COVID-19 effects on mental health of children and adolescents with intellectual disabilities in North Kosovo

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ABSTRACT

Background. People with intellectual disabilities (ID) are susceptible to physical, mental and social implications of the COVID-19 pandemic. Aim. Learning the way young individuals with disabilities dealt with the COVID-19 pandemic and how it affected their lives. Materials and Methods. An epidemiological questionnaire including information on the person's health, mental state, behavior, educational capabilities, and epidemiological and clinical features of the COVID-19 infection was completed by 41 children/young adults and their family members. Results. During the two-year period of the pandemic, we monitored the frequency of COVID-19 infection in children and adolescents with intellectual disorders, children's mental condition, and the occurrence of post-COVID symptoms. We also discussed the role of society regarding economic stability and support for families with a disabled member. Conclusions. The severity of COVID-19 symptoms was the independent predictor of mental status deterioration. Children and adolescents with ID experienced a greater prevalence of COVID-19 infection as well as post-COVID sequelae.

Introduction

Coronaviruses are animal-derived. Human coronaviruses (HCoV-229E, HCoV-OC43, HCoV-HL63, HCoV-HKU1) frequently induce "common cold" symptoms. Middle East respiratory syndrome Coronavirus, which arose in 2002 and 2012, is more infectious and deadly, especially in newborns, elderly, and immunocompromised people. SARS-CoV-2, a coronavirus that causes severe acute respiratory syndrome, emerged in December 2019, triggering a global pandemic.[1-3]

The pandemic has serious physical, emotional, and social effects for people with intellectual disabilities (ID). Cognitive difficulties may hinder this patient's comprehension. Restrictions on everyday activities can cause mental stress, especially in autistic people, which might increase problematic behaviors, placement breakdown, and psychiatric medication use.[4] Persons with ID are vulnerable to exploitation when community support fails.

Intellectual impairment occurs before 22 and lim-

its intellectual capacity and adaptive behavior. In high-income nations, 2% to 3% of children are affected by intellectual impairment, but the incidence in low- and middle-income countries is unclear.

In intellectually disabled persons, COVID-19 infection risk factors include poor nutrition, malnutrition, overnutrition, comorbidities, and related diseases. They are also unaware of the importance of self-isolation and safety.[5]

Aim

The study objective is to evaluate the effects of the global viral SARS-CoV-2 infection on the quality of life of persons with intellectual and developmental disabilities, as well as the impact of the pandemic on the mental well-being of these children and young adults.

Materials and Methods

Our research involves 41 children, adolescents, and young adults with intellectual impairments aged 4-32. All research participants had mental or ID. Before our investigation, a neurologist, psychiatrist, and developmental pediatrician classified them with intellectual impairment. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition was used to assess the severity of the research participants' developmental problems. Participants had varied degrees of intellectual impairment (mild, moderate, severe, and profound). The authors had access to information that identified individual participants during the data collection.

Children and young adults with neurodevelopmental conditions like attention deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, and rare genetic disorders (henceforth referred to as neurodevelopmental disabilities), Down syndrome, microcephalia (caused by intrauterine Cytomegalovirus infection), intrauterine growth retardation, ID of unknown origin, and developmental disability were included.

All patients with intellectual impairment and neurodevelopmental disability received cognitive, adaptive, genetic, and ID therapy.

Pediatricians at the Clinical Hospital Center (KBC), Gracanica, or Health Center Kosovska Mitrovica questioned and assessed all patients from 2020 to 2022. Rapid antigen or antibody titer tests were used to confirm Coronavirus infection.

Respondents or their companions/parents completed the translated version of the questionnaire "The Quality of Life Inventory – Disability". The parent or the child's custodian was interviewed and the questionnaire was filled out at KBC Gracanica when the child/adolescent attended check-ups, or in Kosovska Mitrovica's "Support me" organization. It is a North Kosovo-based organization of parents of children with intellectual and developmental disabilities.

This qualitative study examined participants' understanding and problems, the impact of COVID-19 and related public health responses on their daily lives (well-being, education, financial, emotional, psychological, and social situation), and their attitude toward COVID-19 information and public health responses to reduce COVID spread.

We divided the survey into two sections: one about children with intellectual/developmental disorders during the pandemic (if they were able to attend classes online, how they felt during isolation, and how they felt about their physical health); another focusing on parents (what were their feelings during the two-year pandemic, what was their income during that period, how did they take care of the child; what was their view of the psychological and mental state of their child during that period). During the COVID-19 pandemic in 2020-2022, respondents were asked about their physical and emotional health. The questionnaire also included questions on society's and the local community's involvement.

The study was a part of the project "Multidisciplinary approach for the early recognition, diagnosis and treatment of children with impaired psychomotor development" approved by the Ethical Committee of Faculty of Medicine, K. Mitrovica (decision no 09-09/12.01.2015).

For each participant, an informed written consent filled and signed by their parents/custodians was obtained.

Results

The research comprised 41 children/young adults ranging in age from 4 to 33 years old, with an average age of 15.13±7.43 years. The gender distribution was equal, with 19 girls (46.34%) and 22 boys (53.66%) participating in the study.

During the two-year pandemic caused by several strains of the Coronavirus, 16 of 41 people tested positive for the virus. They were mostly (56.25%, or 9 patients) asymptomatic children and adults or those with mild clinical symptoms, 6 (37.5%) had medium-severe symptoms of infection, and one (6.25%) had a severe type of COVID infection (Table 1). The post-COVID state (long-term COVID) was detected in 19.51% of individuals usually with moderate strength symptoms; however, in 2 respondents (4.88%), post-COVID was associated with symptoms of a more serious scope and duration, and in one respondent (2.44%), post-COVID left lasting repercussions.

At the end of the two-year period (2020-2022), the psychological state of the child with ID was evaluated by a doctor (neurologist, neuropsychiatrist, general

practitioner, *etc*.), and we found that the majority of respondents' (60.98%) mental status remained unchanged and minor change in mental state was found in 2 (4.88%); however, significant deterioration was observed in 16 children/young adults (39.03%) and the condition worsened significantly in 14 (34.15%) of the assessed patients with ID (Table 1).

Since the pandemic's announcement, all educational institutions in Kosovo have shifted to remote learning. Models of such instruction included the teacher recording content that was distributed to pupils via television channels. At the time of the pandemic 24 children, or 58.54% of them, were still in regular education or attended schools specialized to their physical/ID. Three of the kids had a personal companion who helped them follow the teachings. Almost 10% of pupils were unable to follow the educational content after the transition to distance learning (Table 2).

A sad truth is that children with ID were nearly always left in the care of their parents, even after they were afflicted with the virus. At the same time, 14 of them, or 34.15% of the parents, experienced severe clinical symptoms, and one died because of corona infection (Table 3). Furthermore, in three families, the father and mother were infected at the same time. During the parents' illness, one child was cared for by a great-aunt.

The severity of COVID-19 symptoms was significantly related to parents' COVID-19 infection patients' age, pharmaceutical treatment, the appearance of post-COVID symptoms as well as emotional and mental state of the patients (Table 4). The correlation coefficient was mostly of moderate intensity, with the exception of post-COVID symptoms which show a strong association.

School attendance during the pandemic was related to parents' COVID infection, emotional state during the pandemic, and decline in patients' mental state.

The worsening of patients' mental state was moderately to strongly associated with the severity of

Table 1. Distribution of participants according to COVID infection, post-COVID consequences and mental status during the pandemic.

ID individuals infected with COVID-19	**Mild symptoms**	**Moderate symptoms**	**Severe symptoms**	
16 (39.02%)	9 (56.25%)	6 (37.5%)	1 (6.25%)	
ID individuals with post-COVID complications	**Of moderate severity**	**Severe and long-lasting**	**Permanent**	
11 (26.83%)	8 (19.51%)	2 (4.88%)	1 (2.44%)	
ID individuals' mental status during pandemics	**Unchanged**	**Deteriorated**	**Moderate deterioration**	**Severe deterioration**
	25 (60.98%)	16 (39.03%)	2 (4.88%)	14 (34.15%)

ID, intellectual disability.

Table 2. School attendance during COVID-19 and after the pandemic.

Current ability to attend elementary secondary or special school	**Not attending school due to the age**	**Attend regular or special school**	
	14 (34.15%)	27 (65.85%)	
School attendance 2019-2021	**Not attending school due to age**	**Attended a regular or special school, followed classes online**	**Could not follow the classes**
	13 (31.70%)	24 (58.54%)	4 (9.76%)

Table 3. Caregivers of child/young adult during the COVID-19 pandemic and effects of COVID-19 infection on caregivers.

Caregivers during COVID-19 pandemic	**Parents**	**Guardian/institutions/relatives**		
	40 (97.56%)	1 (2.44%)		
Parents COVID-19 infection	**Not infected**	**Moderate symptoms**	**Severe symptoms**	**Deaths**
	22 (53.66%)	4 (9.76%)	14 (34.15%)	1 (2.44%)

COVID-19 symptoms, post-COVID symptoms, as well as emotional state and school attendance during the pandemic (Table 5).

Multivariate regression analysis (Table 6) showed that, while the worsening of mental health was related to several parameters, only the severity of COVID-19 manifestations may predict the deterioration of mental state. Moreover, the increase in severity of clinical symptoms from mild to moderate and from moderate to severe both increase the probability of mental decline 1.58 times, respectively.

Discussion

1-2% of the world has intellectual impairments.[6] People with ID are especially vulnerable to the COVID-19 pandemic because of their physical as well as mental comorbidities and need support services and professionals.[7]

Due to the high number of asymptomatic or mild cases, pediatric COVID-19 is likely underdiagnosed. Kids and teens often have asymptomatic infections. About 15-42% had silent disease.[8] The most prevalent infection symptoms were a cough and a moderately elevated temperature. The lower respiratory tract symptoms were uncommon.[9] In rare instances, certain Coronavirus strains produced enteritis and diarrhea, along with neurological problems (dizziness, seizures, headache, anosmia).

Cardiovascular issues (cardiomyopathy, rhythm abnormalities, pericarditis, myocarditis, cardiogenic shock, pulmonary embolism, coronary heart disease) were described;[10] however, the absolute risk of myocarditis is low (0.15%). Acute kidney injury occurs in 1-70%, depending on the study cohort.[11] Intellectu-

Table 4. The significant correlations between the severity of COVID-19 clinical symptoms and relevant examined parameters.

Severity of COVID-19 clinical manifestations	Correlation coefficient ρ	P-value
Age	0.33	<0.05
Living expenses	0.32	<0.05
Pharmaceutical treatment	0.68	<0.0001
Post-COVID symptoms	0.77	<0.0001
Parents' COVID-19 infection	0.33	<0.05
Emotional state	-0.31	<0.05
Mental state deterioration during pandemic	0.32	<0.05

Table 5. The significant correlations between the deterioration of mental state during the COVID-19 pandemic and relevant examined parameters.

Mental state deterioration during COVID-19 pandemic	Correlation coefficient ρ	P-value
School attendance	-0.41	<0.01
Severity of COVID-19 manifestations	0.32	<0.05
Post-COVID symptoms	0.28	<0.05
Emotional state during pandemic	-0.66	<0.0001

Table 6. The results of multivariate regression analysis of the relation between mental state changes and relevant examined parameters.

Mental state deterioration during COVID-19 pandemic	Regression coefficient	Wald test	P-value	O.R.	O.R. 95% CI	
School attendance	-0.33	0.04	>0.05	0.71	0.006	2.26
Severity of COVID-19 manifestations	0.46	6.67	<0.001	1.58	0.47	6.43
Post-COVID symptoms	-0.38	0.0006	>0.05	0.68	0	1.73
Emotional state during pandemic	-0.36	14.8464	>0.05	0.69	0.00005	2.36

O.R., odds ratio; CI, confidence interval.

ally disabled people, especially those with Down syndrome, die primarily from respiratory tract diseases. ID patients are at risk of severe COVID-19 infection due to obesity.[12,13] Multiple comorbidities, frailty, and underlying conditions increase COVID-19 risk.

In our study, Coronavirus infected 30% of children and young adults. Nine children had relatively mild symptoms – moderately elevated body temperatures, coughs without lower respiratory tract infections, and malaise. Six subjects developed moderate-to-severe COVID infection with anosmia and hyperpyrexia (usually 39-40 degrees). Furthermore, 6.25% had a serious COVID infection, (a lower respiratory tract infection, high fever), and required hospitalization. Our research found that COVID-19 symptoms were substantially related to the parents' COVID infection, the patients' age, the amount of pharmaceutical therapy used, post-COVID symptoms, and the patients' emotional and mental state.

The American Academy of Pediatrics and the WHO use "post-COVID-19 condition" to refer to a range of chronic, recurring, or novel physical and mental health symptoms and illnesses that arise more than 4 weeks following SARS-CoV-2 infection (of any severity). The aforesaid syndrome is called "long COVID" or "post-acute sequelae of SARS-CoV-2 infection". The WHO defines a clinical case as symptoms that last at least two months, cannot be explained by another condition, and have a significant effect on everyday life.[14,15]

Post-COVID symptoms include fatigue, weakness, headache, sleep disturbance, muscle and joint pain, respiratory difficulties, palpitations, and altered smell and taste. Autonomic dysfunction and dizziness may arise.[14,15]

In our study, 11 subjects had post-COVID issues. Weakness and fatigue usually lasted no more than 10 days. Six (37.5%) individuals suffered medium-severe consequences, including a persistent cough, loss of smell, and overall discomfort. One person (2.44%) experienced a change in mental state and post-COVID heart injury with heart rhythm irregularities.

Throughout the two-year pandemic, 19 of 38 parents of intellectually disabled children were infected, with a more severe clinical picture (infection of the lower respiratory tract, high fever, intense cough, severe weakness to the point of inability to walk). Our research found that parents were the sole guardians throughout infection and illness. Only on one occasion was the patient cared for by a relative.

As the pandemic was proclaimed, day centers for disabled children closed to external receptions. This region lacks palliative care and protection institutions, therefore care for persons with ID is solely provided by families regardless of parents' health, occupation, or finances. Diapers, orthopedic aids, medications, physiotherapists, speech therapists, *etc*., are usually needed to care for children with ID, requiring additional financial expenditures.

During the Coronavirus outbreak of 2020-2022, state employees were paid regularly. However, the decreased participation in all governmental sectors has put private businesses in jeopardy (trade, tourism, catering...) Thirteen parents, or one-third of respondents, reported receiving no financial assistance during the period in question, while more than half reported receiving two one-time grants from the state and the parent organization "Support me" 12.11% of parents said that their relatives assisted them during the two-year outbreak.

During the epidemic, 24 of the 41 young people in the research, or 58.54%, were intellectually and physically capable of attending regular or specialized schools. During the pandemic, 4 respondents, or 10%, were unable to take online courses due to the continual teaching process, the difficulty of remaining on certain topics, and individual work with impaired pupils. School attendance during the pandemic was connected to parents' COVID infection, emotional mood, and mental state decrease, according to our findings.

The loneliness and social isolation during quarantine, particularly in adolescents and teens, worsened the distress and anxiety of acquiring the potentially fatal illness.[16] These kids may be more distressed due to major changes in routines and services. Changes include the inability to attend school and a decrease in institutional and informal supports, including restricted interaction with close or wider family members These pressures may increase emotional reactivity, impulsivity, anxiety, mood swings, aggressiveness, and sleep disturbance.[17] Lack of physical activity and increased screen time owing to isolation are likely to indirectly affect health and well-being via weight and sleep issues.[18] According to a current study, parental well-being dropped throughout the pandemic, with greater rates of mental illness, interpersonal violence, and child maltreatment, especially in families with children and adolescents with special needs or vulnerabilities.

Intellectually disabled people live in crowded social facilities, assisted living arrangements, and hospital inpatient units. Many live with elderly parents or relatives, who often have poor health.[4,19] Participants and their parents were found to be significantly more distressed than the overall population of British parents.

Parents are the main and long-term caregivers for intellectually disabled children. Parents have a major influence on their intellectually impaired children's growth and lives.[20] ID in teenage children may be distressing, requiring parental attention, aid, and support. So, intellectually disabled teens' parents have more responsibilities.

Caring for an intellectually disabled child may be stressful and difficult. Parents' caregiving has been a major emphasis in ID research,[21] but little is known about caregiving responsibilities, family connections, family support, and complicated caring goals.

Research shows that parents of disabled children experience higher levels of stress, anxiety, and depression.[22,23] The epidemic made individuals apprehensive, agitated, concerned, and irritated. Originally, there was widespread confusion and fear about the condition, and parents of handicapped children were especially sensitive to anxiety due to anxieties about their children's future.

Community welfare institutions suspended most day programs and other social services for disabled individuals to protect vulnerable people from dangerous illnesses. Disabled people need social care and assistance programs to live independently, but they are unavailable.

Isolation during the Coronavirus epidemic harms disabled children's mental health (including poorer behavior, mood, fitness and social and learning regression). Several parents concerned about their child's mental health and activity levels identified a lack of access to specialist facilities, services, and equipment as a significant reason.[24]

Our respondents' psychological health was affected by the COVID infection and family and community changes, according to our results. 16 young people (39.03%) had mental health declines. 14 exhibited severe psychological changes, including increased anxiety, sadness, aggressiveness, and irritability. 25 children's mental state did not change, according to their parents, since a large majority of respondents in that group were not aware of changes and events in their environment, suggesting a profound intellectual handicap.

During the pandemic, COVID-19 symptoms, post-COVID symptoms, emotional state, and school attendance were moderately to strongly associated with mental health decline. COVID-19 symptom intensity was the sole independent predictor of mental health decrease.

Conclusions

The COVID-19 pandemic had a marked impact on mental and emotional status, and school achievement of children and young adults with ID. It also had a detrimental impact on the parents' emotional condition since they were the only caregivers and had to rely solely on themselves.

The prevalence of post-COVID symptoms in these children is somewhat higher than in the general population. COVID-19 symptoms were the only independent predictor of the deterioration in mental state. Furthermore, increasing the severity of the COVID-19 clinical picture from mild to moderate and moderate to severe increases the likelihood of mental decline by 1.58 times, respectively.

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