



Research Article

Impact of COVID-19 Pandemic on Health Care System, Education, and Mental Well-being of Children with Cystic Fibrosis and their Parents

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Abstract

Background: The COVID-19 pandemic was a concerning time for all with additional co-morbidities putting them at increased risk, including Children with Cystic Fibrosis (CWCF) and their families. The aim of this study is to examine the impact of the COVID-19 pandemic on the lives of CWCF and their families in relation to specialist healthcare, education, and mental well-being. **Methods:** A cross-sectional survey was undertaken by parents of CWCF in late 2020. The consent form and questionnaire developed by University College Dublin (UCD) and Cystic Fibrosis (CF) Ireland were hosted on Smart Survey UK. The survey was advertised widely via social media platforms and the CF Ireland website, during September/October 2020. **Results:** One hundred and twenty-three parents of CWCF responded, 67 (54.9%) had deferred their child's hospital visits since the start of the pandemic due to fear of COVID-19 (38 (56.7%)) or due to hospital unit closure (12(19.4%)), with delays ranging from 1 to 6 months. Many parents found online consultation new (56.1%) and over 80% were satisfied with it. With increasing child age, parents felt more confident that their child could take necessary precautions on their own (4.2% vs 58.3%). Key mental health issues faced by CWCF were increased stress and anxiety levels. There was an upward trend in the proportions of experiencing mental health issues with increasing age. **Conclusion:** COVID-19 has had a huge impact on CWCF and their parents in terms of hospital care and mental health. Parents of older children were more willing to send their children to school. Certain new favoured processes, such as online consultations and emailed prescriptions, may persist as a part of overall care post-pandemic.

Keywords: COVID-19; Cystic Fibrosis; Hospital visits, School; Mental wellbeing

Introduction

Cystic Fibrosis is a chronic and life-threatening disease associated with many health problems including recurrent respiratory tract infections and deterioration of lung function. The emergence of the COVID-19 pandemic significantly challenged the lives of CWCF and their families. The myriad of challenges

includes the disruption in the point of care, challenges to the normal functioning of the health system, and the closing of schools. Ireland had a number of lockdowns in 2020 with school closures and a work-from-home directive.

Prior to the COVID-19 pandemic, a higher prevalence of depression and anxiety among individuals with CF compared to the normal population had been documented [1]. The COVID-19 situation exacerbated mental health conditions. Overall, there was an increase in anxiety about the pandemic in CWCF [1,2].

Furthermore, impediments to receiving academic education negatively impacted the mental health behavior of children as they became more vulnerable to loneliness [2].

Working with National CF registries in Europe, the European Cystic Fibrosis Society (ECFS) established a system to support data collection and reporting to better anticipate the severity of COVID-19 in patients with CF [3]. To further combat the spread of COVID-19, many countries including Ireland, the country with the highest incidence of CF, imposed public health restrictions. The adoption of a multidisciplinary care model involving cocooning, vaccination, maintaining good hand hygiene, staying active by engaging in various activities, and availing psychological support coupled with good nutrition were a few of the recommendations advised to people at risk [4,5].

This study aimed to determine the impact during the first six months of the COVID-19 pandemic on the lives of CWCF and their families in Ireland regarding hospital visits, telemedicine, education, and mental well-being.

Methods

An internet-based questionnaire for parents of CWCF was developed by research teams from UCD and CF Ireland. The questionnaire included questions on demographics, deferral of hospital visits, precautions taken, impact on education, telemedicine, and mental health. A pilot study utilising the questionnaire was undertaken by CF Ireland. The questionnaire was then uploaded onto Smart Survey UK, a GDPR-compliant survey tool for six weeks. A copy of the participant information leaflet was made available to the participants on CF Ireland website. After reading the participant information leaflet, participants had to tick to consent for both data collection and processing of their data. The survey was advertised by CF Ireland to the CF community via the CF Ireland website and various social media channels including Twitter, Instagram, Facebook, and CF WhatsApp groups.

Statistical analysis was performed using SPSS version 26. Descriptive results were presented and logistic regression analysis was used to identify demographic factors independently associated with the mental well-being of parents of CWCF. Ethical approval was obtained from National Research Ethics Committee for this study.

Results

A total of 123 fully filled responses by parents of CWCF were recorded. The impact of COVID-19 on hospital visits is shown

in (Table 1). Sixty-seven (55%) respondents indicated a deferral of hospital visits for their child's CF treatment, with the deferral period ranging from 1 to 6 months. The majority of parents (64%) deferred hospital visits for at least 3 months, with 36% for up to 6 months. Among those who deferred, the key reason was fear of encountering coronavirus (57%) and a smaller proportion found the hospital unit closed (19%).

Variable	Children with CF N(%)
Deferral of hospital visits	
Yes	67 (54.9)
Duration	
1 month	6 (9.0)
2 months	9 (13.4)
3 months	28 (41.8)
4-6 months	13 (19.4)
>6 months	11 (16.4)
Reasons for deferring*	
Hospital unit was closed	62
Yes	12 (19.4)
No	50 (74.6)
Fear of COVID-19	67
Yes	38 (56.7)
No	29 (43.3)

*non-exclusive responses

Table 1: Deferral of hospital visits by children with CF due to COVID-19.

(Figure 1) shows the various ways through which consultations with health professionals took place during the pandemic and (Figure 2) shows the usefulness of each mode of consultation used during COVID-19. The online consultation was new to more than half of the respondents (56%) and the majority (approximately 80%) found it helpful. Overall, 53% received their prescriptions via email and 88% of them found it very convenient. A smaller number of CWCF and their parents used online education and online physiotherapy classes, but those who did find them to be fairly to very helpful.

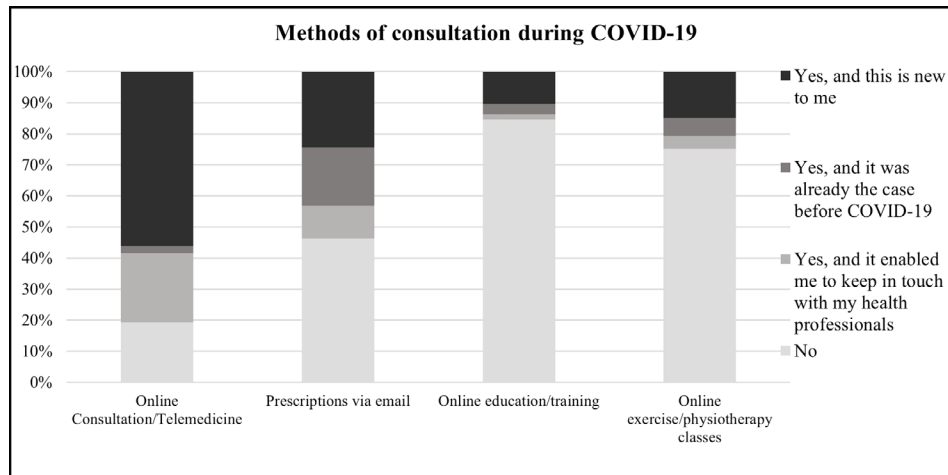


Figure 1: Consultation methods by attitude and previous exposure to methods of consultation during COVID-19.

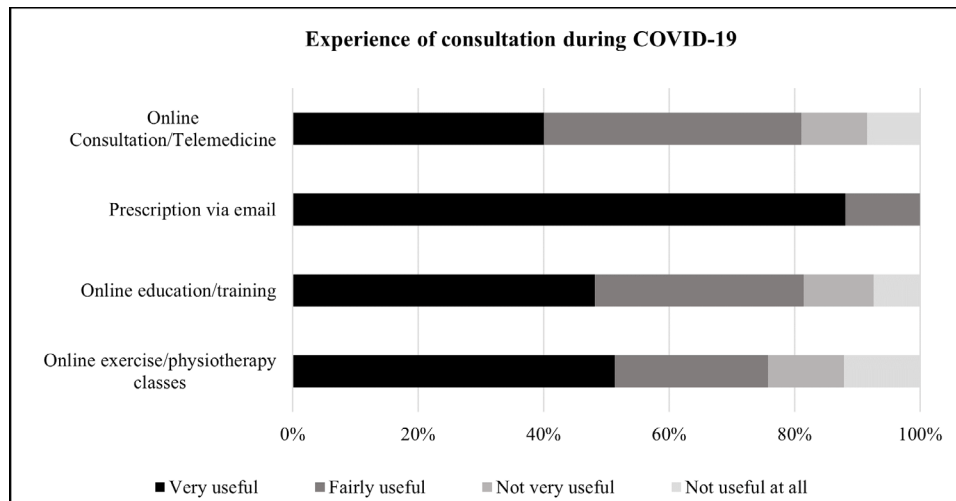


Figure 2: Experience and usefulness of each method of consultation during COVID-19.

The COVID-19 pandemic's impact on the education of CWCF is shown in (Table 2). 51% of parents of primary and 29% of parents of senior school children were willing to send their children to school. Almost half (45%) of parents of children aged up to 4 years were reluctant to send their kids to crèche or playgroup. The majority of parents (46% of primary and 45% of senior school), agreed that their children completely comprehended the extra measures to be taken during COVID-19. With the increasing age of the child, more parents felt confident and secure that their children are able to follow necessary precautions by themselves (4% pre-school children vs 58% senior school children).

Variable	(Age) Pre-school (0-4)	Primary school (5- 11)	Senior school (12 above)	Child with CF N (%)
Willingness to send child to school/creche/ playgroup	29	43	29	101
Yes	12 (20.3)	30 (50.8)	17 (28.8)	59 (58.4)
No	13 (44.8)	9 (31.0)	7 (24.1)	29 (28.7)
Uncertain	4 (30.8)	4 (30.8)	5 (38.5)	13 (12.9)
Knowledge about precautions	23	44	42	109
Yes	8 (9.0)	41 (46.1)	40 (44.9)	89 (81.7)
No	11 (91.7)	1 (8.3)	0 (0.0)	12 (11.0)
Uncertain	4 (50.0)	2 (25.0)	2 (25.0)	8 (7.3)
Ability to follow precautions	27	42	44	113
Yes	3 (4.2)	27 (37.5)	42 (58.3)	72 (63.7)
No	20 (87.0)	3 (13.0)	0 (0.0)	23 (20.4)
Uncertain	4 (22.2)	12 (66.7)	2 (11.1)	18 (15.9)

Table 2: Willingness of parents to send children to their educational institution and ability of children to follow precautions.

(Table 3) shows the impact of COVID-19 on the mental health of CWCF. There was an upward trend in the proportions of CWCF experiencing mental health issues with increasing age, but the difference was not significant between age groups. The key mental issues included increased anxiety (26%) and increased levels of stress (33%). Insomnia and irritability each affected 11% of children. During the COVID-19 pandemic, most children and their parents chose to manage stress by watching TV (10%), doing art and craft activities (8%), gardening (12%), and communicating with loved ones (19%).

Variable	Child with CF (N%)	(Age) Pre-school (0-4)	Primary school (5-11)	Senior school (12 above)	P value
Experienced issues related to mental health	123	35	44	44	0.057
Yes	87 (70.7)	20 (23.0)	31 (35.6)	36 (41.4)	
No	36 (29.3)	15 (41.7)	13 (36.1)	8 (22.2)	
Mental Issues	90	22	32	36	0.594
Excess anxiety	23 (25.6)	6 (26.1)	9 (39.1)	8 (34.8)	
Increased stress	30 (33.3)	8 (26.7)	7 (23.3)	15 (50.0)	
Easy irritability	10 (11.1)	2 (20.0)	3 (30.0)	5 (50.0)	
Difficulty in sleeping	10 (11.1)	1 (10.0)	5 (50.0)	4 (40.0)	
Feeling of insecurity	2 (2.2)	1 (50.0)	0 (0.0)	1 (50.0)	
Other	15 (16.7)	4 (26.7)	8 (53.3)	3 (20.0)	
Stress Management techniques	96	26	31	39	0.916
Breathing exercises	8 (8.3)	1 (12.5)	3 (37.5)	4 (50.0)	
Meditation	10 (10.4)	2 (20.0)	4 (40.0)	4 (40.0)	

Watching TV	10 (10.4)	2 (20.0)	4 (40.0)	4 (40.0)	
Art and craft activities	8 (8.3)	3 (37.5)	4 (50.0)	1 (12.5)	
Gardening	11 (11.5)	3 (27.3)	4 (36.4)	4 (36.4)	
Reading books	8 (8.3)	3 (37.5)	2 (25.0)	3 (37.5)	
Indoor games		0			
Communicating with loved ones	18 (18.8)	4 (22.2)	6 (33.3)	8 (44.4)	
Other	23 (24.0)	8 (34.8)	4 (17.4)	11 (47.8)	

Table 3: Mental health issues reported in CWCF related to COVID-19.

(Table 4) shows logistic regression for the effect of COVID-19 on the mental health of parents of CWCF. After adjustment for gender and employment, parents of CWCF aged < 35 years were more likely to feel “nervous” (Adjusted OR = 5.41; 95% CI = 1.53-19.18, p-value = 0.009) compared to those ≥ 35 years. When age and employment were taken into account, mothers were 5.9 times more likely to experience nervousness than fathers. More parents of CWCF who were in employment were more likely to feel “tired” (Adjusted OR = 2.92; 95% CI = 1.35-6.36, p value = 0.007) as compared to those who did not work when adjusted for age and gender. When adjusted for age and employment, fathers were 3.9 times more likely to be energetic as compared to mothers.

Variable	All /Most good bit of the time N (%)	Some little/None of the time N (%)	Unadjusted OR (95%CI)	P value	Adjusted OR (95% CI)	P value
During lockdown felt a very nervous person						
Age	45	75		0.006*		0.009*
Below 35	10(71.4)	4(28.6)	5.50 (1.64-18.49)		5.41 (1.53-19.18)	
35 and above	35(33.0)	71(67.0)	1		1	
Gender	45	75		0.016*		0.024*
Female	43(42.6)	58(57.4)	6.48 (1.42-29.51)		5.90 (1.27-27.50)	
Male	2(10.5)	17(89.5)	1		1	
Work	43	72		0.28		0.27
No did not work	25(43.9)	32(56.1)	1.51 (0.71-3.18)		1.57 (0.71-3.51)	
Yes, worked	18(31.0)	40(69.0)	1		1	
During lockdown felt so down that nothing could cheer you up						
Age	16	102				
Below 35	0(0.0)	15(100.0)	NA	NA	NA	NA
35 and above	16(15.5)	87(84.5)	NA		NA	
Gender	16	102		0.39		0.65
Female	14(13.9)	87(86.1)	0.58 (0.17-2.01)		0.66 (0.19-2.30)	
Male	2(11.8)	15(88.2)	1		1	
Work	16	97		0.22		0.51
No did not work	7(12.5)	49(87.5)	0.53 (0.19-1.46)		0.51 (0.18-1.43)	

Yes, worked	9(15.8)	48(84.2)			1	
During lockdown felt downhearted and blue						
Age	15	105		0.49		0.48
Below 35	1(7.1)	13(92.9)	0.48 (0.06-3.93)		0.47 (0.06-3.89)	
35 and above	14(13.2)	92(86.8)	1		1	
Gender	15	105		0.60		0.69
Female	12(11.9)	89(88.1)	0.70 (0.18-2.74)		0.76 (0.19-3.03)	
Male	3(15.8)	16(84.2)	1		1	
Work	15	100		0.15		0.14
No, did not work	7(12.3)	50(87.7)	0.44 (0.15-1.33)		0.44 (0.14-1.32)	
Yes, worked	8(13.8)	50(86.2)	1		1	
During lockdown felt tired						
Age	67	52		0.07		0.08
Below 35	11(78.6)	3(21.4)	3.45 (0.92-12.92)		3.33 (0.86-12.85)	
35 and above	56(53.3)	49(46.7)	1		1	
Gender	67	52		0.36		0.38
Female	57(57.0)	43(43.0)	1.58 (0.59-4.21)		1.60 (0.57-4.50)	
Male	10(52.6)	9(47.4)	1		1	
Work	66	49		0.007*		0.007*
No did not work	32(56.1)	25(43.9)	1		1	
Yes, worked	34(58.6)	24(41.4)	2.84 (1.33-6.07)		2.92 (1.35-6.36)	
During lockdown felt full of life						
Age	61	61		0.15		0.13
Below 35	10 (71.4)	4 (28.6)	2.32 (0.74-7.24)		2.49 (0.77-8.05)	
35 and above	51 (47.2)	57 (52.8)	1		1	
Gender	61	61		0.53		0.69
Female	52(50.5)	51(49.5)	1.37 (0.51-3.70)		1.23 (0.45-3.41)	
Male	9(47.4)	10(52.6)	1		1	
Work	58	59		0.02*		0.02*
No, did not work	28 (48.3)	30(51.7)	2.37 (1.13-4.95)		2.46 (1.16-5.19)	
Yes, worked	30(50.8)	29(49.2)	1		1	
During lockdown felt calm and peaceful						
Age	37	83		0.76		0.88
Below 35	4(28.6)	10(71.4)	0.83 (0.25-2.79)		0.91 (0.27-3.11)	

35 and above	33(31.1)	73(68.9)	1		1	
Gender	37	83		0.08		0.09
Female	28(27.7)	73(72.3)	0.41 (0.15- 1.11)		0.41 (0.15-1.13)	
Male	9(47.4)	10(52.6)	1		1	
Work	35	80		0.89		0.94
No did not work	17(29.8)	40(70.2)	0.95 (0.43-2.06)		0.97 (0.44-2.14)	
Yes, worked	18(31.0)	40(69.0)	1		1	
During lockdown you had a lot of energy						
Age	42	78		0.28		0.15
Below 35	7(50.0)	7(50.0)	1.83 (0.61-5.44)		2.29 (0.74-7.14)	
35 and above	35(33.0)	71(67.0)	1		1	
Gender	42	78		0.02*		0.01*
Female	31(30.7)	70(69.3)	1		1	
Male	11(57.9)	8(42.1)	3.24 (1.19-8.82)		3.88 (1.37-11.02)	
Work	41	74		0.07		0.04*
No did not work	17(29.8)	40(70.2)	2.07 (0.94-4.55)		2.35 (1.03-5.36)	
Yes, worked	24(41.4)	34(58.6)	1		1	
During lockdown you have been a happy person						
Age	60	59		0.47		0.42
Below 35	9(64.3)	5(35.7)	1.50 (0.50-4.50)		1.59 (0.52-4.86)	
35 and above	51(48.6)	54(51.4)	1		1	
Gender	60	59		0.89		0.78
Female	50(50.0)	50(50.0)	0.94 (0.35-2.49)		0.87 (0.32-2.35)	
Male	10(52.6)	9(47.4)	1		1	
Work	58	57		0.09		0.08
No did not work	27(47.4)	30(52.6)	1.86 (0.90-3.85)		1.90 (0.92-3.93)	
Yes, worked	31(53.4)	27(46.6)	1		1	

Table 4: Logistic regression showing factors associated with the psychological health of Parents of CWCF

OR = Odds Ratio; CI=Confidence Interval; *P value<0.05.

Discussion

COVID-19 created a global health crisis as a result of its outbreak across the globe [6]. This created a major impact on many aspects of society, especially on children at risk, including their education, and physical and mental well-being. This study assesses the impact of COVID-19 and associated restrictions on CWCF and their families. According to our findings, a considerable majority of parents of CWCF postponed their child's hospital visits. Fear of contracting COVID-19 was the primary reason for the postponement, and in some cases, the hospital CF unit was closed. Deferral of a hospital visit is of great concern as routine examination is crucial for early intervention in infective respiratory exacerbations. There have been similar findings reported by other authors. Havermans et al. reported the cancellation of hospital appointments by more than half of the parents of CWCF in Belgium due to the fear of infection from hospitalised COVID-19 patients [7]. According to an Italian study, there was a cancellation of all face-to-face clinic appointments in Milan by the CF team in order to prevent unnecessary hospital visits and virus spread among patients [8]. A Swiss study conducted in 2020 on 327 subjects observed that around half of the face-to-face clinic appointments of patients with CF were either cancelled/postponed due to COVID-19 lockdowns [9].

Due to the pandemic and the fear of encountering the virus, an online consultation method was introduced in Ireland. A large proportion of CWCF and their families found online consultation new and were satisfied with this method. A US study showed similar results, with 72% of CWCF parents being satisfied and appreciative of Telehealth consultation methods. However, it also observed concerns over certain critical routine assessments such as pulmonary function testing (PFT) and sputum culture which couldn't be performed remotely [10]. A study conducted in the UK found that 91% of parents found telehealth consultations to be user-friendly, and 66% reported that they were as good as face-to-face consultations in terms of quality of care [11]. A study in Milan documented that the CF team cancelled all the routine appointments and monitored the clinical conditions of patients via phone calls or emails. The authors note that respiratory function testing and bronchoscopy were put on hold which can potentially have a negative impact on CF patients in the future [8]. In Ireland, a recent cross-sectional study was conducted to assess the effect of COVID-19 on general practice (GP) consultations. Face-to-face consultations were reduced from 87% to 41% for all GP consultations, whereas telemedicine consultations increased from 10% to 57% [12]. The Corona Citizens Science Project was conducted by the National University of Ireland, Galway in 2021; the results indicated that approximately 25% of participants consulted their GP through the teleconsultation method and two-thirds found it highly effective [13]. As part of health-

related initiatives enforced in Ireland to limit the spread of the deadly virus the Medicinal Products (Prescription & Control of Supply) (Amendment) Regulations 2020 and the Misuse of Drugs (Amendment) Regulations 2020 were signed in March 2020 [14]. Under COVID-19 emergency provisions the "National electronic prescription transfer system" was introduced which permitted prescription to be electronically transferred from the health care professional directly to the dispensing pharmacy [15,16]. This legislation has been well received and supported by the CF community, with more than 80% of respondents to our study being in favor of promoting this COVID-19 related regulatory change to retain and further expand post pandemic as well.

COVID-19 impacted the mental health of CWCF and their parents significantly. The major mental health issues faced by the majority of parents of CWCF during the COVID-19 emergency were increased levels of nervousness, downheartedness, and tiredness. Important aspects of family lives, including work, education, and interpersonal connections, were also significantly disrupted. Parents were concerned about their child's social and emotional development. Studies from several countries including Turkey and the United Kingdom (UK), showed similar findings with increased levels of anxiety, stress, and depression among children with CF and their families [17, 18]. During the early COVID-19 restrictions period (March-April 2020), an Irish study of 1,000 people found that 41% felt lonely, 23% faced depression and 20% reported clinically significant anxiety [19]. The majority of CWCF parents were concerned about the virus, their child's health if they become infected, and the virus's possible impact on CWCF [20]. Although following the restrictions offered some people a safety net, it had a detrimental effect on the mental health of many others. The role of psychologists in CF care teams is crucial in addressing these worries, assisting families in identifying effective coping mechanisms, and providing psychological therapy to individuals going through severe mental health issues. Psychologists who work with CWCF were able to continue providing psychological therapy during the pandemic with the help of video consultations, which lowered stress and depression in patients with CF and their caregivers [21,22]. Despite the fact that psychologists play a crucial role in CF care, our findings indicate that there will be a growing need for these services in the foreseeable future.

The sample size is relatively small in this study but captures an important group of parents and children. This was a self-reported survey of CWCF; however, our results are consistent with those of other authors internationally. This study was conducted at the end of the second wave of COVID-19 in Ireland when the vaccines were still in the trials stage with no certainty of a successful outcome. Thus, it will be valuable to assess at how the vaccination programme may have affected the psychological well-being of CWCF and their families. Overall, the observations made from the

study may aid in guiding psychosocial screening and intervention provided to families of children with chronic illness during these times. Caregivers of CWCF already experience considerable carer burden and anxiety about their child, which may have further increased by the pandemic.

Conclusion

Our results have shown the considerable impact of the COVID-19 pandemic on CWCF and their parents at the end of the first year of pandemic; further research is required to document subsequent and longer-term effects.

Conflict of interest

The authors declare that they do not have any conflict of interest.

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