#### **ORIGINAL ARTICLE**



# Impact of COVID-19 pandemic on health care system, work, and mental well-being of people with cystic fibrosis

Rini Bhatnagar<sup>1</sup> • Sarah Tecklenborg<sup>2</sup> • Ricardo Segurado<sup>1</sup> • Philip Watt<sup>2</sup> • Naula McAuley<sup>2</sup> • Patricia Fitzpatrick<sup>1</sup>

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#### **Abstract**

**Background** COVID-19 pandemic has been challenging for all, particularly for high-risk groups including people with cystic fibrosis (PWCF).

**Aim** This study aims to examine impact of COVID-19 pandemic on the lives of PWCF in relation to hospital visits, use of telemedicine, employment, and mental well-being.

**Methods** A cross-sectional online survey was developed by the Cystic Fibrosis (CF) Ireland research team and uploaded on SmartSurvey UK. The survey was advertised by CF Ireland via their website and social media in October 2020. The University College Dublin research partner team conducted the analysis. Logistic regression was used for the analysis, using IBM SPSS Version 26.

Results One hundred nineteen PWCF responded. 47.5% deferred their hospital visits, with delays ranging from 1 to 6 months. Deferrals impacted rehabilitation therapies, medical care at hospital, and diagnostic tests. For many, online consultation was a new experience (51.7%), and 87.8% were satisfied with this method. Among those who worked during lockdown (47.8%), 87.2% (n = 48) worked at home. PWCF aged < 35 years (9.6%) were more likely to work onsite as compared to those > 35 years (1.9%). When adjusted for gender and employment, PWCF aged < 35 years were more likely to feel "nervous" (OR: 3.28; P = 0.02), "nothing could cheer them up" (OR: 3.24; P = 0.04), and "tired" (OR: 2.76; P = 0.02) as compared to those > 35 years.

**Conclusion** COVID 19 pandemic has greatly impacted PWCF in terms of hospital visits, access to tests, CF care, and psychological well-being. Younger PWCF reported greater impact on psychological health. Online consultation and electronic prescription were welcomed and could have a role post-pandemic.

Keywords COVID-19 · Cystic fibrosis · Employment · Hospital visits · Mental well-being · Ireland

### Introduction

Cystic fibrosis (CF) is a common, inherited, autosomal recessive, life-threatening disorder that affects the respiratory and digestive systems. It is most commonly observed in Caucasians [1]. The cause is a mutation in cystic fibrosis transmembrane conductance regulator (CFTR) gene. The CFTR protein encoded by this gene functions as a chloride channel, enabling the passage of chloride ions across

epithelial cell membranes. Since chloride drives water movement, CFTR plays a vital role in the regulation of water and salt balance in body fluids such as mucus and sweat. Alterations in the CFTR gene result in the production of thicker mucus throughout the body, which leads to persistent lung infections and impairs the functioning of other organs as well [2]. Recent statistics from the "European Cystic Fibrosis Society Patient Registry" show that approximately 50,000 people (both children and adults) with CF reside in 35 European nations [3]. Ireland has the highest prevalence of CF worldwide [4]. According to Cystic Fibrosis Registry Annual Report 2020, 1256 living individuals with CF reside in Ireland; 60.4% are > 18 years [5].

The World Health Organization defined SARS COV-2 as a highly infectious respiratory disease caused by a novel coronavirus [6]. The COVID-19-related public health



Rini Bhatnagar rini.bhatnagar@ucdconnect.ie

School of Public Health, Physiotherapy and Sports Science, University College Dublin, Dublin, Ireland

<sup>&</sup>lt;sup>2</sup> Cystic Fibrosis Ireland, Dublin, Ireland

restrictions have impacted healthcare systems worldwide. The emergence of the pandemic caused great challenges for the care of adults with CF. Although most people infected with the COVID-19 virus experienced mild to moderate respiratory disease and recovered without any special treatment, the majority of hospitalisations and intensive care admissions occurred in those who belonged to a high-risk category. Although, PWCF are more vulnerable to viral respiratory tract infections than the general population; with a novel virus, there was uncertainty about the impact on those living with CF, and data remains limited, but those on immunosuppressant treatment post-transplant were certainly deemed a particularly vulnerable group [6].

As the COVID-19 pandemic developed, most countries including Ireland introduced public health restrictions to stop viral transmission [4]. To reduce the risk, PWCF were advised to cocoon. This included a series of measures aimed at minimising all interaction between themselves and others outside their family unit since the outbreak of the COVID-19 pandemic in Ireland in late March 2020 until the start of vaccinations in 2021 [4]. Most recent guidelines advise that, once fully vaccinated, most people in a high-risk category can follow standard population public health advice. However, vaccination may not be fully effective for some people with weak immune systems or had undergone organ transplants; therefore, they are advised to continue to follow extra precautions even after being vaccinated [7].

COVID-19 caused global economic disruptions leading to furloughs and business closures, resulting in PWCF losing their jobs [8]. Delivery of CF care was greatly impacted during the pandemic. To mitigate and manage the virus, many countries worldwide implemented measures such as the closure of medical units and the redeployment of medical professionals to critical wards such as intensive care units [9]. Staff in CF care centres in the USA experienced salary reductions or layoffs [10]. However, advancements in technology enabled the transformation of face-to-face CF clinics onto online platforms for providing CF care.

The chronic nature and deteriorating health condition of PWCF, along with the inconvenience of CF therapy in general, has often led to higher rates of anxiety and depression among PWCF than in the general population [11]. With CF patients already facing the burden of their health condition, new challenges and uncertainties of the COVID-19 pandemic may have further contributed to the deterioration of their mental health. Thus, it is crucial to address mental health concerns along with physical ones [11].

To the best of the author's knowledge, this is the first national survey conducted specifically among PWCF that addresses the impact of the COVID-19 pandemic on employment-related aspects. There has been no other study conducted in Ireland addressing a similar range of outcomes.

The aim of this study was to determine the impact of the first 6 months of the COVID-19 pandemic on the lives of PWCF in relation to hospital visits, use of telemedicine, employment, and mental well-being.

#### Methods

CF Ireland, the key advocacy organisation for PWCF in Ireland, developed an online self-administered questionnaire with questions adapted from other surveys that were being concurrently conducted for comparative purposes. The surveys from which references were taken for the questions are as follows: Corona Citizens Science project (Waves 1 and 2) conducted by the University of Galway, Dublin City University and the Insight SFI Research Centre for Data Analytics, The Eurordis Rare Barometer Covid Survey, EU survey 2020, The Central Statistics Office, Ireland "Social Impact of COVID-19 Survey April 2020", and the RAND 36-item Short Form Survey Instrument (SF-36) [12–15]. The questionnaire contained questions on demographics, sources of information about COVID-19, deferral of hospital visits, precautions taken, cocooning, impact on employment, telemedicine, and impact on mental health. Mental health questions have been derived from the SF-36 questionnaire [15]. A pilot study was undertaken. The questionnaire was uploaded on SmartSurvey UK, a General Data Protection Regulation (GDPR) compliant survey tool for a period of 6 weeks. The survey was hosted by CF Ireland and advertised widely through various social media platforms including Twitter, Instagram, Facebook, and PWCF WhatsApp groups. A copy of the participant information leaflet was made available on the CF Ireland website for participants to review. After reading the participant information leaflet, a tick was obtained as consent from participants for both data collection and processing of information.

The questionnaire was made available only to those PWCF resident in Ireland and aged 18 or older. Individuals who reported being under the age of 18 years or living outside of Ireland during the completion of the questionnaire were excluded.

At the time of the survey, 759 adults aged > 18 years were registered with CF Registry of Ireland; thus, 119 PWCF respondents accounted for 16% of the total CF population. Power analysis was not conducted for this study.

The data analysis was conducted by the research team from University College Dublin. Pearson's chi-squared test was used to compare the impact of COVID-19 on CF care of PWCF depending on age and gender. Unadjusted and multivariable logistic regression were used to determine independent factors associated with the deferral of hospital visits and mental health effects. Analysis was undertaken using SPSS Version 24.

The study was approved by the National Research Ethics Committee for COVID-19 (20-NREC-COV-090).



Table 1 Deferral of hospital visits by adults with CF

Variable	Adults with CF N (%)
Deferral of hospital visits	
Yes	56 (47.5)
<b>Duration of deferral</b>	56
1 month	11 (20.4)
2 months	8 (14.8)
3 months	12 (22.2)
4–6 months	9 (16.7)
6 months	14 (25.9)
Reasons for deferring	
Hospital unit was closed	52
Yes	6 (11.5)
No	46 (88.5)
Fear of COVID-19	53
Yes	37 (69.8)
No	16 (30.2)

#### Results

During the 6-week period, a total of 119 completed responses were recorded. Sixty-one percent were females and 39% were males; 54% were < 35 years. More than half of the participants (65.5%) were residing in an urban location.

The results for deferral of hospital visits are shown in Table 1. A total of 56 (47.5%) respondents indicated a deferral of hospital visits for CF care. The period of delay ranged from 1 to 6 months. A majority had a deferral of at least 3 months (74%) with 26% deferring for 6 months. Among those who deferred, the key reasons were fear of encountering coronavirus (69.8%) and a smaller proportion found the hospital unit closed (11.5%).

Table 2 shows the results of a logistic regression of factors associated with deferral of hospital visits. Participants aged < 35 years were more likely to defer hospital visits than their older counterparts when adjusted for gender

Table 3 Impact on CF care of PWCF based on their age and gender

Postponed/cancelled							
Based on age of adults with CF							
Variable	All N (%)	<35 years N (%)	≥35 years <i>N</i> (%)	P value			
Rehabilitation therapies	9 (32.1)	5 (29.4)	4 (36.4)	0.70			
Medical care at home	2 (8.0)	1 (6.3)	1 (11.1)	0.67			
Medical care at hospital	25 (56.8)	18 (60.0)	7 (50.0)	0.53			
Transplant	2 (11.7)	1 (12.5)	1 (11.1)	0.93			
Surgery	2 (11.7)	1 (12.5))	1 (11.1))	0.93			
Appointment with GP	13 (35.1)	7 (31.8)	6 (40.0)	0.61			
Diagnostic tests	16 (45.7)	6 (40.0)	10 (50.0)	0.56			
Based on gender of P	WCF						
Variable	All N (%)	Female N (%)	Male N (%)	P value			
Rehabilitation therapies	9 (32.1)	5 (33.3)	4 (30.7)	0.89			
Medical care at home	2 (8)	2 (13.3)	0 (0.0)	0.23			
Medical care at hospital	25 (56.8)	20 (64.5)	5 (38.5)	0.11			
Transplant	2 (11.7)	2 (22.2)	0 (0.0)	0.16			
Surgery	2 (11.7)	1 (11.1)	1 (12.5)	0.93			
Appointment with GP	13 (35.1)	7 (29.1)	6 (46.1)	0.30			
Diagnostic tests	16 (45.7)	11 (50.0)	5 (38.5)	0.51			

and location (55.6% vs 44.4%; adjusted OR: 2.17; 95% CI: 1.00–4.69). No significant association was observed between gender or location and deferral of hospital visits.

Table 3 summarises the impact of COVID-19 on the CF care of PWCF based on age and gender. During the pandemic, a non-significantly greater number of older PWCF

Table 2 Logistic regression: factors associated with deferral of hospital visits

Variable	Deferral of hospital visits							
	Yes	No	Univariate OR (95% CI)	P value	Multivariate OR (95% CI)	P value		
Age	56	62						
<35 years	35 (55.6)	28 (44.4)	2.02 (0.97-4.23)	0.061	2.17 (1.00–4.69)	0.05		
>35 years	21 (38.2)	34 (61.8)	1.0		1.0			
Gender	56	61						
Female	34 (47.9)	37 (52.1)	1.00 (0.47–2.10)	0.995	0.95 (0.44–2.05)	0.95		
Male	22 (47.8)	24 (52.2)	1.0		1.0			
Location	56	62						
Urban	36 (46.8)	41 (53.2)	1.32 (0.63–2.78)	0.458	1.06 (0.48–2.32)	0.88		
Rural	20 (48.8)	21 (51.2)	1.0		1.0			



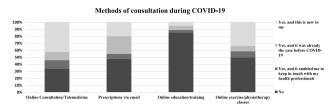


Fig. 1 Consultation methods by attitude and previous exposure to methods of consultation during COVID-19

(aged≥35 years) deferred their rehabilitation therapies (36% vs 29%)), general practitioner (GP) appointments (40% vs 32%) and diagnostic test appointments (50% vs 40%). A nonsignificantly greater proportion of PWCF aged < 35 years experienced interruption in hospital-based medical services as compared to their older counterparts (60% vs 50%).

Comparing PWCF based on gender, a non-significantly higher proportion of females deferred their hospital-based medical care (65% vs 39%) and diagnostic test appointments (50% vs 38.5%) due to COVID-19. COVID-19 had a minimal impact on PWCF surgery based on gender.

Figure 1 shows the various ways through which health professionals were approached during the pandemic, and Fig. 2 shows the usefulness of each mode of consultation. Online consultation was new to approximately half of the participants (47.6%) and the majority found it useful. Overall, 53% received their prescriptions via email, and of those who did, more than 80% of them found it beneficial for them. Small numbers of PWCF used online education or online physiotherapy classes, but those who did found it very helpful.

Among those participants who worked, 41.7% worked from home during the pandemic (Table 4). Very few worked on-site, but this was more common among younger PWCF than older ones (9.6% vs 1.9%). Most employers (91.7%) were sympathetic to the participants who worked from home. More PWCF aged≥35 years stopped working as they were cocooning as compared to their younger counterparts. Over one-third of employers (36.8%) were considered unsympathetic to PWCF who were not working as were cocooning.

Table 5 shows logistic regression results assessing the impact of COVID-19 on the mental health of PWCF. After adjustment for gender and employment status, PWCF aged < 35 years were more likely to report feeling "nervous" (OR: 3.28; 95% CI: 1.23–8.71), "nothing could cheer

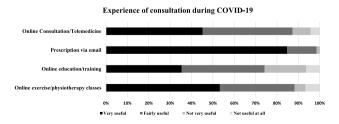


Fig. 2 Experience and usefulness of each mode of consultation



them up" (OR: 3.24; 95% CI: 1.07-9.84), and "tired" (OR: 2.76; 95% CI: 1.21-6.27) compared to those  $\geq 35$  years. On the contrary, a greater proportion of PWCF aged  $\geq 35$  years felt "calm and peaceful" (OR: 2.25; 95% CI: 1.02-4.93) and "happy" (OR: 2.30; 95% CI: 1.05-5.07) as compared to the younger PWCF. When adjusted for age and gender, PWCF who were employed were 2.24 times more likely to feel energetic as compared to those who were unemployed (OR: 2.24; 95% CI: 1.02-4.91).

#### Discussion

The COVID-19 pandemic has created a global public health emergency, and public health restrictions have been in place in most countries [16]. This study was designed to assess the impact of COVID-19 and associated restrictions on PWCF. Our study showed that a large proportion of PWCF deferred their hospital visits. The major reason for deferral was fear of contracting COVID-19, and in a small number of cases, the hospital CF unit was closed. This deferral rate among those aged < 35 years was almost twice than in those  $\geq$  35 years. However, no such pattern was highlighted during this study with respect to gender and location of the PWCF. Deferrals also impacted rehabilitation therapies, medical care at the hospital, and appointments with GP. A non-significantly greater proportion of respondents aged≥35 years had to put off their diagnostic tests as compared to those aged < 35 years. Deferral of a hospital visit is of great concern as a routine examination is key to early intervention in infective respiratory exacerbations and other CF-related diseases. Online consultation method has been well-received by PWCF who have found it to be a convenient alternative for aspects of multidisciplinary care [17]. Many PWCF found online consultation new and were satisfied with this method. Prescription through email was also popular among study participants. Most countries introduced similar measures to reduce the transmission of COVID-19. Havermans et al. reported cancellation of hospital appointments by patients in Belgium due to the fear of infection from hospitalised COVID-19 patients [18]. The CF team in Milan cancelled all routine clinic face-to-face appointments to avoid unnecessary hospital visits and virus spread [19]. A Swiss study conducted during the pandemic on 327 subjects found that half of the outpatient clinic appointments of PWCF were either cancelled/postponed due to lockdown [20]. Another Italian study, conducted by Nobili et al., found that patients who were followed up at their clinics tried to avoid unnecessary hospital access and stayed at home as recommended, delaying their scheduled hospital visits [21]. The Eurordis Rare Disease COVID-19 survey report, which included 6945 respondents from 36 European countries and covered 1250 rare disease types, including CF, found that

 Table 4
 Impact on employment of PWCF based on age and sympathy of employers during the pandemic

	Based on age			Sympathy of employers	
Variable	Total N (%)	<35 years N (%)	≥35 years <i>N</i> (%)	Yes N (%)	No N (%)
Worked from home	48 (41.7)	25 (39.7)	23 (44.2)	44 (91.7)	4 (8.3)
Worked onsite as an essential worker	3 (2.6)	3 (4.8)	0 (0.0)	3 (100.0)	0 (0.0)
Worked onsite but not as an essential worker	4 (3.5)	3 (4.8)	1 (1.9)	3 (100.0)	0 (0.0)
Not working as, I am (temporarily) laid off	5 (4.3)	4 (6.3)	1 (1.9)	2 (50.0)	2 (50.0)
Not working due to other reasons	24 (20.9)	11 (17.5)	13 (25.0)	1 (50.0)	1 (50.0)
Not working as, I am cocooning	22 (19.1)	11 (17.5)	11 (21.2)	12 (63.2)	7 (36.8)
Other	9 (7.8)	6 (9.5)	3 (5.8)	1 (50.0)	1 (50.0)

almost half of the respondents did not visit the hospital due to fear of contracting COVID-19; 34% reported that they were not allowed to visit the hospital if their health problem was not related to COVID-19; and 25% reported that their hospital or rare disease care provider unit was closed [13].

Online medical consultations were introduced and 87.8% of PWCF found them useful. Other countries followed suit: a study from Western Australia showed similar findings, with more than 90% of participants with CF strongly agreed/ agreed that teleconsultation could be an excellent way of managing CF care [22]. A further study of telehealth performed at Virginia Commonwealth University Adult CF Center showed that 100% of the patients considered access to telehealth for improved care during the pandemic, and 80% supported telehealth implementation in the future in VCU CF Center [23]. A study in Milan documented the cancellation of routine appointments by the CF team who monitored the clinical conditions of patients via phone calls or emails [19]. According to the Eurordis Rare Disease COVID-19 survey report, 50% of the participants engaged in online consultations. Among those who did, 90% found online consultation/telemedicine services, and online education tools designed to assist in managing their rare disease themselves beneficial [13].

The Medicinal Products (Prescription & Control of Supply) (Amendment) Regulations 2020 and the Misuse of Drugs (Amendment) Regulations 2020 were signed into law in March 2020 as part of health-related initiatives enforced in Ireland to curb the viral spread [24]. They introduced the "national electronic prescription transfer system" which allows a prescription to be electronically transferred from the health care professional directly to the pharmacist [25, 26]. This was welcomed by the CF community, with 88% in our study in favour. Repeat prescriptions emailed directly to pharmacy will be continued.

COVID-19 significantly increased the unemployment rate, and decreased hours of work and labour force participation during that period [27]. In our study, it was

observed that a greater proportion of older adults stopped working while they were cocooning. Also, over one-third of employers were perceived as unsympathetic towards PWCF who were not working as cocooning. Those who were employed were more energetic and happier as compared to those who were not employed. No significant difference by gender was observed.

The key mental health issues faced by the majority of PWCF during the pandemic were increased levels of nervousness and tiredness. PWCF aged < 35 years experienced more mental distress during the pandemic as compared to the older group, particularly in terms of nervousness and feeling downhearted. Cocooning was recommended at the start of the pandemic by the Irish Government for older people and those considered highly vulnerable to COVID-19, including those living with CF [4]. Studies from several countries including Turkey, the United Kingdom (UK), Belgium, and Italy showed similar findings with high levels of anxiety and depression among PWCF and their families [19, 28, 29]. From a general population perspective, an Irish study of 1000 people in March and April 2020 (during the initial restrictions) found that 41% of respondents felt lonely, 23% recorded depression, 20% reported anxiety, and 18% reported clinically relevant post-traumatic stress [30]. Another survey conducted by the Central Statistics Office in Ireland, titled "Social Impact of COVID-19 Survey April 2020", reported that 35.5% of respondents from general Irish households reported feeling very nervous, 32.4% felt downhearted and depressed, and 26.6% felt lonely "at least some of the time" in April 2020 [14]. Those with CF were deemed to be in the 'highly vulnerable' group, which confers an additional psychological burden.

A limitation of this study is that this was a self-reported study of PWCF recruited through social media and the CF Ireland website. Findings of our study however concur with other authors internationally. This study was conducted at the end of the second wave of COVID-19 in Ireland, a time when



**Table 5** Logistic regression showing psychological health of PWCF when adjusted by age, gender, and work

Variable	All/most/a good bit of the time	Some/a little/ none of the time	Adjusted OR	95% CI	P value
During the period of	pandemic restriction	ons, you felt full of	life		,
Age	61	57			
<35 years	27 (42.2)	37 (57.8)	0.47	0.22 - 1.02	0.06
≥35 years	34 (63.0)	20 (37.0)	1.0		
Gender	61	56			
Female	38 (53.5)	33 (46.5)	1.18	0.54-2.58	0.69
Male	23 (50.0)	23 (50.0)	1.0		
Work	58	56			
No	26 (44.1)	33 (55.9)	0.57	0.26 - 1.22	0.15
Yes	32 (58.2)	23 (41.8)	1.0		
During the period of	pandemic restriction	ons, you felt a very	nervous person		
Age	28	87			
<35 years	20 (32.8)	41 (67.2)	3.28	1.23-8.71	0.02*
≥35 years	8 (14.8)	46 (85.2)	1		
Gender	28	86			
Female	19 (27.5)	50 (72.5)	1.50	0.58 - 3.90	0.41
Male	9 (20.0)	36 (80.0)	1		
Work	27	84			
No, did not work	16 (27.6)	42 (72.4)	1.74	0.69-4.34	0.24
Yes, worked	11 (20.8)	42 (79.2)	1		
During the period of	pandemic restriction	ons, you experience	ed that nothing co	uld cheer you	up
Age	21	93			
<35 years	16 (26.2)	45 (73.8)	3.24	1.07-9.84	0.04*
≥35 years	5 (9.4)	48 (90.6)	1		
Gender	21	92			
Female	13 (19.1)	55 (80.9)	1.06	0.37 - 3.00	0.91
Male	8 (17.8)	37 (82.2)	1		
Work	20	90			
No, did not work	13 (22.8)	44 (77.2)	2.18	0.77 - 6.22	0.15
Yes, worked	7 (13.2)	46 (86.8)	1		
During the period of	pandemic restriction	ons, you have been	calm and peaceful	l	
Age	47	68			
<35 years	20 (32.8)	41 (67.2)	1		0.04*
≥35 years	27 (50.0)	27 (50.0)	2.25	1.02-4.93	
Gender	47	67			
Female	26 (37.7)	43 (62.3)	0.78	0.35 - 1.74	0.55
Male	21 (46.7)	24 (53.3)	1		
Work	47	64			
No, did not work	21 (36.2)	37 (63.8)	0.55	0.25 - 1.21	0.14
Yes, worked	26 (49.1)	27 (50.9)	1		
During the period of	pandemic restriction	ons, you had a lot o	of energy		
Age	52	63			
<35 years	23 (37.7)	38 (62.3)	0.55	0.25-1.20	0.13
≥35 years	29 (53.7)	25 (46.3)	1		
Gender	52	62			
Female	31 (44.9)	38 (55.1)	0.80	0.36-1.77	0.58
Male	21 (46.7)	24 (53.3)	1		
Work	48	63			
No, did not work	20 (34.5)	38 (65.5)	1		
Yes, worked	28 (52.8)	25 (47.2)	2.24	1.02-4.91	0.04*



 Table 5 (continued)

Variable	All/most/a good bit of the time	Some/a little/ none of the time	Adjusted OR	95% CI	P value
During the period of	pandemic restriction	ons, you felt downhe	arted and blue		,
Age	23	92			
<35 years	15 (24.6)	46 (75.4)	1.76	0.66-4.66	0.26
≥35 years	8 (14.8)	46 (85.2)	1		
Gender	23	91			
Female	13 (18.8)	56 (81.2)	0.78	0.30 - 2.03	0.61
Male	10 (22.2)	35 (77.8)	1		
Work	22	89			
No, did not work	13 (22.4)	45 (77.6)	1.45	0.55 - 3.79	0.45
Yes, worked	9 (17.0)	44 (83.0)	1		
During the period of	pandemic restriction	ons, you have been a	happy person		
Age	63	52			
<35 years	28 (45.9)	33 (54.1)	1		
≥35 years	35 (64.8)	19 (35.2)	2.30	1.05-5.07	0.04*
Gender	63	51			
Female	37 (53.6)	32 (46.4)	0.94	0.42 - 2.09	0.88
Male	26 (57.8)	19 (42.2)	1		
Work	62	49			
No, did not work	29 (50.0)	29 (50.0)	0.58	0.27 - 1.28	0.18
Yes, worked	33 (62.3)	20 (37.7)	1		
During the period of	pandemic restriction	ons, you felt tired			
Age	64	50			
<35 years	40 (65.6)	21 (34.4)	2.76	1.21-6.27	0.02*
≥35 years	24 (45.3)	29 (54.7)	1		
Gender	63	50			
Female	36 (52.9)	32 (47.1)	0.65	0.28-1.49	0.31
Male	27 (60.0)	18 (40.0)	1		
Work					
No, did not work	38 (65.5)	20 (34.5)	2.56	1.14-5.74	0.02*
Yes, worked	23 (44.2)	29 (55.8)	1		

Data are presented as numbers (percentage)

there was talk of vaccines, but all were in the trial stages with no definite hope yet. Future work should look at how the rollout of vaccination may change the psychological wellbeing of adults with CF.

#### **Conclusion**

Online consultation worked in part during the peak of the pandemic period and may be of some value going forward. However, virtual CF care, although a convenient method, is suboptimal for complete ongoing CF care [10]. New prescription via email was a COVID pandemic change due to the increase in telemedicine; as in-person clinical care reopened, this is less of a requirement but repeat

prescriptions can continue to be available from pharmacies [31]. Mental health was also affected during the pandemic; the role of the psychologist in CF care is already well recognised, but our findings suggest that there will be a greater need for these services in the short-term and possibly long-term future.

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#### **Declarations**

**Conflict of interest** The authors declare no competing interests.



<sup>\*</sup>P value less than 0.05

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## References

- Mall MA, Boucher RC (2014) Pathophysiology of cystic fibrosis lung disease. Eur Respir Monogr 64:1–13
- Brown SD, White R, Tobin P (2017) Keep them breathing: cystic fibrosis pathophysiology, diagnosis, and treatment. J Am Acad Physician Assist 30(5):23–27
- Radtke T, Haile SR, Dressel H, Benden C (2020) Recommended shielding against COVID-19 impacts physical activity levels in adults with cystic fibrosis. J Cyst Fibros 19(6):875–879
- Cystic Fibrosis Ireland (2020) CFI update: people with CF to cocoon. [cited 2022 Sep 28]. Available from: https://www.cfireland. ie/about-cf/latest-news/cfi-update-people-with-cf-to-cocoon
- McKone E, Fletcher GJ (2020) CF Registry of Ireland 2020 Annual Report. Available from: https://pub.flowpaper.com/docs/ https://cfri.ie/wp-content/uploads/2022/05/CFRI-2020-Annual-Report-Final.pdf
- World Health Organization. Coronavirus (2021) [Internet]. Geneva: World Health Organization. [cited 2022 Apr 14]. Available from: https://www.who.int/health-topics/coronavirus#tab=tab\_1
- HPSC (2022) COVID-19 guidance for people at risk of severe disease on reducing risk of COVID-19 infection. [cited 2023 May 5].
   Available from: https://www.hpsc.ie/az/respiratory/coronavirus/novelcoronavirus/guidance/peopleatincreasedriskofsevereillness/othersatincreasedriskofsevereillness/Guidance%20For%20Older%20People%20and%20Others-Reducing%20COVID-19%20Exposure%20Risk.pdf
- 8. Albon D, Bruschwein H, Soper M, List R, Jennings D, Gettle L et al (2021) Impact of COVID-19 on social determinants of health for adults with cystic fibrosis. Ther Adv Respir Dis 15:1–10
- 9. Flume PA, Saiman L, Marshall B (2022) The impact of COVID-19 in cystic fibrosis. Arch Bronconeumol 58(6):466–468
- Sawicki GS, Van Citters AD, Dieni O, Sabadosa KA, Willis A, Benitez D et al (2021) Financial impacts of the COVID-19 pandemic on cystic fibrosis care: lessons for the future. J Cyst Fibros 20:S16–S20
- Humaj-Grysztar M, Rachel M, Śmiech-Michalec O, Bonior J (2022) Mental health of cystic fibrosis patients and the COVID-19 pandemic in Poland: a single-center comparative study. Int J Environ Res Public Health 19(23)
- Corona Citizens Science Project. Corona study University of Galway. [cited 2023 Mar 15]. Available from: https://www.universityofgalway. ie/corona-study/.
- How has COVID-19 impacted people with rare diseases? (2022)
   Eurordis. [cited 2023 Apr 22]. Available from: https://www.eurordis.org/publications/how-has-covid-19-impacted-people-with-rare-diseases/
- Social impact of COVID-19 survey CSO central statistics office (2021) CSO. [cited 2023 Apr 22]. Available from: https://www.cso. ie/en/releasesandpublications/ep/p-covid19/covid-19information-hub/socialandwellbeing/socialimpactofcovid-19survey/
- 36-Item Short form survey instrument (SF-36). RAND Corporation. [cited 2023 Apr 23]. Available from: https://www.rand.

- $org/health-care/surveys\_tools/mos/36-item-short-form/survey-instrument.html$
- Economic and Social Research Institute (2020) The environmental and economic impacts of the COVID-19 crisis on the Irish economy. [cited 2023 Mar15]. Available from: https://www.esri.ie/system/files/publications/RS106\_2.pdf
- Davis J, Nesmith A, Perkins R, Bailey J, Siracusa C, Chaudary N et al (2021) Patient and family perceptions of telehealth as part of the cystic fibrosis care model during COVID-19. J Cyst Fibros 20:e23–e28
- Havermans T, Houben J, Vermeulen F, Boon M, Proesmans M, Lorent N et al (2020) The impact of the COVID-19 pandemic on the emotional well-being and home treatment of Belgian patients with cystic fibrosis, including transplanted patients and paediatric patients. J Cyst Fibros 19(6):880–887
- Colombo C, Burgel PR, Gartner S, van Koningsbruggen-Rietschel S, Naehrlich L, Sermet-Gaudelus I et al (2020) Impact of COVID-19 on people with cystic fibrosis. Lancet Respir Med 8(5):e35–e36
- Radtke T, Haile SR, Dressel H, Benden C (2021) Recommended shielding against COVID-19 impacts physical activity levels in adults with cystic fibrosis. J Cyst Fibros 20(2):e26–e27
- 21. Nobili RM, Gambazza S, Spada MS, Tutino AL, Bulfamante AM, Mariani A et al (2021) Remote support by multidisciplinary teams: a crucial means to cope with the psychological impact of the SARS-COV-2 pandemic on patients with cystic fibrosis and inflammatory bowel disease in Lombardia. Int J Clin Pract 75(7):1–8
- Wood J, Mulrennan S, Hill K, Cecins N, Morey S, Jenkins S (2017) Telehealth clinics increase access to care for adults with cystic fibrosis living in rural and remote Western Australia. J Telemed Telecare 23(7):673–679
- Womack C, Farsin R, Farsad M, Chaudary N (2020) Emerging alternatives to conventional clinic visits in the era of COVID-19: Adoption of telehealth at VCU adult cystic fibrosis center. Int J Gen Med 13:1175–1186
- Government Publication (2020) Medicinal products (prescription and control of supply) (amendment) regulations 2020 [Internet]. [cited 2023 Mar 16]. Available from: http://www.irishstatutebook. ie/eli/2020/si/98/made/en/pdf
- Lynch M, O'Leary AC (2021) COVID-19 related regulatory change for pharmacists – The case for its retention post the pandemic. Res Soc Adm Pharm 17(1):1913–1919
- 26. PSI-The Pharmacy Regulator (2020) Guidance for prescribers and pharmacists on legislation changes to facilitate the safe supply of medicines during the COVID-19 pandemic [Internet]. Dublin: PSI-The Pharmacy Regulator. [cited 2023 Mar 16]. Available from: https://www.thepsi.ie/Libraries/COVID/Guidance\_for\_prescribers\_and\_pharmacists\_on\_legislation\_changes\_to\_facilitate\_the\_safe\_supply\_of\_medicines\_during\_the\_COVID-19\_pandemic.sflb.ashx
- Fana M, Torrejón Pérez S, Fernández-Macías E (2020) Employment impact of covid-19 crisis: from short term effects to long terms prospects. Journal of Industrial and Business Economics 47(3):391–410
- Collaço N, Legg J, Day M, Culliford D, Campion A, West C et al (2021) COVID-19: impact, experiences, and support needs of children and young adults with cystic fibrosis and parents. Pediatr Pulmonol 1–9
- Pinar Senkalfa B, Sismanlar Eyuboglu T, Aslan AT, Ramasli Gursoy T, Soysal AS, Yapar D et al (2020) Effect of the COVID-19 pandemic on anxiety among children with cystic fibrosis and their mothers. Pediatr Pulmonol 55(8):2128–2134
- 30. Kelly BD (2020) Impact of covid-19 on mental health in Ireland: evidence to date. Ir Med J 113(10):1–6
- 31. Community Pharmacies. HSE.ie. [cited 2023 Apr 12]. Available from: https://www.hse.ie/eng/services/list/2/pharmacy/

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