



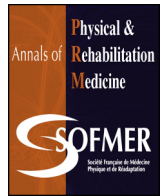
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Original article

Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: The ECHO French survey



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ABSTRACT

Background: The daily lives of children with physical disabilities and their families have been significantly affected by the COVID-19 pandemic. The children face health risks, especially mental, behavioral, social and physical risks.

Objective: This study aimed to identify potential healthcare issues relating to the wellbeing of disabled children, continuity of rehabilitation and medical care, and parental concerns during the COVID-19 lockdown.

Methods: The Enfant Confinement Handicap besOins (ECHO [child lockdown disability needs]) national survey was developed by a multidisciplinary group and disseminated in France from April 6, 2020 via email and social networks. This online survey was addressed to the parents of children with physical disabilities aged 0 to 18 years. It explored the experiences of children and their families during the lockdown. Information regarding children's wellbeing, rehabilitation and family organization was collected. The first 1000 eligible surveys were analyzed.

Results: The children (mean [SD] age 9.5 [4.8] years) mostly had cerebral palsy (42%) or neuromuscular diseases (11%). The lockdown had negative effects on morale (44% of children), behaviour (55% of children) and social interactions (55% no contact with other children). Overall, 44% of children stopped physical activities; 76% were educated at home; 22% maintained medical follow-up, and 48% and 27% continued physiotherapy and occupational therapy respectively. For more than 60% of children, parents performed the therapy. The main parental concern was rehabilitation (72%) and their main difficulty was the mental load (50%); parents complained of lack of help and support (60%).

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Conclusions: This study highlighted substantial effects on the health of children with physical disabilities and loss of opportunity, with a massive interruption of medical follow-up and rehabilitation, during the lockdown. Regular assessment of the health benefit/risk is essential to support families and ensure continuity of care during a pandemic.

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1. Introduction

In March 2020, the World Health Organisation reported more than 118,000 cases of coronavirus disease 2019 (COVID-19) worldwide and declared the situation a pandemic [1]. After health campaigns recommending preventative measures and social distancing, lockdowns were established in numerous countries to limit the spread of the infection (> 3.4 billion people confined worldwide on March 31). In this unprecedented situation, schools were closed, the possibility to go out was limited, direct contact with friends and other family members was stopped, and rehabilitation and medical follow-up were interrupted.

This exceptional situation abruptly changed daily life for children with disabilities and their families. In France, since the 2005 disability law, many children with physical disabilities attend school; 85% in regular schools and 12% in specialized establishments [2]. They also have regular medical appointments and rehabilitation sessions (physiotherapy, occupational therapy, psychological counselling, etc.), which are based on goals that are pre-determined with the children and their families [3]. According to one study, children with cerebral palsy consult a physician about 5 times a year and attend almost 4 therapy sessions per week [4]. Moreover, family management was totally disrupted during the pandemic.

The sudden and unexpected changes induced by the lockdown are likely to create new difficulties and needs for children with disabilities and their parents. The pandemic is likely to have a large impact on the health of these children, including their physical, mental and social wellbeing as defined by the WHO in the International Classification of Functioning (ICF) [5]. During the first weeks of the lockdown, some families of children with disabilities around the world alerted health systems to the effects of the lockdown on both the health and loss of opportunity for their children. However, a collective vision was required to highlight the specific needs of children and their families during the pandemic and to provide efficient services after the lockdown. We hypothesized that children with disabilities faced health risks, especially relating to mental health, behavioral disorders, social isolation, sedentarism in a context of rehabilitation and interrupted medical follow-up. Consequences on the family were also expected.

A large national survey of parents of children with physical disabilities was developed to 1) gain knowledge of the effects of lockdown on these families and 2) provide data on which to base decisions for the appropriate adaptation of rehabilitation services to improve care both individually and collectively. The survey's specific aim was to report the experiences, difficulties and needs of children with physical disabilities and their parents during the lockdown. The study we describe here focused on healthcare issues via the exploration of the child's wellbeing (morale, behavior, social interaction, physical activity), continuity of rehabilitation and medical care, and parental concerns.

2. Methods

2.1. Ethical and regulatory considerations

This study was a cross-sectional study conducted in France with an online survey and following the STROBE guidelines [6]. It began

on April 6, 2020, 3 weeks after the start of the lockdown in France (March 17 to May 11, 2020), and was conducted according to current French legislation (loi Jardé, no. 2012-300) [7]. Responders could not be identified from the survey (no email or IP address), so anonymity was guaranteed [8]. The survey was registered at ClinicalTrials.gov (NCT04395833).

2.2. Development of the survey

Given the unprecedented situation, the ECHO survey (Enfant Confinement Handicap BesOins [child lockdown disability needs]) was specifically created to report the experiences, difficulties and needs of children with physical disabilities and their parents during the COVID-19 lockdown. It was addressed to parents or legal guardians of children with physical disabilities (cerebral palsy, neuromuscular disease, orthopedic disease, etc.), with or without other associated impairments, who were 0 to 18 years old.

To ensure face and content validity [9], the survey was developed by a national multidisciplinary group that included 7 parents of children with physical disabilities, representatives of 3 family organizations and 3 learned societies, researchers, medical and rehabilitation professionals who were all experienced in disability care (see acknowledgements). In a biopsychosocial perspective [10], the conceptual framework of the ICF describing the individual in terms of activity, participation and environment was used [5]. The content and formulation were in French and were approved by all stakeholders before launching. The survey was conceived to be short and to take less than 20 min to complete. The survey was tested by the 7 families before its diffusion to check comprehensibility of the instructions, items, response options and completion time.

The survey was developed by using the online tool SurveyMonkey (San Mateo, CA, USA). The completion could only be proposed online because of the lockdown measures. The survey consisted of 115 questions. The first part related to general information about the child. This part collected data on age, sex, region of residence, type of residence during the lockdown, motor function (autonomy level rated A to D for the following items: walking, dominant upper-limb use, non-dominant upper-limb use and fine motor skill, where A indicates "activity possible without difficulty or help" and D "not possible" [11]), diagnosis and rehabilitation setting (outpatient clinic, rehabilitation center or specialized services [provided at home, at school or in an establishment]). The second part of the survey related to the child's condition and the third to the parents' experience. The questions on the child's condition corresponded to medical follow-up, rehabilitation and daily life (schooling, physical activity, morale, behavior and social interaction) during the lockdown. The section on parent experience asked about family management, concerns, difficulties and needs during daily life in the lockdown. Most questions had closed answers, either binary (yes/no) or multiple choice. All questions did not have to be answered (e.g., children without physiotherapy follow-up did not have to answer questions related to physiotherapy). For more details, all questions and responses to the ECHO survey are available at <https://fr.surveymonkey.com/r/TESTECHO>.

2.3. Dissemination strategy

The survey was promoted nationally through parent groups, advocacy groups, learning societies and professional bodies. It was widely disseminated via email and social media (Facebook, LinkedIn and Twitter) to collect real-time information on the impact of the lockdown on daily life and to obtain data on children with a wide range of ages and situations. It was also diffused countrywide, in all regions of France, to limit local bias. Weekly reminders were sent to families, patients, learned societies, organizations etc. to encourage completion and diffusion until the end of the lockdown. Care was taken to ensure that the survey reached family networks.

Because of the unprecedented situation, the number of required responses could not be estimated. However, a sample of at least 1000 responses was considered appropriate to provide consistent information on the experience of children with physical disabilities and their parents during the lockdown.

2.4. Statistical analysis

The variables and questions relating to general information about the children, child's wellbeing, continuity of rehabilitation and medical care, and parental concerns were selected for the present study from the larger ECHO survey. Thus, data on demographics, morale, behavior, social interaction, physical activity, medical follow-up, rehabilitation, main parental concerns, difficulties and needs were analyzed. We excluded from the analysis only surveys that were not completed by parents or legal guardians, that were not finished, or if the child was not living at home during the lockdown. Descriptive analysis was performed on the first 1000 responses that fulfilled the inclusion criteria. Results are provided for all possible responses to each question. Quantitative results are expressed as mean (standard deviation) and categorical results as number (%).

3. Results

3.1. Population description

Between April 6 and April 17, 2020, 1416 questionnaires were completed (Table 1). We excluded questionnaires completed by a person other than the child's parents or legal guardian ($n = 27$), were not finished ($n = 353$), or children were not living at home during the lockdown ($n = 36$). In total, 1000 questionnaires were analyzed (Fig. 1).

The mean age of children was 9.5 (4.8) years; 46% were female. Responses were received from 12 of 13 regions of France, with 3 regions more represented (Table 1). Most of the children had cerebral palsy (42%) or neuromuscular diseases (11%). They had various levels of motor function: 38.5% could not walk and 38.2% needed help or stimulation for fine motor skills. Associated impairments were reported for 67% (cognitive [41%], behavioral [25%] and sensory [15%]). Rehabilitation during the lockdown was mostly performed by specialized services (62%). Mothers completed 88% of the questionnaires.

3.2. Wellbeing of children with physical disabilities

A negative effect of lockdown on morale was reported for 43% of children; 55% no longer had contact with other children during this period (Table 2). In total, 55% of children showed behavior changes, mostly behavioral problems (32%) and sleeping difficulties (22%). Among the 732 children who usually practiced physical activities, 44% had stopped them during the lockdown.

Table 1

Characteristics of respondents to the ECHO survey.

Children with physical disabilities	
Age (years) ($n = 1000$)	
Mean (SD)	9.5 (4.8)
Range [min-max]	[1-18]
Sex ($n = 1000$)	
Female	459 (46%)
Male	541 (54%)
Region of residence in France ($n = 1000$)	
Auvergne-Rhône-Alpes	301 (30%)
Brittany	121 (12%)
Ile-de-France (Paris region)	118 (12%)
Pays de la Loire	88 (9%)
Aquitaine-Limousin-Poitou-Charentes	76 (8%)
Languedoc-Roussillon-Midi-Pyrénées	74 (7%)
Alsace-Champagne-Ardenne-Lorraine	64 (6%)
Centre-Val de Loire	31 (3%)
Normandy	31 (3%)
Bourgogne-Franche-Comté	30 (3%)
Nord-Pas-de-Calais-Picardie	29 (3%)
Provence-Alpes-Côte d'Azur	27 (3%)
Overseas	10 (1%)
Corsica	0 (0%)
Pathologies ($n = 1000$)	
Cerebral palsy	418 (42%)
Genetic diseases or congenital malformations	245 (25%)
Neuromuscular diseases (Duchenne muscular dystrophy, spinal amyotrophy, etc.)	111 (11%)
Other neurological lesions (dysraphism, traumatic brain injury)	55 (6%)
Orthopedic diseases (bone malformations, amputation, bone tumor etc.)	15 (2%)
Other	156 (16%)
Functional abilities ($n = 1000$)	
Walking	
Possible without difficulty or help	208 (21%)
Possible with difficulty but no help	185 (19%)
Possible with human help or stimulation	222 (22%)
Not possible	385 (39%)
Fine motor skills	
Possible without difficulty or help	97 (10%)
Possible with difficulty but no help	273 (27%)
Possible with human help or stimulation	382 (38%)
Not possible	248 (25%)
Associated impairments ($n = 906$)	
Cognitive	367 (41%)
Behavioural	227 (25%)
Sensory	139 (15%)
Other	161 (18%)
None	303 (33%)
Rehabilitation main setting ($n = 1000$)	
Specialized services ^a	619 (62%)
Outpatient clinic	208 (21%)
Rehabilitation centre	55 (6%)
Other	118 (12%)
Person answering the questionnaire	
Respondents ($n = 1000$)	
Mother	875 (88%)
Father	117 (12%)
Legal guardian	8 (1%)

^a Specialized services, at home, at school or in establishment, included CAMSP (Centre d'action médico-sociale précoce [early medical-social center for action]), SESSAD (service d'éducation spéciale et de soins à domicile [special education and home health service]), IME (Institut Médico-Educatif [medical-educational institution]), IEM (Institut d'Education Motrice [educational institution for children with physical disabilities]).

3.3. Rehabilitation and medical follow-up

For 77% of children, medical consultations were cancelled or postponed during the lockdown (Table 2). Consultations that were maintained were performed face to face (4%) or by telehealth (18%). Physiotherapy, occupational therapy, speech therapy,

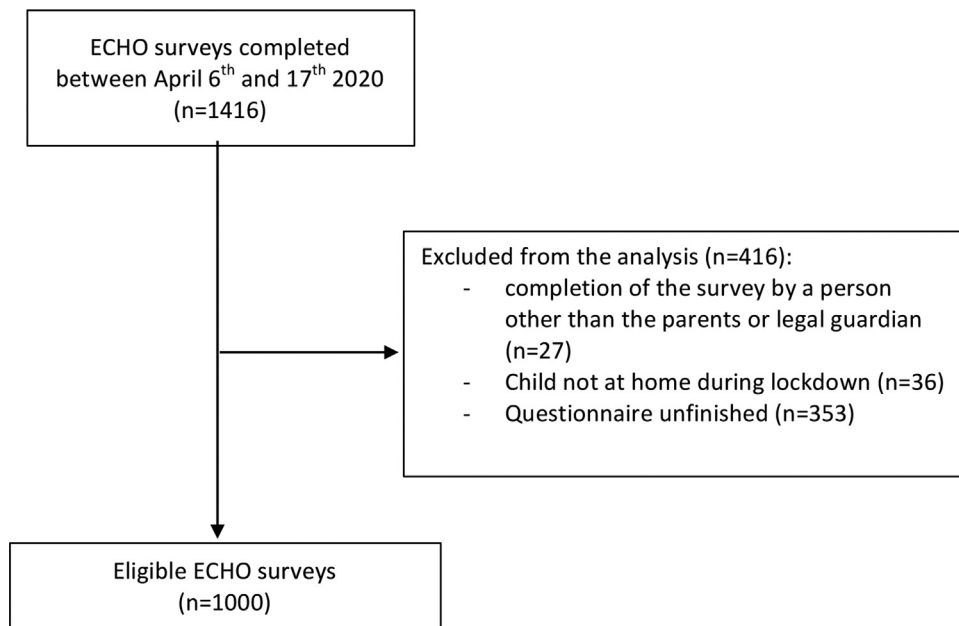


Fig. 1. Flow of participants in the study. ECHO, Enfant Confinement Handicap besOins.

psychomotor therapy and orthoptic sessions were continued for 48%, 27%, 32%, 31% and 13% of children, respectively. Therapy was performed by parents (physiotherapy, occupational therapy, speech therapy, psychomotor therapy and orthoptist) for 83%, 77%, 80%, 79% and 62% of children, respectively.

3.4. Parental concerns during the lockdown

Overall, 76% of children were educated at home; 81% of these required significant parental help (Table 2). For 72% of parents, the primary concern was rehabilitation. Other major concerns were social interactions (46%) and risk of COVID-19 infection (45%). For 50% of parents, mental load was the main daily difficulty; 60% reported a need for support in terms of human resources, psychological support or schooling recommendations.

4. Discussion

The ECHO survey was an original, national, multidisciplinary, family-centered initiative to describe the experiences of children with disabilities and their families during the COVID-19 pandemic. The responses revealed that families faced major difficulties, and many of their needs were unmet owing to the cessation of medical follow-up and rehabilitation. From the beginning of the lockdown, all children's care, rehabilitation, schooling etc. had to be performed at home, placing all the onus on parents.

4.1. Health-related risks for children and their families

This survey highlighted the negative effects of the lockdown on the children's wellbeing and their mental and social health (morale, behavior, social interaction and physical activity), similar to a recent report on children without disability [12]. The psychological effects of the lockdown, including post-traumatic stress symptoms, confusion and anger have been reported in the general population and are related to the duration of the lockdown [13–15]. Children with physical disabilities have an increased risk of mental health symptoms [16–18], which could be exacerbated during the pandemic. The lack of social interaction may not only affect their morale but may also lead to a regression in their

communication ability. Moreover, the development or worsening of behavioral disorders could further affect their wellbeing and increase the parental sensation of helplessness. Children with physical disabilities have higher risk of sedentarism and its consequences than other children [19,20]. As was found for children without disability [21], the results of the present survey showed that during the lockdown, the level of physical activity of children with disabilities was reduced considerably. Furthermore, these children are likely to experience a loss of motor skills because motor capacity is related to physical activity and sedentary time negatively affects motor skills [22,23].

The most frequent parental concern was the lack of rehabilitation during the lockdown. The purpose of regular rehabilitation is to maintain or progress motor skills and to prevent complications that could further alter mobility and increase difficulties in daily life, such as orthopedic deformities or physical deconditioning. Therefore, the interruption or modification of medical care and rehabilitation could inevitably deteriorate the child's physical status and functional ability.

The greatest difficulty reported by the parents was the mental load faced daily. Usual family life was disrupted by the need for intensive parent intervention in activities that are usually performed by a multidisciplinary team (rehabilitation professionals, teachers, etc.). The parents of children with disabilities already have to cope with the physical and mental health challenges associated with having a child with disabilities in normal times and are therefore particularly vulnerable during the pandemic [24,25]. The closure of schools and some specialized services and establishments in France during the lockdown increased the pressure on these parents, generating a high risk of parental exhaustion [25,26].

The results of this survey highlight the secondary impact of the COVID-19 pandemic on the care and wellbeing of children with physical disabilities, as was shown in other chronic conditions [27]. The Cerebral Palsy Rehabilitation Charter [28], which promotes the rights of children with disabilities in terms of shared, participation-related goals, whatever the situation, was not applied during the lockdown for a large proportion of children. Similarly, the concept of the "F words" (Function, Family, Fitness, Fun, Friends, and Future [29]) that support the implementation of the ICF, promoted by the WHO [5], was not applied.

Table 2

Main results for child wellbeing, rehabilitation, and parent concerns in the ECHO survey (based on 1000 answers).

Questions	Number of responses (n)	(%)
Child wellbeing		
Morale	1000	
Positively impacted		128 (13)
Negatively impacted		433 (43)
Not impacted		439 (44)
Interaction with other children	1000	
Yes		454 (45)
No		546 (55)
Changes in children	1000	
Behavioural disorders (agitation, anger, isolation, etc.)		318 (32)
Sleeping difficulties		218 (22)
Somatic complaints (pain, etc.)		136 (14)
Eating disorders		89 (9)
Regression		80 (8)
Other		97 (10)
None		466 (47)
Physical activity (among children who practiced an activity before the lockdown)	732	
Yes		408 (56)
No		324 (44)
Rehabilitation		
Planned medical follow-up consultation	588	
Cancelled		262 (45)
Delayed		189 (32)
Telehealth		103 (18)
Held		26 (4)
Maintained but cancelled by parents due to COVID-19 fear		8 (1)
Rehabilitation maintained by the therapist, parents or the child ^a		
Physiotherapy	872	418 (48)
Occupational therapy	644	176 (27)
Speaking therapy	548	176 (32)
Psychomotricity	604	186 (31)
Orthoptist	208	27 (13)
Rehabilitation performed by parents during the lockdown ^a		
Physiotherapy	418	345 (83)
Occupational Therapy	179	138 (77)
Speaking therapy	178	142 (80)
Psychomotricity	188	149 (79)
Orthoptist	26	16 (62)
Parent concerns		
Schooling	786	
At home		596 (76)
At school or usual establishment		29 (4)
Not maintained		161 (21)
Parental help with home-schooling	594	
Extensive help		483 (81)
Little help		86 (15)
Child independent		25 (4)
Main concern for the parents	1000	
Rehabilitation		720 (72)
Social interaction		462 (46)
Risk of COVID-19 infection		453 (45)
School learning		376 (38)
Medical follow-up		345 (35)
Morale		324 (32)
Physical activities		296 (30)
Leisure activities		232 (23)
Behaviour		236 (24)
Other		31 (3)
None		31 (3)
Difficulties in everyday life for the parents	1000	
Mental load		503 (50)
Feelings of helplessness		398 (40)
Daily life coordination		321 (32)
Prioritization of the child's needs		313 (31)
Lack of human support		289 (29)
Lack of time		272 (27)
Lack of material support		207 (21)
Financial concerns		131 (13)
None		159 (16)
Other		56 (6)
Claim for need of support (human or material)	359	
Yes		215 (60)
No		144 (40)

^a Questions relating to maintained therapy sessions or sessions performed by parents were only answered if the child usually had rehabilitation.

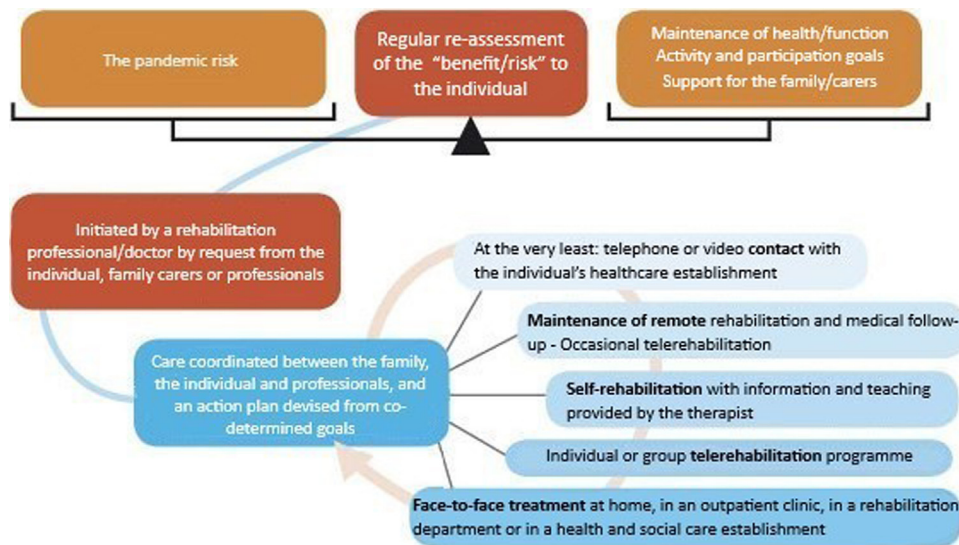


Fig. 2. Coordination of rehabilitation for children with disabilities during the COVID-19 lockdown and during easing of the lockdown. A proposition for regular evaluation of the “benefit/risk” to the individual during the pandemic situation to obtain a balance between the risk of the spread of the infection, and overall health, activity and participation goals for the child as well as providing support for the family and carers. The assessment may be initiated by the rehabilitation professional/doctor, the individual or the family. The aim is for care to be coordinated between all those concerned and based on co-determined goals in the interest of the individual. The action plan may be graduated according to the individual's needs, from telephone or video contact with the family to face-to-face treatment at home.

4.2. Evaluating the benefits and healthcare-related risks during the lockdown and progressive easing of the lockdown

One of the main results of the ECHO survey was that the effects and experiences of the lockdown differed among families. This finding demonstrates the importance of assessing each situation individually to maintain and promote quality of life in children and their families, including during and after the lockdown. The lockdown resulted in an extended period with no access to usual care, which is set to continue during the progressive easing of the lockdown. Surveys such as ECHO will increase our understanding of the challenges that children with disabilities and their families face during the COVID-19 pandemic and should lead to new propositions for prompt action and the promotion of collaboration. Care must be centered around the children and their families at all times and in all settings, and rehabilitation professionals should aim to prevent the secondary effects of the health crisis on children and their families [30,31]. During the health crisis, the individual “benefit/risk” ratio should be regularly re-evaluated to ensure a balance between the pandemic risk and the maintenance of overall health, activity and participation goals for the child as well as provide support for the family and caregivers (Fig. 2). The risk of COVID-19 infection is considered low for children [32–34]; however, the pandemic has large, potentially long-lasting, indirect consequences for children with disabilities.

Rehabilitation must remain organized according to activity and participation goals that are co-determined with the child and the family to help them adapt to the situation and self-manage as far as possible [35]. A key worker or coordinator should be appointed for each child, as is already recommended with the health crisis, but is even more necessary in the present context [36]. Depending on the individual's needs, the provision of rehabilitation can be graded from a simple telephone contact with the family to a home visit when absolutely necessary. The level of provision must be regularly re-evaluated because the child's and family's needs may change. Existing new approaches for the long-term continuity of care should be implemented during the lockdown and its easing

as well as in usual-care situations [3]. For example, telerehabilitation provides a means for therapy sessions that is fully compliant with barrier measures. Large-scale studies of the indirect effects of the pandemic on children with disabilities are required, along with the development of innovative healthcare management approaches that are patient- and family-centered to provide continuous care and support for these children and their families.

The findings of this survey, performed during the lockdown, regarding medical care and rehabilitation, child well-being and parental concerns, must be considered in the context of the actual health situation and social distancing measures and also for the usual management of some children (e.g., those living in isolated regions). We now need innovative care systems that follow the principles of the child's rehabilitation, prevent the secondary effects of the lockdown on children and their families, and can be used both in a pandemic situation as well as usual care.

4.3. Limitations

The representativeness of the responders could not be ensured in this study. However, the receipt of a large number of responses in just a few days from parents of children with disabilities of varying severity, associated disorders and family situations from all over France demonstrates the importance of the issue and their great concern for their children's condition and therefore must be closely considered. This article presented the descriptive results of the first 1000 responses to the ECHO survey, but a larger sample size is expected at the end of the collection period. This larger sample will allow specific questions to be addressed using multivariate analyses (e.g., the impact on daily life or on medical follow-up and rehabilitation) in further studies. Addressing the survey to parents and not children may have led to some response bias. The survey was specially created for the COVID-19 pandemic, designed to be rapidly diffused during the lockdown and was only available online. Therefore, it was not available to people who do not have access to the Internet, who may have faced even greater difficulties during the lockdown. The unfinished surveys were not

analyzed so as to obtain the same number of responses in all domains explored, but this could have affected the generalizability of results. Although healthcare systems and the measures taken to cope with the pandemic differ among countries, some of the data from this French survey could be used for studies in other countries.

5. Conclusions

The lockdown in France in response to the COVID-19 pandemic has disrupted daily life for children with physical disabilities and their families. This study revealed major consequences for the wellbeing of the children. Rehabilitation services were massively interrupted, and this was the main parental concern. Parents were faced with the burden of managing the child's daily life as well as providing rehabilitation. The situation of the child and family must be regularly re-evaluated and goals must be family-centered, adapted and prioritized as a function of the "benefit/risk" balance.

Disclosure of interest

The authors declare that they have no competing interest.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.rehab.2020.08.001>.

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