

Original Article

The Effect of COVID-19 on the Disabled Children and Their Families: A Case from Turkey

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Abstract

Background: Children with disabilities are among the most vulnerable groups in unforeseen and unexpected circumstances, such as pandemics that can cause a change in the vital order. **Aim:** The research was conducted to reveal the conditions of children with disabilities and their families affected by the COVID-19 pandemic for descriptive characteristics and to identify situations making a difference. **Methodology:** The research is in quantitative method. The data were collected in an internet-based digital environment. Disabled children of the participants have mental, hearing, vision, physical disabilities, pervasive developmental disorder, and special learning disabilities.

Results: In the study, it was recognized that children with disabilities had other illnesses apart from their disabilities, their rehabilitation was incomplete, families were left alone with the process and they were away from professional follow-up. It was discovered that the problems of both the family and the child increased, and they did not have the desired behavior pattern in solving the issues.

Conclusions: The COVID-19 pandemic has increased negative consequences for both the disabled children and their families.

Keywords: COVID-19, disabled children, family of children with disabilities, impact of COVID-19,

Introduction

COVID-19 still maintains its “global impact in all age groups” (Dong et al., 2020). Today, it is stated that the age limit of the disease in children is 1.5 months -17 years (Ozdemir and Pala, 2020). In a study based on the data of the TriNetX COVID-19 Research Network platform, the incidence of COVID-19 in disabled children aged 0-17 years old was explained as 26.4% and the rate of death due to illness as 8.8%. In children of this age range and without disabilities, the incidence of the disease was reported as 2.7% and the mortality rate as less than 0.01% (Turk et al., 2020). Functional limitations of children with disabilities will become more difficult with the additional barriers imposed by the society; giving importance and priority to the rights of children with disabilities in accessing services is remarked (Schiariti, 2020). It is stated that individuals with physical, mental or sensory disabilities have more difficulty in accessing

health services, as in many functions, and those who have more health requirements are faced with further problems such as stigma and discrimination (Lee, 2022). The World Health Organization has created guidelines for individuals with disabilities to experience the COVID-19 process in a more rights-based way (WHO, 2019).

Background

Along with the COVID-19 outbreak, many measures have been taken in Turkey, and one of the actions taken is to implement education and training via remote online-based applications. Although this application is a pandemic-related solution, it has also generated problems. One of these problems is manifested in a way that children with disabilities experience formal education difficulties like other children, and this education of children receiving rehabilitation is interrupted. Additionally, children have to

live in their homes with limited opportunities, which has increased the coping difficulties experienced by families. If the family and community are required to adapt to the disabled child successfully, the needs of the child and the family should be met. Furthermore, the problems not resulting from the disability should be reduced, because, regardless of the type of disability, the presence of a child with disabilities in a family brings several particular difficulties such as psychological, social, physical, economic, and educational issues (Karakus and Kirlioglu, 2019).

This study aims to outline at what level and in which form children with disabilities at various levels and their families have been affected by the COVID-19 pandemic and to discover whether sociodemographic characteristics make a difference in the investigated conditions in Turkey.

Methodology

The research is of a descriptive cross-sectional type in quantitative design. Since the data used in the research was categorical, $n=t^2*p/q/d^2$ formula was used in the sample calculation. The latest official data on the rate of children with disabilities in Turkey belong to 2012. Since these data are very old, the notification on <https://www.cnnturk.com/saglik/turkiyede-3-milyon-engelli-cocuk-var> was used as a statistical indicator. The site reports that the proportion of children with disabilities in Turkey has been around 12% as of 2019. After the calculations, it was decided to include a minimum of 250 people in the sample. It was chosen to get the data in an internet-based digital environment, based on both the ongoing pandemic and the prediction that access to families of children with disabilities would be "faster and easier." And data on those with children over the age of 18 were excluded from the scope of the research. For the participation of the research to be voluntary, the first option of the questionnaire was designed as a "volunteering tab," thereby allowing volunteers to access other questions. The data were obtained between May 26 and June 13, 2020.

Participants: The mean age of the children with disabilities in the study is 10.94 ± 4.56 (Min-max:2-18 ages). It has been

observed that the rate of the child's disability is 73.9 ± 21.81 (Min-max: 10%-100%). Due to the pandemic, the rate of the increase in time spent by the child on technological devices such as television, computer / tablet, and the phone is 3.63 ± 2.93 (min-max: 0-18 hour). 10.4% of the participants declared that they were primary school graduates, and 1.6% were literate. It was stated that 96.8% of the children's parents were alive, only mothers of 2.0% were alive, only fathers of 0.4% were alive, and none of the parents of 0.8% were alive. The working parent ratio was stated as 30.4% for mother + father, 4.0% for only mother, 52.4% for only father, and 13.2% of the parents were not working. Family types of children with disabilities are nuclear family (9.6%), and broken family (4.8%). It was observed that 37.2% had high expenses.

Data Collection Tools: The questionnaire consists of 28 questions. The questions are aimed to define the disabled child and family's condition as to some variables in the COVID-19 process.

Ethical Principles and Permission: Written permission was received from the Ministry of Health Scientific Research Platform for the research (2020-05-31T20-53-44), and the participants were notified within the scope of Helsinki criteria with the informative text at the beginning of the questionnaire form.

Statistical Analysis: The data obtained from the study were evaluated on SPSS-22 software. Chi-square analysis was done, and $p < 0.05$ was accepted as the statistical significance level.

Results

The participants were asked which protection measures they practiced when they took the child out. 21.2% of the families stated that they only made their children wear a mask, 19.6% only observed the social distancing rule, 9.6% made their children wash their hands after going out, and 49.4% of them apply several methods at the same time. 4.0% of the families reported that they had been diagnosed with COVID-19.

The distribution of the factors affecting the changes in the child's progress in the pandemic process is given in Table 3. It has been observed that the variables such as gender, child's disability, occurrence time of disability, child having another illness other than the disability, and a continuous treatment that requires receiving service in the hospital were not effective. Besides, the child's formal education, type of family, if the child goes out, if a new hobby that had not been done before the pandemic process started, the type

of technological equipment used by the child during the pandemic, the child's parents being alive, the status of whether the parent is working or not, and the guidance / counselling to the family through any communication channel during the epidemic were not effective. It has been observed that the variables of starting a new hobby with the child, the income level of the family, and the participants' thought that their mental health was affected created a difference.

Table 1. Some descriptive characteristics of children with disabilities (N = 250)

Variable	Characteristic	Number	%
Having a disease other than disability status	Yes	78	31.2
	No	172	68.8
Having another illness that requires hospital treatment	Yes	97	38.8
	No	153	61.2
The status of meeting his/her needs	Dependent on someone else	95	38.0
	Meets them partially himself/herself	130	52.0
	Meets his/her own needs	25	10.0
Being able to go out in the pandemic process	Yes	174	69.6
	No	76	30.4
Parents starting a new hobby with the child due to the pandemic	Yes	99	39.6
	No	151	60.4
A new change in the child's development during the pandemic process	Yes	132	52.8
	No	118	47.2
Change in the child during the pandemic process (n=147)	Negative change	113	76.9
	Positive change	34	23.1

Table 2. Some descriptive characteristics of the families of disabled children (N=250)

Variable	Characteristic	Number	%
What is the most challenging issue in the pandemic process	Nutrition of the child	3	1.2
	The child's sleep pattern	22	8.8
	Current treatment of the child	18	7.2
	Restriction of the child's movements	68	27.2
	Worry that the health of the child will be affected	55	22.0

	Education of the child	66	26.4
	Economic troubles	10	4.0
	Inability to spare time for himself/herself	8	3.2
Guidance/counseling provided for the family by those who follow the child during the pandemic process	Yes	62	24.8
	No	188	75.2
The state of the pandemic process affecting mental health	Yes	182	72.8
	No	68	27.2

Table 3. Distribution of factors affecting the change of child's development and the shape of the change in the pandemic process(N=250)

Variable and Characteristic		Change in Child's Development*		Test Value
		Yes n (%)	No n (%)	
Age Range	10 years and below	75 (56.8)	43 (36.4)	$\chi^2 = 18.000$ p = 0.001
	Between 11-13 years old	29 (22.0)	21 (17.8)	
	14-16 years old	17 (12.9)	28 (23.7)	
	17 and older	11 (8.3)	26 (22.0)	
The condition of education at the rehabilitation center	Yes	117 (88.6)	78 (66.1)	$\chi^2 = 18.437$ p = 0.001
	No	15 (11.4)	40 (33.9)	
Family income level	More income	12 (9.1)	12 (10.2)	$\chi^2 = 9.982$ p = 0.007
	More expense	61 (46.2)	32 (27.1)	
	Equal income and expenses	59 (44.7)	74 (62.7)	
A new problem (leaving work, getting sick, etc.) in the pandemic process	Yes	31 (23.5)	9 (7.6)	$\chi^2 = 11.657$ p = 0.001
	No	101 (76.5)	109 (92.4)	
Participants' thought that their mental health was affected during the pandemic process	Yes	104 (78.8)	78 (66.1)	$\chi^2 = 5.064$ p = 0.024
	No	28 (21.2)	40 (33.9)	
		What kind of change		
		Negative change n (%)	Positive Change n (%)	

Starting a new hobby with the child	Yes	42 (37.2)	22 (64.7)	$\chi^2 = 8.063$ p = 0.005
	No	71 (62.8)	12 (35.2)	
Family income level	More income	13 (11.5)	0 (0.0)	$\chi^2 = 10.335$ p = 0.006
	More expense	56 (49.6)	11 (32.4)	
	Equal income and expenses	44 (38.9)	23 (67.6)	
Participants' thought that their mental health was affected during the pandemic process	Yes	93 (82.3)	19 (55.9)	$\chi^2 = 10.056$ p = 0.002
	No	20 (17.7)	15 (44.1)	

*Column percentage is taken.

Table 4. Distribution of factors affecting participants' thought that their mental health was affected in the pandemic process (N=250)

Variable and Characteristic		If the participant thinks that his mental health was affected*		Test Value
		Yes n (%)	No n (%)	
Family income level	More income	15 (88.2)	9 (13.2)	$\chi^2 = 6.311$ p = 0.043
	More expense	76 (41.8)	17 (25.0)	
	Equal income and expenses	91 (50.0)	42 (61.8)	
A new problem in the pandemic process	Yes	35 (19.2)	5 (7.4)	$\chi^2 = 5.197$ p = 0.023
	No	147 (80.8)	63 (92.6)	
Method of coping with the pandemic process	Not watching the news	57 (31.3)	11 (16.2)	$\chi^2 = 6.026$ p = 0.049
	Using relaxation methods	86 (47.3)	37 (54.4)	
	Not feeling the need to cope	39 (21.4)	20 (29.4)	

*Column percentage is taken.

Discussion

In the literature, although the uncertainty that children with disabilities are at risk of more complications due to COVID-19 is highlighted, the importance of addressing these groups as vulnerable groups must be clarified (Boyle et al., 2020).

This study, children with disabilities had problems other than the current disability, some of them required hospital treatment, and approximately half of the children were not sufficient to meet their needs. The presence of a disease accompanying the condition in a

child with a disability will decrease the effect on treatment (Sartorius, 2013). The interaction between the child and the healthcare staff will reduce in the outbreak (Golberstein et al., 2020), and this situation requires extra sensitivity for these children.

The first measure taken by many countries in the COVID-19 pandemic was to limit coming together in common living spaces. Schools and workplaces were closed for a while, and these places opened when suitable conditions were met. This is among the methods applied by Turkey, as well. Yet, especially children with disabilities were removed from the

school without creating buffering systems, which caused families, in addition to experiencing new situations, to lack professional support in dealing with the existing burdens, to be uneasy about going to the hospital, and problems to increase. Other results acquired from this research, include mostly mothers in taking care of the disabled child and experiencing anxiety that the child's health will change. The perception that the education of the child will be prevented is high, and new problems are added to the pandemic process in many families. The activity of providing guidance / counselling to the family by the institution where the child goes to is at a low level. Because of all this, there are impairments in mental health with the pandemic process in a sense. Likewise, another study found that families with children with disabilities reported little institutional support in the process (Asbury et al., 2021). Thus, some countries have initiated home-based training to increase the ability to cope with the pandemic's adverse effects and to ensure that both families and children are less affected (Longo et al., 2020). Turkey also implemented a program in this direction. This application was only towards meeting the formal educational requirements of children, any application beyond the information brochure for disabled children and their families was beside the point. This study was observed that the situation of the child with disabilities being in a group of children aged 10 years old and below, the state of receiving education from the rehabilitation center, the family's expenses being high, the occurrence of a new problem (leaving work, sickness, etc.) during the pandemic, the participants' thought that their mental health was affected in the pandemic process had a distributional difference in noticing the change of the child's development at higher rates. It was observed that the positive change in the participants who started a new hobby with their children, in those with equal income and expenditure levels, was higher, and the fact that the participants think that their mental health was affected created the difference with higher negative change effect of the COVID-19 pandemic on the disabled child. Parents who have children with disabilities and have a positive self-perception immediately begin to try coping strategies. Furthermore, it is difficult for parents who have negative

thoughts to adapt to and deal with a child who has special needs (Avsaroglu and Gilik, 2017).

Conclusion: Children with disabilities in the research had additional problems and had conditions requiring them to go to the hospital; those who attended the rehabilitation center were at a high rate. Still, they were away from practices that might have a healing effect due to the COVID-19 pandemic, and this situation triggered the negativity of both the family and child. Besides, it was observed that they did not make use of professional support sufficiently and spent time with technological devices. The families did not adapt to the behaviors such as starting a new hobby with the child, benefiting from the experience in the solution of the possible problem, and tend to avoid the situation. Regardless of how, both the administrative authority and education and health institutions should be prepared for the changes in the organization to which the children with disabilities will be exposed. Professional support networks for children and their families should be encouraged to be included in the process in an active and planned way.

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