

COVID-19: Impact, experiences, and support needs of children and young adults with cystic fibrosis and parents

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Abstract

Background: Little is known about the impact of COVID-19 and the United Kingdom's (UK) national shielding advice on people with cystic fibrosis (CF) and their families. This study explored the experiences and support needs of children and young adults (CYAs) with CF, and parents who have a child with CF, during the COVID-19 pandemic.

Methods: CYAs with CF and parents of CYAs with CF completed a UK wide online survey with open and closed questions exploring experiences, information and support needs and decision-making processes. Qualitative thematic content analysis and descriptive quantitative analyses were undertaken.

Results: CYAs aged 10–30 years ($n = 99$) and parents of CYAs aged 0–34 years ($n = 145$) responded. Parents (72.7%) and CYAs (50.0%) worried about the virus, and both were vigilant for virus symptoms (82.7% and 79.7%). Over three-quarters of CYAs were worried about their own health if they caught the virus. CYAs worried about feeling more isolated during the virus (64.9%). Qualitative findings reported the following themes: (1) Disruption—caused by isolation, (2) impact on psychological wellbeing, (3) safety of shielding, and (4) healthcare and treatment provision—changes to care, access and support.

Conclusions: The impact of COVID-19 and UK shielding advice to have no contact with anyone outside the household caused disruption to the lives and routines of individuals in relation to work, education, social lives, relationships, CF management routines and support. Parents and CYAs highlighted the need for clear, up-to-date and tailored advice on individualized risks and shielding.

KEYWORDS

COVID-19, cystic fibrosis, mental health, pandemic, well-being

1 | INTRODUCTION

The COVID-19 (SARS-CoV-2) pandemic has had a global impact on healthcare facilities, economy and psychosocial life. Whilst children and young adults (CYAs) comprise only 1%–2% of cases of COVID-19 worldwide,^{1–3} and seem to have a lower risk of infection than adults⁴; the virus and its impact has caused significant worry and anxiety for children with serious conditions and their parents.^{5,6}

Infection with SARS-CoV-2 primarily causes respiratory illness ranging from mild disease to severe life-threatening acute respiratory distress syndrome.⁷ Respiratory viral infection in cystic fibrosis (CF) patients is associated with acute pulmonary exacerbations and typically cause significantly greater morbidity than in non-CF individuals.⁸ Consequently, during the initial stages of the pandemic, it was presumed that individuals with CF would be particularly vulnerable to infection with SARS-CoV-2 with a high risk of serious illness.⁵ However, subsequent data established that infection gave rise to a similar spectrum of outcomes to that seen in the general population with a more severe clinical course associated with older age, CF-related diabetes, lower lung function in the year before infection and having received an organ transplant.⁹ A further international observational study on the clinical characteristics of SARS-CoV-2 in 105 children with CF across 13 countries (infants to adolescents) found that infection in children with CF is usually associated with a mild illness in those without pre-existing severe lung disease.¹⁰ Several characteristics of CF airway pathophysiology have been proposed which may abrogate the severity of COVID-19 in CF. These include altered autophagy (required for SARS-CoV-2 replication), increased levels of serine protease inhibitor (reducing SARS-CoV-2 entry into epithelial cells) and elevated ACE2 (leading to increased conversion of pro-inflammatory angiotensin II to anti-inflammatory angiotensin-1-7).^{11,12}

The baseline incidence of anxiety and depression is elevated in individuals with CF and their parents.¹³ Research has demonstrated that individuals with CF and their families experience high rates of clinically significant symptoms of depression and anxiety^{14–16} compared with community samples.^{17,18} There is also increasing evidence of the significant psychological impact of the COVID-19 pandemic on individuals with CF. A Belgian study assessed the impact of COVID-19 on emotional wellbeing of patients with CF (mean age 32.2 years) and parents of children with CF (mean age 39.4 years); reporting increased stress, fear and worry about CF and the future.¹⁹ Two further studies have evaluated the impact of COVID-19 on anxiety in children with CF^{20,21} and their mothers²¹ reporting increased anxiety primarily amongst mothers of children with CF as well as those with non CF children compared to children with CF.^{20,21}

The UK government initially considered children and young adults with CF to be clinically extremely vulnerable to COVID-19 and recommended “shielding”—that is, to remain at home at all times and have no face to face contact with anyone outside of their household, except to attend to medical needs.²² Information regarding the pandemic is constantly evolving and families are continually having to assess the information they receive from multiple potential sources in relation to COVID-19 and make decisions accordingly. Whilst previous studies have focused on the psychological impact of COVID-19 on children and their families,^{19–21} we utilised a UK wide online survey to explore the

pandemic's wider impact in relation to the impact of restrictions such as “shielding,” parents' views on school attendance, decision-making related to the virus and perceived information and support needs.

2 | MATERIALS AND METHODS

2.1 | Study design

A survey study was conducted on CYAs with CF (ages 10–30 years) and parents/carers of CYAs with CF. The survey assessed views and experiences, information and support needs, decision making, shielding, exercise and treatment. We developed this survey with input from CYAs, parents, clinicians, youth workers and patient advocacy groups, and their involvement took place from study design to piloting of the survey. This survey is part of a larger longitudinal study assessing the experiences of CYAs with serious pediatric medical conditions and their parents.⁶

We collected surveys between May and July 2020. This time period encompassed the first UK “national lockdown” as well as a period when restrictions were eased.

The study was approved by the University of Southampton and UK NHS Health Research Authority Ethics Committees (IRAS nr. 282176).

2.2 | Participants

Parents of a CYA with CF and CYAs with CF aged between 10 and 30 years who were able to read and respond in English were invited to take part in the survey. We recruited participants through the Southampton pediatric and adult service by email and through a national CF charity (The Cystic Fibrosis Trust) using their website and targeted closed Facebook group page. Electronic consent was obtained before completing the online survey. The aim was to recruit approximately 150–200 respondents to ensure sufficient numbers of participants to identify the range of issues and experiences,²³ and provide rich data from the open text qualitative responses.^{24,25}

2.3 | Survey

The survey content was informed by available literature^{26–28} and input from expert clinicians, CYAs and parents. We sought feedback on the survey's phrasing of questions and completeness, and changes were made accordingly before dissemination. The survey comprised of 6 key sections including open and closed item questions: experiences, information, shielding, decisions, exercise/treatment and support needs. A small number of items differed between the parent and CYA surveys including additional questions on returning to school found only in the parent version under the “Shielding” section. Response options for the closed statement items were *Not at all*, *A little*, *Quite a bit*, *Very much* (except for conditional questions with *Yes/No* as response options). Each section began with a free text box for comments to open questions. Demographic information (age, treatment, ethnicity) was also collected (see Table 1).

TABLE 1 Respondent characteristics

Surveys	Children and young adults (CYA)	Parents
Completed by, <i>n</i>	99	145
Participant age, years, median (range)	24 (10–30)	40 (27–66)
Child's age, years, median (range)		8 (0–17)
Young adult's age, years, median (range)		24 (18–34)
Gender		(of parents child)
Female	70 (70.7%)	78 (53.4%)
Male	19 (19.2%)	65 (44.8%)
Missing	10 (10.1%)	2 (0.8%)
Relationship to CYA		
Mother		127 (87.6%)
Father		16 (11.0%)
Carer		1 (0.7%)
Missing		1 (0.7%)
Ethnicity, <i>n</i> (%)		
White	91 (91.9%)	140 (96.6%)
Mixed/multiple ethnic groups	0 (0.0%)	3 (2.0%)
Other ethnic group	0 (0.0%)	1 (0.7%)
Missing	8 (8.1%)	1 (0.7%)
Respondents by region, <i>n</i> (%)		
England	75 (75.8%)	128 (88.3%)
Scotland	11 (11.1%)	6 (4.2%)
Wales	5 (5.1%)	5 (3.4%)
Northern Ireland	0 (0.0%)	5 (3.4%)
Missing	8 (8.0%)	1 (0.7%)
Hospital admissions (past 12 months), <i>n</i> (%)		
0	45 (49.5%)	91 (62.8%)
1	23 (25.3%)	30 (20.7%)
2	10 (10.9%)	10 (6.9%)
3	3 (3.3%)	3 (2.0%)
4	4 (4.4%)	3 (2.0%)
5	4 (4.4%)	2 (1.4%)
6	1 (1.1%)	1 (0.7%)
>6	0 (0.0%)	3 (2.1%)
Missing	1 (1.1%)	2 (1.4%)

(Continues)

TABLE 1 (Continued)

Surveys	Children and young adults (CYA)	Parents
Taking regular nebulized antibiotics		
Yes	65 (65.7%)	67 (46.2%)
No	26 (26.3%)	77 (53.1%)
Missing	8 (8.0%)	1 (0.7%)
CYA FEV ₁ percent at last review, <i>n</i> (%)		
Above 90%	26 (26.3%)	70 (48.3%)
Below 50%	20 (20.2%)	1 (0.7%)
Between 50% and 70%	15 (15.2%)	13 (9.0%)
Between 71% and 89%	30 (30.3%)	30 (20.7%)
Don't remember	0 (0.0%)	21 (14.5%)
Missing	8 (8.0%)	10 (6.8%)

2.4 | Data analysis

We carried out descriptive statistics using IBM Statistical Package for Social Science (SPSS) to summarize demographic data and descriptive statistics of closed item statements (collapsing the lowest two response options *Not at all*, *A little* and the highest two response options *Quite a bit*, *Very much* into a binary outcome).

Thematic content analysis was conducted on the free text data, and informed by a three stage coding process^{29,30}: (1) We openly coded initial responses into broad comment categories (NC, MD, JL), refining the framework, and resolving any conflicts with another researcher (ASD); stage 2) the framework was used to categorize all responses from the data, with further refinement after discussion as a team (NC, MD, JL, ASD); stage 3) overarching themes were identified from the analysis of content between categories. Number of comments were counted to identify weight of themes. The total number of comments does not match the number of participants due to overlaps in comments to categories.

3 | RESULTS

One hundred and forty-five parents responded to the survey of which 88.3% (*n* = 128) were mothers, 11.0% (*n* = 16) were fathers and 0.7% (*n* = 1) foster carer. The majority of parent respondents 96.6% (*n* = 140) were White. The median age of the CYAs of responding parents was 9 years. The majority of respondents were from England 88.3% (*n* = 128).

Ninety-nine CYAs responded to the survey and the majority of CYAs 91.9% (*n* = 91) were White. The median age of CYAs completing the survey was 24 years old. Respondents were predominantly located in England, 75.8% (*n* = 75). Table 1 summarizes respondents' characteristics.

3.1 | Closed item statements

The study generated quantitative results from the closed statement items. These are presented for parents (Figure 1) and CYAs (Figure 2) as numbers and percentage of total that responded “Quite a bit” and “Very much” to each statement.

3.2 | Parent survey

Parents worry about the virus (72.7%) and are vigilant for virus symptoms (82.7%) or their child's CF symptoms triggered by the virus (97.3%). They reported feeling worried about their child feeling more isolated during the virus outbreak (71.8%) and many had concerns about the hospital no longer being a safe place during the virus outbreak (59.1%). Just over half of respondents reported receiving information from the clinical team about the virus (52.7%) and a vast majority obtained information from the Cystic Fibrosis Trust (94.5%). The majority of parents read information about the virus on social media (76.8%), however only a small minority of parents reported being influenced by social media in relation to what they do and think about the virus. Few parents trust the advice given by social media (9.6%). Over two-thirds of parents reported worry that they would catch the virus and that their child would catch it from them (67.0%).

Additional questions specifically focusing on exercise/treatment, shielding and return to school indicated that the majority of parents reported that the amount of treatment their child had done in the last month had stayed the same (68.6%) with 19.0% reporting an increase in treatment. Parents reported a reduction in their CYA's level of exercise activity in most cases (55.9%). Parents reported feeling anxious about their child coming off the shielding list (54.3%) and returning to school (53.3%).

3.3 | Children and young adults survey

CYAs were also worried about the virus (50.0%) and about their own health if they caught the virus (75.3%). CYAs were vigilant about recognized symptoms of the virus (79.7%), and its potential impact on their CF symptoms (90.5%). CYAs worried about feeling more isolated during the virus outbreak (64.9%). The majority of CYAs used information provided by the Cystic Fibrosis Trust about the virus (91.8%). Although the majority of CYAs read information on social media about the virus (81.3%), a minority of CYAs (21.3%) reported that social media influenced the way they think and what they do in relation to the virus. Few CYAs trust the advice given on social media (4.9%). Additional questions specifically focusing on exercise/treatment, shielding

Parents of Children and Young Adults with Cystic Fibrosis

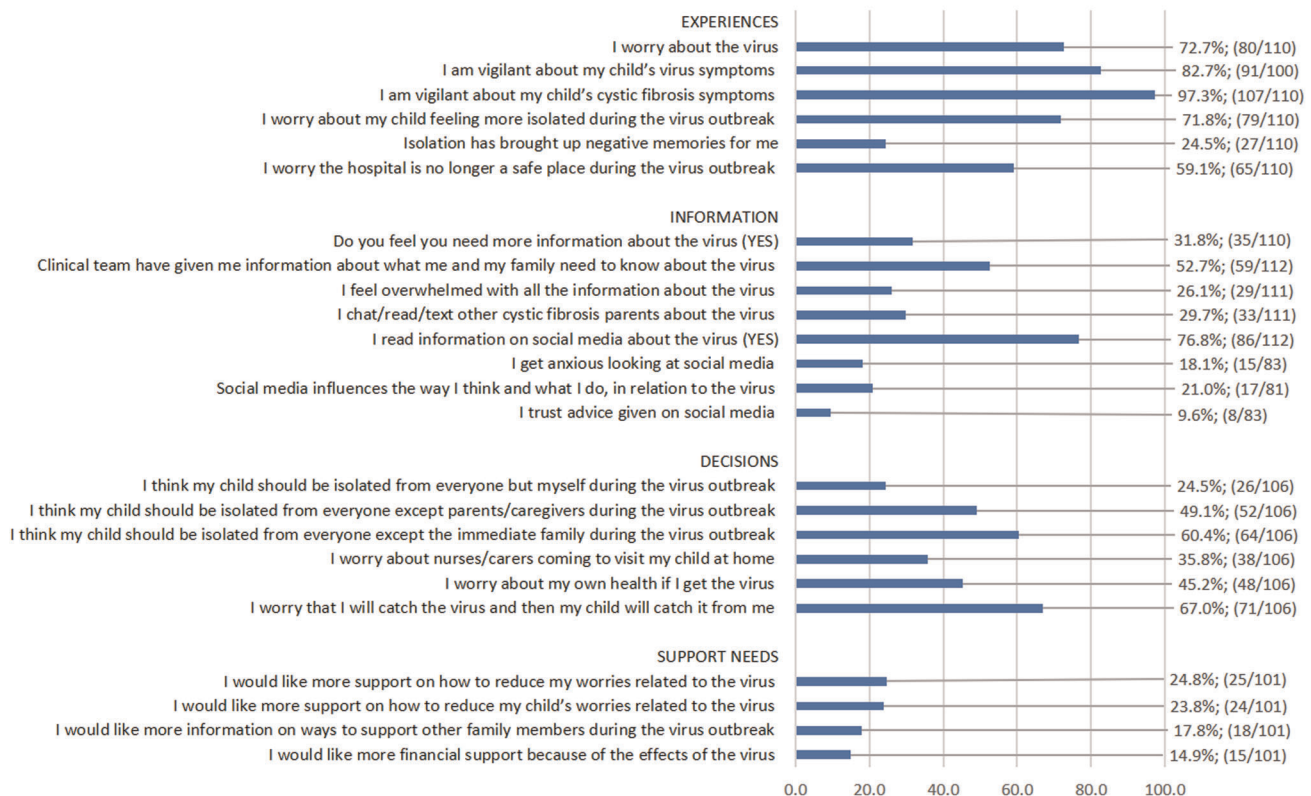


FIGURE 1 Parents of children and young adults with cystic fibrosis [Color figure can be viewed at wileyonlinelibrary.com]

Children and Young Adults aged 10–30 years with Cystic Fibrosis

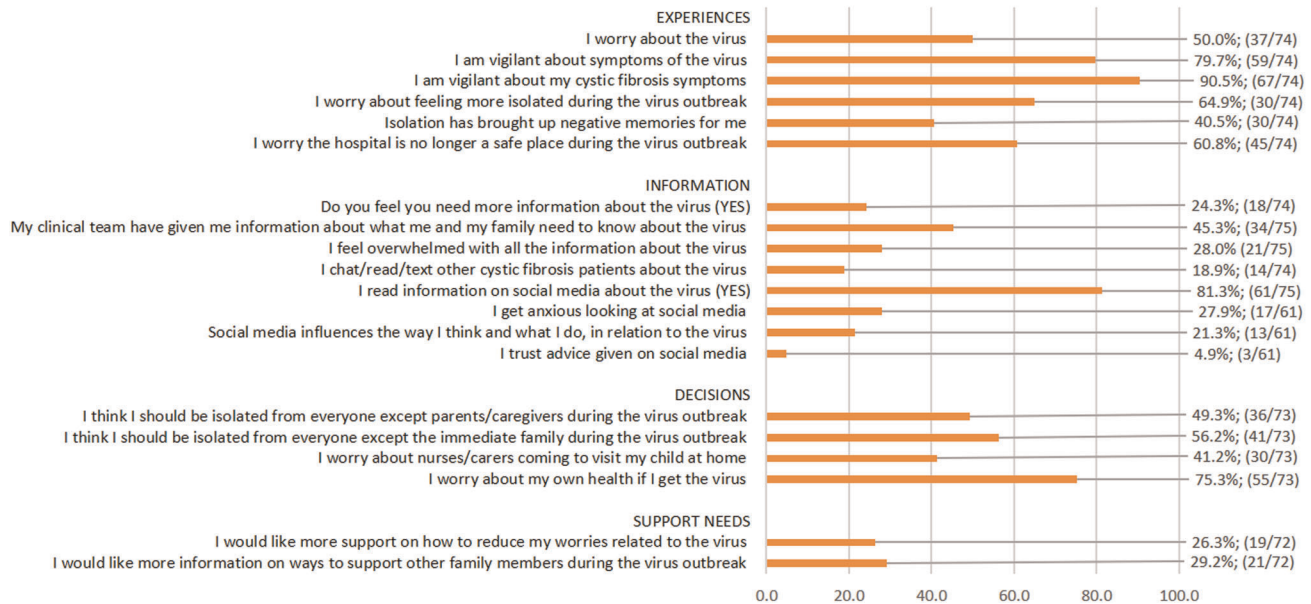


FIGURE 2 Children and young adults aged 10–30 years with cystic fibrosis [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

and return to school revealed that a minority of CYAs reported that the guidance provided about shielding was clear and easy to understand (42.5%). CYAs reported feeling anxious about being taken off the shielding list (40.5%), and for those who were school age, a small number were anxious about returning to school (25.7% of all CYAs). CYAs reported that they were receiving the same amount of CF treatment in the last month (65.3%) with 16.7% reporting an increase in treatment. CYAs reported that their level of exercise activity had reduced in most cases (60.6%).

3.4 | Open text boxes

Responses to open questions contained a total of 1,302 quotes (173 Experiences, 175 Information, 253 Shielding, 73 Return to school (parent only), 167 Decision making, 307 Exercise/Treatment and 154 Support—totalled from CYA and parent responses). Parents (71.3%) and CYAs (72.7%) completed the “Experiences” open text box, and between 65% and 75% of parents and CYAs completed the other open text boxes. Respondents appeared to repeat their responses from the “Experiences” open text box in subsequent open text boxes. To avoid replication of findings, the themes from the “Experiences” open text box are described below and presented with additional quotes in Table 2 (see online Supporting Information file).

Four main themes were identified: disruption, impact on psychological wellbeing, safety of shielding, and healthcare and treatment provision.

3.5 | Disruption

The lives of parents and CYAs were significantly disrupted due to lockdown and shielding. Many parents and CYAs reported missing social engagements/support, education, and their work life:

It's also been hard on us as a family because we've not been able to lean on our family as we would want to for support, nor have they been able to hold and cuddle her. She's changing so much and everyone around us is missing out on these precious times (Parent).

Shielding impacted upon future plans for some individuals with CF who were due to start university, or enter employment:

I have worried about how long the effect of the virus will last for and how much I could potentially miss out on due to my CF (in relation to uni or gap year). I have found it hard to see a light at the end of the tunnel (CYA, 18 years).

Particular concerns relating to employment and relationships with partners were expressed by some young adults with CF:

With the extension of shielding it has made me feel anxious about returning to work. I do not feel it would be safe [...], but I could not financially last any longer on the current pay I am receiving (CYA, 21 years).

3.6 | Impact on psychological wellbeing

Parents reported feelings of anxiety, fear and overwhelm due to the impact of lockdown on their life. The majority of parents reported worries over their child potentially catching the virus, how it could affect their child, and its long-term implications on their child's health. Many

parents and CYAs also commonly reported concerns about the psychological impact of shielding due to reduced social activities, lack of physical exercise and absence from school/university/work:

Initial worries as to the potential risk and harm that the virus could have upon his health and well-being. Not only physical health but also that of his mental health, i.e. his emotions. As the virus has led to lockdown and shielding our concerns have stretched beyond that of the virus and the impact upon his future health and well-being (Parent).

CYAs reported feelings of loneliness, isolation, anxiousness and being scared:

I want to see my family and give them a hug, without putting myself at risk. I just don't want all of this to be for nothing (CYA, 24 years).

The virus has also made a minority of parents and CYAs more hypervigilant of hygiene practices.

3.7 | Safety of shielding

Some parents and CYAs felt that being in lockdown kept their child/themselves safe and would want to continue to do so when restrictions were eased. Many CYAs and some parents reported that keeping safe under lockdown was difficult when others in society were not respecting social distancing rules or implementing appropriate hygiene practices, which subsequently made them feel more anxious and wary about going out:

As a family we want to be out and about. We have felt this very difficult, [...], we find that others are not social distancing meaning it is hard for us to get out. If people aren't considering others it makes us not to want to leave the house (Parent).

Some CYAs were anxious or worried about returning to work and even leaving the house after being advised to shield for a long time:

[...] as soon as we are allowed to go back to normality and I have to return to work, this is what scares me and I will get a lot of anxiety [...] (CYA, 30 years).

3.8 | Healthcare and treatment provision

A minority of parents reported challenges in keeping updated with their treatments and appointments, and also concerns about visiting the hospital. Some parents acknowledged that they had received good information and support from their CF clinical team; *"It has been comforting to know our CF team are readily available on the phone should we need them [...]"* (Parent). However, a few CYAs felt that they had not received the same access to standard CF care due to missed appointments and delays with treatment: *"I've had cancelled clinic appointments and no contact from clinic"* (CYA, 26 years).

The responses to the other additional open text boxes relating to information, return to school, and support further reinforce the themes presented above and some key points are summarized below; for more details see Table 3 (see online Supporting Information file).

The majority of parents and CYAs reported a lack of clear guidance and information on shielding, and the need for personalized

explanations and guidelines specific to how families should shield based on individual circumstances. Parents and CYAs also reported the need for frequent communication from HCPs by checking in with families throughout the lockdown period. Many parents reported a need for an assessment of safety procedures put in place at school before they felt it was safe for their child to return to school.

4 | DISCUSSION

To our knowledge, this is the first study to examine the impact of the coronavirus pandemic and the UK government response on CYAs with CF and parents. The study found that the majority of parents and CYAs had worries about the virus, their own health if they caught the virus and its potential impact on CF symptoms. For some parents, the hospital no longer felt like a safe place during the lockdown.

The qualitative findings highlighted that families faced significant challenges in relation to the advice to maintain complete isolation. Although shielding provided a safety net for some individuals, for many there was a negative impact on their psychological wellbeing. Psychologists working in CF teams have an important role to play in talking through these concerns, helping families identify adaptive coping strategies and offering psychological therapy to those experiencing longer term difficulties. The increased use of video appointments has enabled psychologists working with people with CF to continue to deliver psychological services during the pandemic,³¹ and reported to be effective in reducing stress and depression in individuals with CF and caregivers.³²

Significant disruption was also caused to important aspects of families lives such as work, education and social relationships. CYAs felt they were missing out and parents worried about the impact on their child's social and emotional development. These findings are in accordance with a recent Belgian study which also reported a significant psychological impact on CF patients due to COVID-19, albeit in the absence of specific governmental shielding guidance.¹⁹ People with CF have an increased risk for mental health problems due to their chronic condition, and may therefore be at risk for developing further/exacerbated psychological problems during the pandemic.¹³ A study that assessed the impact of shielding in the UK, on the mental wellbeing of adults with CF found that although depression levels were low and stable; anxiety levels significantly increased—however this was reported to be a normal response to an external threat (COVID-19), and was reported to have improved adherence to shielding.³³ Another study conducted in Turkey also found that the pandemic caused significant increase in anxiety amongst mothers of children with CF, as well as those with healthy children when compared to children with CF (13–18 years).²¹ Lower anxiety scores in children with CF compared to age-matched healthy control group has also been reported elsewhere.²⁰ It was postulated that a potential reason for lower anxiety scores in children with CF may relate to previous exposure to stressful illness experiences, necessitating the early development of adaptive coping strategies when compared to a healthy control group who may be experiencing a serious health problem for the first time.

Both parents and CYAs reported hypervigilance of hygiene practices. Individuals with CF and their parents are likely to have been participating in self-quarantining and social distancing behaviors for most, if not all their lives, and have a greater understanding of preventing cross-infections through distancing measures, frequent handwashing and use of personal protective equipment³⁴ compared to the general population. This may in part explain the high levels of anxiety and concern expressed regarding returning to “normality” once shielding restrictions were lifted due to a perceived lack of adherence to infection prevention measures in society. Countries around the world implemented different measures to contain and reduce virus transmission, including travel bans, closure of country borders and lockdowns. Measures to protect vulnerable groups varied across the world with some countries such as France and South Korea, not initially employing specific measures for individuals with chronic health conditions. Other countries such as Canada, Norway, Singapore and Switzerland put in place some measures to protect vulnerable groups introducing “protective self-separation” which included avoidance of face to face social interactions and physical contact with others.³⁵ Whilst the UK government advised clinically extremely vulnerable individuals to shield (i.e., self-isolate at home), it is possible that being identified as vulnerable influenced individuals perceptions of their illness,³⁵ particularly if they did not identify themselves as vulnerable before the pandemic. Being identified as “vulnerable” may have resulted in individuals with CF taking their condition more seriously and therefore being hypervigilant in their hygiene practices and self-management care.

Exercise forms an important part of CF management,³⁶ and the results from our study suggest that the majority of CYAs (60.6%) and parents (55.9%) reported reduced levels of exercise activity likely due to a combination of shielding guidance to avoid contact with others and the closure of gyms, exercise clubs and activities during this period. This finding contrasts with a Belgian study of patients with CF which identified an increase in exercise levels in over 40% of patients since the start of the pandemic.¹⁹ This perhaps reflects the fact that whilst Belgium was in lockdown for a period of time, patients with CF did not have any specific guidance akin to the shielding program in the UK and would have had more freedom to exercise. Patients with CF in the Belgian study were also provided with weekly exercise programs by physiotherapists at a CF center to encourage and motivate maintaining exercise.

Many of the study respondents used online/digital services and their clinical team to gather information, however there were distinct gaps identified in the type of information respondents needed. Both CYAs and parents wanted more clear and personalized guidance and support on how the virus could affect CYAs with CF to help them make decisions about how to live alongside shielding guidance. As restrictions ease, CF multidisciplinary teams (MDTs) are well placed to have ongoing supportive conversations with families to help weigh up the pros and cons of returning to different activities (work, education and exercise, etc.), and to consider the impact on both their physical and mental health. As the situation with COVID-19 continues to evolve with the roll out of vaccines and new variants; providing up to date and clear information and having ongoing conversations between patient and MDTs may help resolve anxiety and ambivalence thus promoting confidence in managing the psychological impact of the disruption caused to their lives.

4.1 | Strengths and limitations

One major strength of this study is that it is a national study using a survey that has been co-produced with both parents and CYAs. This enables a comprehensive understanding of issues that are directly relevant to CF CYAs and their families. The qualitative data collected enables further exploration into patients and parents experiences, providing valuable insights that can inform healthcare professionals which areas should be prioritised for attention and relevant support.

The study was limited by its use of digital media for recruitment which potentially excluded those without access to digital devices. The study was only available in English and providing translated material would undoubtedly improve recruitment and ethnic diversity of respondents in future. Another limitation was the inability to triangulate the data between CYAs and their respective parents which would have enabled potentially valuable correlative data. The majority of parent participants were mothers and therefore the data is more representative of mothers’ experiences than other types of parent (i.e., father, carer, etc.).

In conclusion, the impact of COVID-19 and experiences of shielding have caused significant disruption to the lives of individuals with CF and parents who have a child with CF, which has had a subsequent impact on individuals psychological wellbeing. The study identified that CYAs and parents need clear tailored information about individual risk and practical shielding guidelines from trustworthy and reputable sources. Challenges remain in coordinating support to keep pace with the inevitable and ongoing changes caused by the pandemic to support individuals living well with CF during this stressful period.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Nicole Collaço: formal analysis (lead); project administration (lead); writing original draft (lead); writing review and editing (equal). **Julian Legg:** formal analysis (supporting); writing review and editing (supporting). **Maria Day:** formal analysis (supporting); writing review and editing (supporting). **David Culliford:** data curation (lead); writing review and editing (supporting). **Anna Campion:** formal analysis (supporting); writing review and editing (supporting). **Carolyn West:** formal analysis (supporting); writing review and editing (supporting). **Anne-Sophie Darlington:** conceptualization (lead); formal analysis (supporting); project administration (lead); writing review and editing (supporting).

DATA AVAILABILITY STATEMENT

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

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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