Parent satisfaction with medical and rehabilitation services for children with physical disabilities during lockdown

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Dear editor,

During the COVID pandemic, the first full lockdown in 2020 dramatically disrupted service delivery for children with physical disabilities, forcing a high level of parental involvement [1].

We analysed the impact of these massive and sudden changes on children with physical disabilities and their families [1,2] with a national survey called Enfant Confinement Handicap besOins (ECHO [child lockdown disability needs]). The ECHO survey was a prospective, cross-sectional study conceived by investigators with different professions and user organizations (clinicaltrials.gov: NCT04395833), conducted in France, and diffused online (SurveyMonkey®, San Mateo, California, USA). Its development and diffusion are explained in two previous articles [1,2]. The ECHO survey was adapted to the French care system in which paediatric rehabilitation is mainly delivered by rehabilitation centres, outpatient clinics (non-specialised), or specialized services (at home, at school or in institutions) [3,4]. The questionnaires were addressed to the parents or legal guardians of children with physical disabilities up to 18 years of age and disseminated across France during the first full lockdown (April 13−May 11, 2020). It was composed of 115 closed questions (available at https://fr.surveymonkey.com/r/TESTECHO). We only excluded 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.

This paper reports on the third study from these data. The first showed that medical follow-up and rehabilitation were massively disrupted and that this was a major concern for families [1]. The second revealed that continued rehabilitation delivery protected from difficulties with daily life activities and maintained well-being, whereas associated impairments (e.g., behavioural disorders) and parental stress during the pandemic increased difficulties [2].

The third study was about the possible enhancement of service delivery to improve the support provided to children with disabilities and their families during a pandemic situation, and even after. Considering parent-reported outcomes is key for this purpose [5] and complementary to feedback from clinicians and healthcare providers. Parental satisfaction is one of the most important indicators of paediatric healthcare quality [6–8]. Evaluation of parental satisfaction and its determinants in the unprecedented context of the pandemic could highlight some aspects of medical and rehabilitation service delivery that required prioritisation during the pandemic and that should also be improved after [9]. The present work addressed two goals. First, we characterized the interruption of medical and rehabilitation service delivery for children with physical disabilities during the first full lockdown and evaluated parental satisfaction with this service delivery. Second, we identified determinants of satisfaction in a large sample of parents during the first lockdown in France. We further hypothesized that the level of satisfaction would depend on child and family characteristics and support received, particularly continued rehabilitation (by health professionals or themselves).

First, we analysed parental satisfaction related to care disruption. A total of 1376 questionnaires were included in the analysis (Appendix A.1 and A.2 [2]). Parents reported that 634/821 (77%) consultations scheduled before the lockdown were cancelled. Those that were maintained were performed by telephone or teleconsultation in 142/187 (78%) cases (Table 1). Among the 1376 children included, 1337 usually had rehabilitation (one or more therapies). Rehabilitation was totally disrupted for 555/1337 (40%). For the other 60%, rehabilitation was mostly carried out by the parents (63−82% depending on the therapies) and was mostly performed at home (55−83% depending on the therapies). Telephone guidance and telerehabilitation were provided for up to 39% of children depending on the therapies (Table 2). This disruption of medical and rehabilitation service delivery was in line with the findings of studies in other countries [9]. Parental satisfaction with both medical and rehabilitation service delivery was assessed using a French version of the client satisfaction questionnaire 8 (CSQ-8) [10,11]. This self-administered questionnaire is a validated measure of satisfaction and was adapted for medical and rehabilitation service delivery. It consists of 8 questions addressed to parents (Appendix A.3), each rated on a 4-point Likert scale from 1 to 4 (total range 8−32), with higher scores denoting higher levels of satisfaction. The mean CSQ-8 score was 18/32 (SD 6) points. As hypothesized, our results revealed parental dissatisfaction with medical and rehabilitation services during the first full lockdown in France. This was consistent with an American study performed on a smaller sample with a non-validated scale that reported a 44% rate of low parental satisfaction with their child's therapy services during this period [8]. Those results contrast with previous reports of generally high levels of satisfaction with health care before the pandemic [6,12,13]. The children and their parents faced a massive and unprecedented interruption of care provision, including both medical and rehabilitation services, which forced them to adapt.

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Table 1
Description of medical consultations.

Medical consultation planned during the lockdown (*n* = 1376)	
Yes	821 (60%)
No	555 (40%)
Maintained during the lockdown (*n* = 821)	
Yes (*n* = 187)	187 (23%)
By phone call or teleconsultation	142 (76%)
Face-to-face	45 (24%)
No (*n* = 634)	634 (77%)
Cancelled consultation	361 (57%)
Delayed consultation	263 (42%)
Maintained but not performed	10 (2%)
Difficulties (*n* = 1376)	
Difficulty accessing a physician	108 (8%)
No support	487 (35%)
Physician did not listen sufficiently	81 (6%)
Difficulty obtaining new treatments prescribed during the lockdown	287 (21%)
Difficulty with access to urgent care facilities	79 (6%)
None	510 (37%)
Other	151 (11%)

The majority of parents felt that they had no choice but to perform their child's rehabilitation themselves at home during the lockdown [14]. The dissatisfaction of most parents with rehabilitation services highlights the importance of systematically evaluating the amount and nature of the involvement that parents desire to have in the rehabilitation process [15,16].

Second, we evaluated determinants of satisfaction among child, family, and service delivery characteristics reported by parents. For child characteristics, we explored age, sex, pathology (e.g., cerebral palsy, neuromuscular diseases, etc.), type of accommodation (apartment or house), region of France, associated impairments (e.g., behavioural disorders, visual impairment etc.), and level of dependence. The level of dependence was assessed with a custom-made dependency score composed of two sub-scores: a prehension score (3 items) and a mobility score (3 items) (Appendix A.4). Each item was rated from 0 to 3 (total sub-scores from 0 to 9): higher scores indicate greater dependence. For family characteristics, we explored lone parents and the number of children at home. For service delivery characteristics, we explored the continuity of medical consultations and rehabilitation sessions during the lockdown and the child's usual rehabilitation setting (rehabilitation centre, outpatient clinic or specialized services). We devised a 3-category scale to evaluate the extent of rehabilitation disruption during the lockdown period: no disruption, moderate disruption, and total disruption. We analysed the CSQ-8 scores as dependent variables with one-way ANOVA to explore the effects of the 3 sets of factors (child, family, and service delivery characteristics). Factors that were significant in the univariate analysis (one-way ANOVA) were included in multivariate analyses involving a stepwise general linear model (GLM) to further explore their relationship with satisfaction. For the "child characteristics" model, prehension score was the only factor that independently affected satisfaction. CSQ-8 score was higher for high than low prehension scores (B = 2.5, 95%CI 0.9; 4.1, p = 0.03) (Table 3). No family characteristics influenced satisfaction. For the "service provision characteristics" model, continued rehabilitation was the strongest factor that independently affected satisfaction: CSQ-8 scores were higher for no disruption of rehabilitation and moderate disruption of rehabilitation than for total disruption of rehabilitation (respectively B = 6.6, 95%CI 5; 8.3, $p < 0.001$ and B = 3.7, 95%CI 2.5; 4.9, $p < 0.001$). Rehabilitation setting was the second factor: CSQ-8 scores were lower for non-specialised outpatient and other settings than for specialized services (respectively B = 2.8, 95%CI 1.2; 4.3, $p < 0.001$ and B = 2.4, 95%CI 2; 4.7, p = 0.04). Maintained medical consultations was the third factor: CSQ-8 scores were higher when consultations were maintained than when they were cancelled (B = 2.2, 95%CI 0.2; 4.2, p = 0.03). Some determinants of parental dissatisfaction were highlighted (continuity of medical and rehabilitation care, delivery by specialised services and prehension capacity); they can be used to guide improvements in rehabilitation delivery [16]. The fact that low prehension capacity was the only "child characteristic" that determined parental satisfaction during the pandemic shows that specific attention should be paid to supporting vulnerable children with reduced autonomy and their families. Even before the pandemic, the dependency of individuals with cerebral palsy was highlighted as a determinant of satisfaction [6]. These children often have more severe disabilities, thus providing regular rehabilitation, assistive products/technology or human help is crucial to reduce the family burden. The parents expressed higher levels of satisfaction when their child's rehabilitation was usually carried out in a specialized centre, rather than in a non-specialised outpatient clinic or other settings. During the lockdown, such services may have been more able to respond efficiently to the situation by proposing specific family-centred solutions to support and maintain the link with the children and their families [1]. However, the rehabilitation setting is also

Table 2
Description of rehabilitation.

	Physiotherapy	Occupational therapy	Speech therapy	Psychomotricity	Orthoptic therapy
***Therapy before lockdown* (*n* = *1376*)**					
Yes	1186 (86%)	868 (63%)	740 (54%)	830 (60%)	286 (21%)
No	190 (14%)	508 (37%)	636 (46%)	546 (40%)	1090 (79%)
Continued during Lockdown	*n = 1186*	*n = 868*	*n = 740*	*n = 830*	*n = 286*
Yes	584 (49%)	238 (27%)	243 (33%)	264 (32%)	40 (14%)
No	602 (51%)	630 (73%)	497 (67%)	566 (68%)	246 (86%)
Who performed the rehabilitation?	*n = 584*	*n = 238*	*n = 243*	*n = 264*	*n = 40*
Usual practitioner	129 (22%)	68 (29%)	79 (33%)	74 (28%)	15 (38%)
Relay by another professional	25 (4%)	2 (1%)	2 (1%)	2 (1%)	2 (5%)
Parents	478 (82%)	180 (76%)	185 (76%)	204 (77%)	25 (63%)
The child themselves	51 (9%)	24 (10%)	6 (3%)	21 (8%)	1 (3%)
How was it performed?	*n = 585*	*n = 238*	*n = 243*	*n = 264*	*n = 40*
In the clinic	49 (9%)	17 (7%)	14 (6%)	22 (8%)	10 (25%)
At home	485 (83%)	166 (70%)	148 (61%)	187 (71%)	22 (55%)
Phone guidance/telerehabilitation	140 (24%)	78 (33%)	99 (39%)	73 (28%)	8 (20%)
Self-rehabilitation video protocol	53 (9%)	16 (7%)	14 (6%)	17 (6%)	0
Written self-rehabilitation protocol	113 (19%)	51 (21%)	41 (17%)	36 (14%)	0
Apps	14 (2%)	21 (9%)	28 (16%)	11 (4%)	3 (8%)
Others	33 (6%)	3 (1%)	5 (2%)	6 (2%)	5 (13%)

Table 3
Determinants of satisfaction, multivariate analysis.

	B	95% CI	*P*-value
Child characteristics*			
Prehension Score			
0-3 (*n* = 506)	2.5	0.9; 4.1	0.03
4-6 (*n* = 388)	1	-0.7; 2.7	0.25
7-9 (*n* = 482)	ref	NA	NA
Associated Disorders			
Yes (*n* = 944)	-1.2	-2.8; 0.4	0.15
No (*n* = 432)	ref	NA	NA
Adjusted R^2 of the model above =0.04			
Service provision characteristics**			
Rehabilitation main location			
Outpatient clinic[a] (*n* = 293)	-2.8	-4.3; -1.2	<0.001
Rehabilitation centre (*n* = 80)	0.4	-3; 3.8	0.8
Other (*n* = 155)	-2.4	-4.7; -2	0.04
Specialised services[b] (*n* = 848)	ref	NA	NA
Continuity of rehabilitation			
No disruption (*n* = 243)	6.6	5; 8.3	<0.001
Moderate disruption (*n* = 539)	3.7	2.5; 4.9	<0.001
Total disruption (*n* = 554)	ref	NA	NA
Maintenance of medical consultations			
Yes (*n* = 187)	2.2	0.2; 4.2	0.03
No medical consultations planned (*n* = 555)	0.8	-0.3; 2	0.16
No (*n* = 634)	ref	NA	NA
Adjusted R^2 of the model above = 0.21			

NA = not applicable
We analysed the effects of the 3 sets of variables (child, family and service provision characteristics) on CSQ-8 scores with the one-way ANOVA. To take the multiple comparisons into account, we adjusted the *p*-value of the univariate analysis using a Bonferroni correction, thus p was set at 0.0033 (0.05/15). Variables that were significant in the univariate analysis were included in multivariate analyses by stepwise general linear model (GLM) to further explore their relation with satisfaction. Unless otherwise indicated (corrections), a two-tailed $p < 0.05$ was considered statistically significant. All statistical analyses were performed with SPSS 24.0.

[a] Outpatient clinic: clinic run by a private, non-specialised practitioner; individuals are reimbursed by the state

[b] Specialised community services, at home, at school or in an institution, included CAMSP (Centre d'action médico-sociale précoce [medical-social centre for young children]) and 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]).

* No interaction was found between 2 variables.

** No interaction was found between 3 variables.

influenced by the child's age, type of condition and community resources, among other factors. Clinicians and healthcare providers should reflect together on the development of allied healthcare interventions that follow a child-centred approach with multidisciplinary teams, and that can ensure coordinated care during the pandemic and after [5]. Priorities should be identified because the healthcare system cannot provide these services to children of all ages, disability types and severities on an ongoing basis. Despite the low level of evidence supporting long-term regular multidisciplinary rehabilitation, and the burden of such long-term care on the family [4], continued rehabilitation was the strongest determinant of satisfaction in this study. In such an unexpected situation, new needs and stressors for families emerged (e.g. limited leisure and social activities, school shutdowns, emotional distress due to family illness, etc.), however, the provision of specific rehabilitation support to ensure continuity of care delivery was helpful and highlighted by parents as a priority [1].

This study has several limitations. The focus was on parent satisfaction, which is only one facet of service delivery quality. The determinants explored were not exhaustive. The lockdown was an unprecedented situation and other family factors (e.g., stress, modification of daily life, etc.) may have influenced parent satisfaction, even if rehabilitation was the main concern for the parents of children with physical disabilities at this time [1]. We only measured satisfaction in the early phase of the lockdown when most services (health, education and other services) were temporarily shut down; therefore, the results could also have been influenced by factors such as government announcements during the pandemic. Measurements of child pathology, associated impairments and level of dependence were not performed with validated measures but with parent-report questionnaires. The survey and results are specific to France and may not be relevant to countries with different healthcare systems and that responded differently to the pandemic.

In conclusion, the full COVID-19 lockdown was the first experience of a massive interruption of care delivery, which imposed home care for many children with physical disabilities. Parental dissatisfaction with the changes in care delivery during the lockdown highlighted the perceived importance of regular rehabilitation sessions and the need for services to provide specific family-centred solutions and support. Future steps should involve evaluation of parental satisfaction and concertation with clinicians and healthcare providers to improve the quality of medical and rehabilitation services provided to children with disabilities in any context, and the development of adaptative approaches (e.g., telehealth).

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Declaration of Competing Interest

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.rehab.2022.101726.

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