

The impact of the COVID-19 pandemic on children with disabilities and their parents or caregivers

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ABSTRACT

Objectives: The study aimed to determine the impact of the pandemic on parents/caregivers and children with neurologic disabilities.

Patients and methods: This multi-center cross-sectional study was conducted with 309 parents/caregivers (57 males, 252 females) and their 309 children (198 males, 111 females) with disabilities between July 5, 2020, and August 30, 2020. The parents/caregivers were able to answer the questions and had internet access. The survey included questions on the utilization of educational and health care services (whether they could obtain medicine, orthosis, botulinum toxin injection, or rehabilitation) during the pandemic. A Likert scale was used to evaluate the effect of the specific health domains, including mobility, spasticity, contractures, speech, communication, eating, academic, and emotional status. The Fear of COVID-19 Scale was used to assess fear of COVID-19.

Results: Among the children, 247 needed to visit their physician during the pandemic; however, 94% (n=233) of them could not attend their physician appointment or therapy sessions. The restricted life during the first wave of the pandemic in Türkiye had negatively affected 75% of the children with disabilities and 62% of their parents. From the perspective of the parents/caregivers, mobility, spasticity, and joint range of motion of the children were affected. Forty-four children required repeated injections of botulinum toxin; however, 91% could not be administered. The Fear of COVID-19 Scale scores were significantly higher in the parents who could not bring their children to the routine physician visit (p=0.041).

Conclusion: During the pandemic, access to physical therapy sessions was disrupted in children with neurological disabilities, and this may have harmful consequences on the functional status of children.

Keywords: Cerebral palsy, disability, pandemic.

Due to the global spread of the coronavirus disease 2019 (COVID-19) infection, World Health Organization declared a pandemic on March 11, 2020.^[1] In an effort to stop the spread of the virus, social distancing was promoted as the best public health strategy. Due to lockdowns in many countries, all domains of the healthcare system were interrupted, including rehabilitation and medical follow-up.^[2,3]

There are at least 93 million children with disabilities in the world, and approximately 400,000 of them live in Türkiye.^[4,5] Cerebral palsy, spina bifida, and neuromuscular disorders are the most common causes of disabilities during childhood. The majority of these children require therapy, such as speech, occupational, or physical therapy, either at hospitals or clinics, and also special education. Moreover,

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children with disabilities often have comorbidities, such as seizures, gastroesophageal reflux, and feeding and swallowing difficulties, that require careful follow-up.^[6] During the pandemic, children were deprived of these services as these centers were either closed or limited. The consequences of losing education and medical support are prominent, significantly increasing the caregiver burden and potentially endangering the child's overall health and well-being.^[7] Consequently, for parents or caregivers of children with disabilities, certain challenges have emerged.

The COVID-19 pandemic has pushed many families to a breaking point. The marked uncertainty of the pandemic and associated disruptions in the routine increased stress on the parents.^[8] Among 1,200 caregivers, 289 (24.1%) had moderate mental distress (K6 score of 5-9), and 352 (29.3%) had severe mental distress in Japan, whereas depression and anxiety were over 40% in Iran.^[9,10]

The intensive demands of caregiving contributed to this tension. Parents were supposed to be employees, therapists, teachers, and caregivers for their children with disabilities all at once. Although homecare interventions play an important role in the rehabilitation, caregivers might not have learned the techniques in an appropriate manner to achieve the desired functional outcomes.^[11] At this point, the improved use of technology, such as telemedicine, telerehabilitation, or exercise games, can be considered.^[7]

This study aimed to determine the impact of the pandemic on parents/caregivers and children with neurologic disabilities.

PATIENTS AND METHODS

This multi-center cross-sectional study was conducted with 309 parents/caregivers (57 males, 252 females) and their 309 children (198 males, 111 females) with disabilities in four centers in Türkiye between July 5, 2020, and August 30, 2020, which was the time for the return to normality phase for the first wave in Türkiye.

Parents/caregivers of the children with neurologic disabilities, including cerebral palsy, muscular dystrophies, spina bifida, brachial plexus injury, brain injury, autism, intellectual disability, epilepsy, who were able to speak Turkish, answer the questions, and had internet access were included in the study.

A survey was generated by the physiatrists experienced in the field of pediatric rehabilitation following the semistructured interviews with five parents/caregivers regarding the difficulties experienced by them and their children during different phases of the pandemic, the initial 'preparation' phase (where social distancing, shutdown, and general measures of hygiene was practiced) and the following 'punctum maximum' phase (the highest incidence of new cases and mortality rate peaks).^[12] Survey questions consisted of six parts: (i) sociodemographic data of the parent; (ii) demographic and clinical data of the child; (iii) the child's utilization of educational and health care services (whether they could obtain medicine, orthosis, botulinum toxin injection, or rehabilitation) during the pandemic; (iv) impact of the pandemic on the child regarding some specific health domains, including mobility, spasticity, contractures, speech, communication, eating, academic, and emotional status, on a 3-point Likert scale (worse, similar, or better); (v) impact of the pandemic on the general well-being of the child and the parent/caregiver on a 5-point Likert scale (extremely positive, moderately positive, neither positive nor negative, moderately negative, or extremely negative); (vi) the application of the Fear of COVID-19 Scale (FCV-19S).

The Fear of COVID-19 Scale, a seven-item scale, is reliable and valid in assessing fear of COVID-19 among the general population.^[13] The minimum score is 7 points, and the maximum score is 35 points. Each item is scored on a 5-point Likert scale; a higher score indicates more fear of COVID-19. Turkish version of the FCV-19S was used in this study.^[14]

The Functional Ambulation Scale (FAS) was recorded from the patient files. The FAS was established for neurologically impaired individuals. Five ambulation levels were defined. In the first level, the patient needs support and supervision for walking, and in the fifth level, the patient can walk at every speed and everywhere independently.^[15]

The survey was administered to 10 parents/caregivers to address the understandability of the items and the representativeness of the choices. Afterward, the survey was sent via the Qualtrics™ program (Qualtrics Survey Software) to the parents'/caregivers' smart devices or electronic mail.

Statistical analysis

The sample size calculator (Raosoft Inc., Seattle, USA) was used in the study. The total sample size was

calculated as 270 subjects for a power of 80%. Type 1 error was defined as 0.05. Statistical analyses were conducted using IBM SPSS version 26.0 software (IBM Corp., Armonk, NY, USA). Conformance of the data to normal distribution was assessed by the Shapiro-Wilks test and box plots. Student's t-test and one-way analysis of variance were utilized for the analysis of data showing normal distribution. Mann-Whitney U, Kruskal-Wallis, and Dunn tests were studied for nonnormally distributed data. The Pearson chi-square test and Fisher exact test were used to compare the qualitative data. The correlations were evaluated using the Spearman and Pearson correlation test. A *p* value <0.05 was considered statistically significant.

RESULTS

The plan of the survey study concerning the inclusion of the participants is provided in Figure 1. Sociodemographic features of the parents/caregivers are given in Table 1. Participants lived in 40 different cities of Türkiye, and the majority (65%) lived in Istanbul. More than half (59%) were housewives, and five women left their career to take care of their disabled children. During the pandemic, 67% of the participants reported to have economic problems; nearly half reported that they encountered economic problems only in this period. Eighty-one (26%) participants had been receiving disability support

pension. Sixteen (5%) parents reported to have more than one disabled child.

Demographic and clinical features of the 309 disabled children are given in Table 2. Two (0.6%) children (one with Angelman Syndrome and one with Becker muscular dystrophy) were infected by COVID-19, and the child with Becker muscular dystrophy was hospitalized in an intensive care unit.

Forty (13%) children had some health problems other than COVID-19 during the lockdown period, and 25 of them (62.5%) were not brought to a physician or a hospital due to several reasons, such as fear of COVID-19 infection (n=16, 64%), difficulties in transportation (n=5, 20%), and inability to reach a nonpandemic hospital or their physicians (n=4, 16%).

The utilization of disability-related healthcare services during the pandemic period is provided in Table 3. Although 247 (80%) children had scheduled physical medicine and rehabilitation follow-up visits during the lockdown period, only 14 (6%) of them applied to the outpatient clinics. One hundred seventy-two (70%) parents/caregivers preferred not to go to a hospital/physician during the pandemic, and 24% of the appointments were canceled due to changes

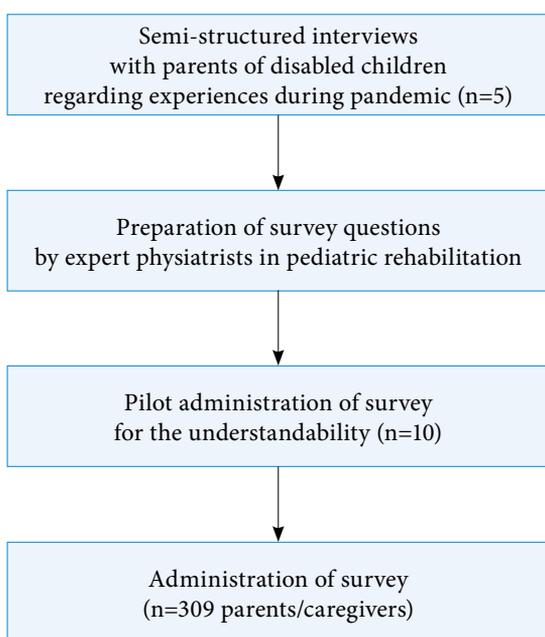


Figure 1. The plan of the survey.

Variables	n	%
Sex		
Male	57	18
Female	252	82
Caregiver		
Mother	235	76
Father	57	18
Other (e.g. grandparent, aunt)	17	6
Age (year)		
<20	6	2
20-30	43	14
31-40	151	49
41-50	93	30
51-65	15	5
>65	1	0
Education		
Illiterate	3	1
Literate	6	2
Primary school	69	22
Middle school	70	23
High school	80	26
University or postgraduate	81	26
Marital status		
Married	281	91
Single	28	9

in the healthcare system, such as physical medicine and rehabilitation physicians being assigned to work in COVID-19 units.

Scheduled physiotherapy or speech sessions were missed in 94% of the children. Only 12 children was able to attend telerehabilitation sessions, and two children were able to continue physiotherapy sessions at home by a physiotherapist. Parents/caregivers of 73 (25%) children reported not to perform home exercises, and another 49 (17%) reported to perform exercises but found it unsatisfactory.

Among children with cerebral palsy (n=137), 91 (66%) were administered botulinum toxin before the pandemic. Forty-four children were scheduled to receive repeated injections of botulinum toxin in the

pandemic period, and 40 (91%) of them could not be administered. The reasons were parents'/caregivers' preference not to go to a hospital during the pandemic (74%), postponement of the visit by the healthcare system (10%), inability to get an appointment (8%), or personal reasons (8%).

During the pandemic, in terms of educational services, among 236 school-age children, only 21% and 24% attended homeschooling completely and partially, respectively. Together with 33% of the children who had no available remote education program (for example, for some kindergarten students, there was no online education program), 55% of all school-age children could not attend any manner of remote education.

The perceptions of the parents/caregivers regarding changes in the functions of their children during the outbreak are shown in Figure 2. Emotional status and joint motion were reported as the most severely affected domains during the pandemic.

The perceptions of the parents/caregivers regarding the impact of the pandemic on the general well-being of themselves and their children are demonstrated in Figure 3. The most frequent reasons according to the parents/caregivers for the perception of negative impact on children were staying at home and deprivation from the therapy sessions or education. The most common reason reported by parents/caregivers for the perception of positive impact on children was spending longer and more effective time with their family. One of the parents/caregivers reported that the pandemic provided the opportunity to improve her child's skills of technology use. The perceptions of the parents/caregivers regarding the impact of the pandemic on the general well-being of themselves and of their children were positively correlated ($r=0.517$, $p<0.05$). However, the impacts both on themselves and children were not significantly correlated with the age of children, disability status (FAS) of children, and age or education level of parents/caregivers.

The FCV-19S was answered by 252 parents/caregivers. Females had significantly higher mean FCV-19S scores than males (20.7 ± 6.0 vs. 17.3 ± 5.6 , $p=0.001$). The FCV-19S scores were significantly higher in the parents/caregivers who could/did not bring their children to the routine physician visit ($p=0.041$). The FCV-19S scores were not significantly different between families according to the diagnoses of the children. The scale scores were higher in the parents who reported worse communication with their children during the pandemic than parents who

TABLE 2

Demographic and clinical features of the children

Variables	n	%
Age (year)		
0-1	7	2
2-5	79	26
6-10	82	27
10-13	56	18
>13	85	28
Sex		
Boy	198	64
Girl	111	36
Diagnosis		
Cerebral palsy	137	44
Muscular dystrophy (DMD, BMD, SMA)	54	17
Genetic diseases	25	8
Spina bifida	28	9
Brachial plexus lesion	10	3
Epilepsy	8	3
Autism	11	4
Brain injury	5	2
Visual or hearing disability	6	2
Intellectual disability	6	2
Others (eg, hormonal)	19	6
Functional ambulation scale		
1	105	34
2	54	17
3	19	6
4	89	29
5	42	14
Education		
Mainstream education (Public/private school)	94	30
Special education*	142	46
Not attending school or younger than school age	73	24

DMD: Duchenne muscular dystrophy; BMD: Becker muscular dystrophy; SMA: Spinal muscular atrophy; * Including inclusive education (n=32) and homebound education (n=5)

TABLE 3 The utilization of disability-related health care services during the pandemic		
	Number of children	%
Physician visits needed due to a new complaint	27/309	9
Actualized visits due to a new complaint	11/27	41
Physician visits needed as routine follow-up	177/309	57
Actualized visits as routine follow-up	12/177	7
Medication		
Children using medication	116/309	38
Difficulty in obtaining medication	5/116	4
Orthosis		
Children using orthosis	118/309	38
Need of change/revision in orthosis	39/118	33
Difficulty in obtaining change of orthosis	18/39	46
Botulinum toxin (children with cerebral palsy n=137)		
Children with previous toxin injection	91/137	66
Children who needed repeated injection during pandemic	44/137	32
Children couldn't get the repeated injection due to pandemic	40/44	91
Exercise program		
Exercises prescribed	291/309	94
By parents at home	153/291	53
By physiotherapist at home	2/291	1
Telerehabilitation	12/291	3
At a rehabilitation center	2/291	1
At home but unsatisfactory	49/291	17
None	73/291	25

reported similar or better communication (p=0.006). The FCV-19S scores were not correlated with FAS scores, age of the children, or age and working or educational status of the parents/caregivers.

DISCUSSION

The first wave of the pandemic in Türkiye negatively affected 75% of the children with disabilities and 62% of their parents/caregivers.

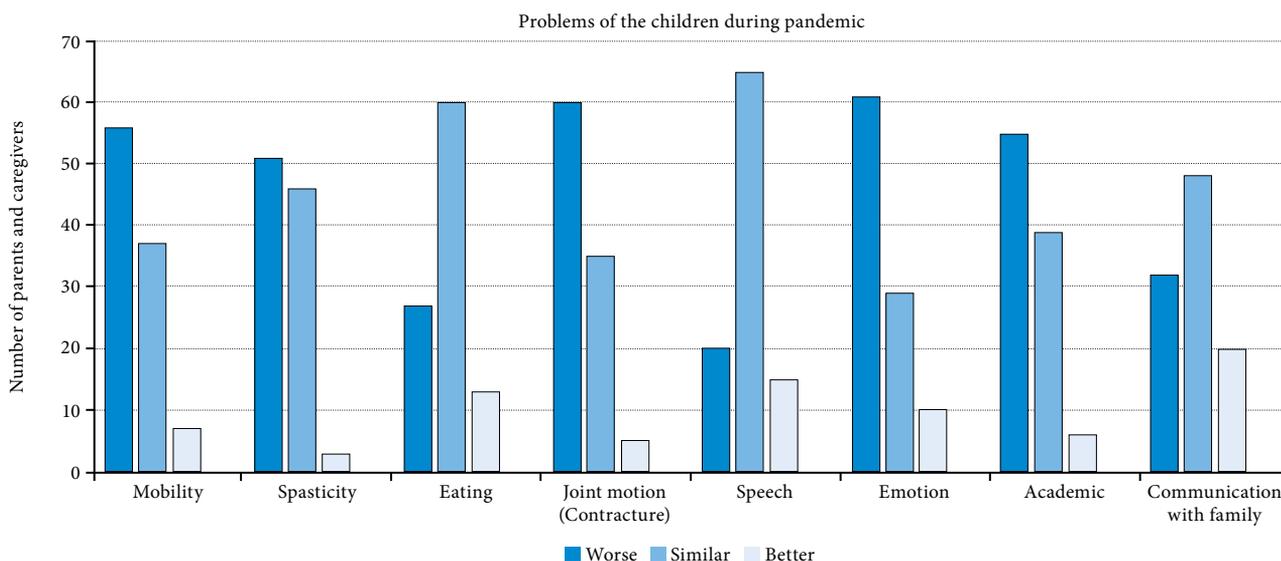


Figure 2. The perceptions of the parents/caregivers regarding changes in the functional domains of their children during the pandemic.

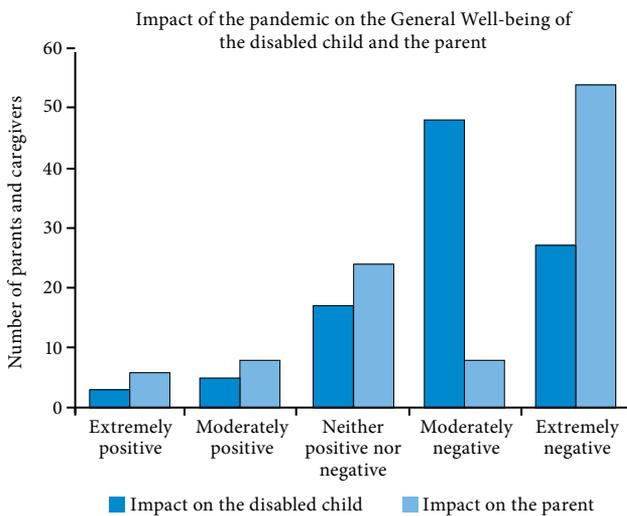


Figure 3. Perceptions of the parents/caregivers regarding the general effect of pandemic on their children and themselves.

Among 247 children who needed to visit their physician during the pandemic, 233 (94%) could not attend their physician appointment or therapy sessions, similar to the results of the French survey.^[16]

The main reason of the parents/caregivers for canceling/postponing their appointments was to protect themselves and their children. Although COVID-19 is rare and milder in children, accounting for 1 to 5% of total cases diagnosed, there is a lack of data on its incidence in children with disabilities.^[17] Among 220 children with COVID-19, Cura Yayla et al.^[18] reported that 1.8% had a neurologic disease. In our study, 0.6% of the children with disabilities were infected.

The parents/caregivers stated no difficulty in obtaining medicines regularly since the government allowed the pharmacy to provide chronic disease medications without prescriptions to reduce the admissions to the hospitals in Türkiye. However, healthcare services requiring face-to-face interactions with a specialized staff, such as therapy sessions, orthotic revisions, or botulinum toxin injections, were postponed or canceled under the pandemic conditions. Furthermore, all rehabilitation centers were either closed or worked in limited hours in Türkiye. Our findings demonstrated that only 6% of the children were able to continue therapy sessions in the hospital, whereas in the French survey, this ratio was 48% for physiotherapy, 27% for occupational, and 32% for speech therapy.^[16] The differences between the health care systems in the two countries might also play a role

in this discrepancy. Home exercises were performed by 53% of the parents/caregivers in our study and by 83% of the parents in the French survey. It was observed that some parents/caregivers who applied exercises at home found their performance unsatisfactory in our study. Telerehabilitation, underutilized during the pandemic, might remotely provide a guide for a more effective parental exercise. A systematic review about telerehabilitation for children with disabilities found that, even with a wide variety in practice and outcomes, telerehabilitation might be as effective as face-to-face intervention and suggested a coaching approach for family-type telerehabilitation.^[19] Twelve children had physiotherapy sessions with telerehabilitation in our study. In Türkiye, there were not any services and organizations for telerehabilitation. Telemedicine has emerged as a safe and effective method to support the needs of families and help alleviate their concerns.^[20]

In our study, since orthosis centers were not closed during the pandemic, parents/caregivers did not have difficulty changing the children's orthoses as in therapy sessions. Furthermore, the nature of the orthotic arrangement is different from that of therapy sessions requiring continuity.

The assignment of experienced physical medicine and rehabilitation physicians to COVID-19 wards in the hospitals and uncertainties regarding the safety of botulinum toxin injections were other obstacles. Following cessation of the first wave, many children were admitted with different complaints, such as increased spasticity, deteriorated mobility, limited joints, and need for repeated injections of botulinum toxin. Similarly, in our study, it was reported that the negative effects of spasticity increased. Recommendations regarding spasticity management and botulinum toxin injections during the pandemic in cerebral palsy were recently reported.^[21]

The interruptions in the healthcare services had some consequences. From the perspective of the parents/caregivers, mobility, spasticity, joint range of motion, emotions, and academic status of the children were affected in a worse but predictable manner. Emotional state was adversely affected in more than half of the children with disabilities in our study, similar to the French study.^[16] Changes in emotional state and behaviors were even higher (85.7%) in Spanish and Italian healthy children.^[22] Increased levels of anxiety and depression were observed in Chinese children and adolescents during the pandemic.^[23]

In our study, the mental health and anxiety levels of the parents/caregivers were not evaluated.

Farajzadeh et al.^[9] studied 106 caregivers of children with cerebral palsy, and they reported an increased rate of depression and anxiety.

In addition to the restriction of health care services, the closure of schools and kindergartens negatively affected the children. Parents/caregivers reported that their children academically deteriorated in our study. Homeschooling might require some arrangements due to their physical and intellectual disabilities, which was also underlined in the French ECHO study.^[16] We believe that parental support and education on such modifications would increase the rate and effectiveness of homeschooling. Being unable to physically go to school might further lead to physical inactivity. In this context, during the pandemic, it was shown that 44% of children with disabilities restricted their physical activities.^[16] Among Chinese healthy children, the prevalence of physical inactivity increased from 21 to 66%, and the median time spent in physical activity also reduced from 540 min/week to 105 min/week during the pandemic.^[24]

Nonetheless, staying at home seemed to offer some opportunities, such as family cohesion. One-fifth of the parents/caregivers mentioned the communication of the child with the family improved. The importance of family-centered programs in the management of children with disabilities is underlined by the unprecedented pandemic.^[25,26] Well-organized programs with families are needed to continue physical therapy and homeschooling during the pandemic.

During the pandemic, fear and anxiety globally increased.^[13] To our knowledge, prevalence of the fear of COVID-19 was not studied in parents/caregivers with disabled children. As expected, fear was higher in parents/caregivers who did not bring their children to scheduled physician appointments and who reported worsening communication between family and child.

There are limited studies examining the effect of the quarantine and pandemic on children with disabilities. The main strength of this study was the wide representation of children with different neurologic disabilities and from many parts of the country. Furthermore, it revealed the problems faced by children with disabilities and their families in the pandemic in more detail.

One of the limitations of our study is the inability to reach families who may not have internet access. Another limitation is that we did not question domestic violence and maltreatment, which is a threat to children with disabilities.^[12] In addition, the mental

health and anxiety levels of the parents/caregivers of the children with disabilities were not evaluated.

In conclusion, the detrimental consequences on several functional domains of children with neurologic disabilities when the continuity of care was disrupted during the first wave of the pandemic were demonstrated in this study. The healthcare system should be modified, and rehabilitation specialists should take action to maintain the continuity of care for children with specific needs. The COVID-19 pandemic has underlined the importance of a family-centered approach and use of technology, which were found to be markedly underutilized in our study.

Ethics Committee Approval: The study protocol was approved by the University of Health Sciences, Gaziosmanpaşa Training and Research Hospital, Ethics Committee Clinical trial number: NCT04525742, August 25, 2020. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Patient Consent for Publication: A written informed consent was obtained from each participants and for themselves and for children.

Data Sharing Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author Contributions: Idea: N.Ç., Ö.Ö.T., E.Y.; Design: N.Ç., E.K.S., E.Y., Ö.Ö.T., Control: R.A., B.H.; Data collection: E.Y., Ö.Ö.T., B.H., E.K.S.; Analysis: N.Ç., Ö.Ö.T., B.H.; Literature review: B.H., R.A.; Writing of manuscript: E.Y., N.Ç., Ö.Ö.T., B.H., E.K.S.; Critical review: N.Ç., Ö.Ö.T., E.K.S., E.Y., B.H., R.A.; Materials: E.Y., B.H., R.A.

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