this study were not infected by COVID-19, we cannot examine the association between infection and the frequencies of infection-prevention behaviors in children. Accumulative evidence suggests that infection countermeasures, such as physical distancing and facial masks, are effective in reducing the risk of COVID-19 (Doung-Ngern et al., 2020; Kwon et al., 2021; Li et al., 2021), although it may depend on the condition in the area and other local contexts (Escandon et al., 2021). Compliance with infection prevention measures and early detection would be effective methods to prevent outbreaks in people with or without disabilities (Akaishi et al., 2021; Hollis et al., 2021). The findings of this study may contribute to helping people learn non-pharmaceutical infection countermeasures in the education and welfare sectors. Because the findings are based on a small sample and are all from one region, limiting external validity, further research is required to improve strategies for learning and maintaining infection prevention measures in people with Down syndrome. Besides, potential confounding variables (e.g., if the individual with Down syndrome was isolated at home and did not need to wear a mask frequently vs. if the individual was frequently in a public space necessitating a mask) were not collected, which could have affected the results.

Irritability in individuals with Down syndrome may also cause serious caregiver stress. School closure and stay-home circumstances increase the respondents' time spent with their children. Children's emotional issues may hinder daily life activities and their care during the pandemic as caregivers receive limited support and social resources (Cluver et al., 2020; Vogelbacher & Attig, 2022). Increased caregiver stress and teaching roles can be accelerators of depressive and anxiety symptoms during this period (Davis et al., 2020; Kimura et al., 2021). As previous studies have suggested, the bidirectional effect of the pandemic on mental health issues in caregivers and child behavioral problems may be a target for

families with difficulties (Spinelli et al., 2020; Ueda et al., 2021). For example, parents experiencing child-rearing stress or mental health problems may perceive their child's behavior as having worsened (Spinelli et al., 2020). In addition to the emotional support for both children and parents, reducing the risk of infection (e.g., vaccination) and caregiver burden regarding disinfection for the child would alleviate the parenting stress of caregivers, which may lead to mitigation of parental distress (Fazzi & Galli, 2020; Tambling et al., 2021). Securing access to support resources may alleviate parental stress even in circumstances where there are restrictions on going outside owing to the spread of infectious diseases (Dababnah et al., 2021). It is also important to note that these questionnaires were developed for the current study by the authors, and there was no evidence to support the validity of the measures. Using validated measures that fit the COVID-19 pandemic is strongly recommended in future research. Additionally, variables of interest (e.g., caregiver support or caregiver employment) were not gathered and could not be evaluated as potential mediating variables. Therefore, careful interpretation of the results is required.

A previous study suggested that unmet mental health care needs among caregivers of individuals with intellectual disabilities are at risk for caregivers themselves and those for whom they care (Willner et al., 2020). Additionally, parents of children with intellectual disabilities had worse mental health and less social support during COVID-19 pandemic (Willner et al., 2020). When caregivers cannot access education and community resources, virtual interaction (online communication tools) can be a useful tool for connecting with services (Bjornstad et al., 2021). However, this is not necessarily the same for individuals with intellectual disabilities (Constantino et al., 2020). More physical contact, direct interaction, and attention to motivational conditions may be required for effective treatment and education for individuals with intellectual disabilities.

In comparison with a survey conducted on the Japanese general population in the Tokyo metropolitan area where the per capita infection rate was higher, 11% of respondents had severe psychological distress based on the K6 scale, compared to 4% of the caregivers in the present study

(Kikuchi et al., 2020). This difference could have been due to disparities in behavioral restrictions and lifestyle changes based on the regional situations.

Limitations

The first limitation of this study is the small sample size, which may have prevented the detection of significant differences or associations. Additionally, the target population was limited to only one region in Japan and parents who participated in a support group. The degree of living restrictions would have differed due to differences in the per capita infection rate throughout Japan, and consequently, the burden on caregivers would have differed. This may limit the external validity and generalizability of the findings as discussed above. Accordingly, an increase in the number of participants and a nationwide survey would be more desirable. The second limitation is that the survey was designed to be answered retrospectively for April 2020. Since it was a retrospective survey, the passage of time could have distorted the results due to memory bias. Third, the information about family characteristics, including the number of family members at home, marital status, and received services or support, was limited. Other potential confounding variables, such as the frequency of opportunities to go out with children and a lack of need for disinfection behaviors, may affect the findings. Fourth, we did not find a significant association between health comorbidities and caregiver child-related stress. The reason for the factor not being correlated with parental strains is not clear, but it may be because we did not evaluate the severity of the comorbidities, which would affect the perception of the threat of COVID-19 in caregivers.

Conclusion

This study examined the infection-prevention behaviors of Japanese individuals with Down syndrome, child-related stress, and psychological distress using a retrospective survey. Hand hygiene and mask

wearing were well-practiced, while physical distancing was performed less frequently during this period. Caregivers' stress was associated with the irritability of children and the burden of infection-prevention behavior for people with Down syndrome. Access to support resources for the emotional responses of children may mitigate parental stress even in circumstances where there are restrictions on going outside owing to the spread of infectious diseases.

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Table 1. Characteristics of the respondents

	n = 73	(%)
Individuals with Down syndrome		
Gender		
Male	32	(43.8)
Female	41	(56.2)
Age		
<6	28	(38.4)
7-12	22	(30.1)
13-18	6	(8.2)
>18	17	(23.3)
Attending school (age≤18)		
Yes	41	(56.2)
Major comorbidities		
Heart defects	22	(30.1)
Thyroid diseases	23	(31.5)
Epilepsy	1	(1.4)
Other diseases	12	(16.4)
Intellectual disability		
Mild to moderate	43	(58.9)
Severe	23	(31.5)
Unknown	7	(9.6)
Caregiver variables		
Relationship		
Mother	65	(89.0)
Other	8	(11.0)
Age		
<40	20	(27.4)
40-49	31	(42.5)
>50	22	(30.1)
Employment status		
Not employed	32	(43.8)
Partly	21	(28.8)
Employed	20	(27.4)

Table 2. Frequency of infection countermeasure implementation in children

	Did not perform at all		Performed it sometimes or partially		Performed it usually or habitually	
	n	(%)	n	(%)	n	(%)
Hand washing, Alcohol-based hand disinfection						
Wash with soap	7	(9.6)	10	(13.7)	56	(76.7)
Wash finger tips and between fingers	8	(11)	30	(41.1)	35	(47.9)
Take time (about 30 secs) to wash	15	(20.5)	37	(50.7)	21	(28.8)
Wipe hands with a clean handkerchief or towel after hand washing	6	(8.2)	13	(17.8)	54	(74)
Wash hands after returning home or before meal	5	(6.8)	16	(21.9)	52	(71.2)
Gargle when returning home	20	(27.4)	23	(31.5)	30	(41.1)
Use an alcohol sanitizer to enter or leave a room or a facility	5	(6.8)	25	(34.2)	43	(58.9)
Wearing a mask						
Wear a mask when going out	16	(21.9)	15	(20.5)	42	(57.5)
Wear a mask in the presence of others or when talking to others	17	(23.3)	23	(31.5)	33	(45.2)
Wear a mask without pulling it around the chin	19	(26.4)	19	(26.4)	34	(47.2)
Remove the mask while holding the ear loops	30	(41.1)	25	(0.3)	18	(24.7)
Physical distance						
Keep a distance from others	21	(28.8)	39	(53.4)	13	(17.8)
Avoid talking face-to-face	34	(47.2)	32	(44.4)	6	(8.3)
Do not yell	24	(32.9)	32	(43.8)	17	(23.3)
Ventilate by opening windows, etc.	8	(11)	28	(38.4)	37	(50.7)
Others						
Do not touch one's eyes, nose, or mouth with one's hands	32	(43.8)	34	(46.6)	7	(9.6)
Take one's temperature every day	3	(4.1)	13	(17.8)	57	(78.1)

Table 3. Understanding of infection-prevention behavior in individuals with Down syndrome\

	Not understood at all/Not understood much		Neither		Understood to some degree/Understood well	
	n	(%)	n	(%)	n	(%)
Need for hand washing and alcohol-based hand disinfection	12	(16)	11	(15)	50	(68)
Need for wearing a mask	19	(26)	11	(15)	43	(59)
Need for social distancing (physical distance)	31	(42)	15	(21)	27	(37)
Need for infection preventive measures	25	(34)	16	(22)	32	(44)

Table 4. Behavioral changes in children with Down syndrome during school closure period

	Never/Rarely (about twice a month)		Sometimes (once or twice a week)/Often (three to four times a week)	
	n	(%)	n	(%)
Lack of motivation to participate in activities	65	(89)	8	(11)
Irritability	64	(88)	9	(12)
Difficulty concentrating or attention problems	66	(90)	7	(10)
Sleep problems	70	(96)	3	(4)
Self-harm or violence among family members	73	(100)	0	(0)

1

Table 5. Associated factors with psychological distress and child-related stress of caregivers

	Psychological distress			Child-related stress		
	AOR			AOR		
	(crude OR)	95% CI	P-value	(crude OR)	95% CI	P-value
Behavioral issues in children						
Lack of motivation to participate in activities	0.53 (0.54)	0.09-3.00	0.470	0.38 (0.34)	0.04-3.55	0.393
Irritability	4.21 (4.16)	0.92-19.18	0.063	8.44 (7.11)	1.69-42.09	0.010
Difficulty concentrating or attention problems	1.33 (1.33)	0.27-6.67	0.724	4.11 (4.15)	0.80-21.20	0.090
Sleep problems	3.75 (3.65)	0.30-46.83	0.300	1.65 (1.34)	0.13-21.48	0.697
Disinfection						
Burden of disinfection for the child	1.36 (1.36)	0.76-2.42	0.291	4.26 (4.06)	1.88-9.65	0.001

AOR was adjusted for intellectual disability

AOR: adjusted odds ratio; CI: confidence interval.

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3