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Cough in adolescent with cystic fibrosis, from nightmare to COVID-19 stigma: A qualitative thematic analysis

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ABSTRACT

Purpose: Cough is part of the daily life of patients with Cystic fibrosis (CF) and its most common symptom. This study explored the experiences of adolescents with CF in Iran during the COVID-19 pandemic in relation to their cough.

Design and methods: In this qualitative study, we conducted 32 semi-structured interviews with 21 adolescents with CF. We analyzed the data thematically.

Results: We identified three main themes among adolescents with CF in relation to coughing: 1. Cough is a permanent companion; 2. Coughing raises fear of double stigma; 3. Patients' individualized coping strategies to deal with coughing. Participants complained that cough interrupted daily tasks and sleep, drew unwanted attention in public places, and elicited questions about whether they were COVID-19 patients or substance users—both highly stigmatized identities.

Conclusion: Although coughing is a protective mechanism for CF patients, frequent coughing often causes major challenges, particularly during the COVID pandemic, when people were acutely sensitive and aware about coughing. During the COVID-19 pandemic, in addition to taking care of themselves and managing the disease, CF patients therefore had to also overcome issues related to social stigma and isolation.

Practice implications: Healthcare workers play an important role in increasing public awareness about CF and its symptoms, including cough. During the pandemic, healthcare workers can help reduce the stigma of coughing through public education. Healthcare workers can actively communicate with patients to identify severe and ineffective cases of cough due to exacerbation of the disease and refer them to a specialist.

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Introduction

Cystic fibrosis (CF) is a multisystem genetic disorder that affects the airways, reproductive system, sweat glands, and gastrointestinal tract. The disease is caused by a mutation in the CF transmembrane conductance regulator (CFTR) gene, leading to abnormal reabsorption of water and sodium in the airways (Reisi et al., 2020). Progressive respiratory failure is the leading cause of mortality and morbidity from CF (Turcios, 2020).

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CF was first recognized more than 80 years ago, and raising the life expectancy of these patients over the past decades has been a major medical breakthrough (Balfour-Lynn & King, 2020). The UK Cystic Fibrosis Registry data indicate CF mortality rate declined by 2% per year between 2006 and 2015. Moreover, according to evidence in 2015, the average survival rate for patients born with CF F508del homozygous was estimated as 41 years for women and 46 years for men (Keogh et al., 2018).

The production of excessively thick mucus characterizes CF, blocks secretion of the glands in various parts of the body, and hurts lungs. To clear the trapped mucus, the patient has to cough, sometimes persistently and suddenly (Niv et al., 2021). Cough is part of the life for patients with CF and is both a symptom and natural defense mechanism for clearing their airways (Vilozni et al., 2014). However, excessive cough leads to airway collapse with insufficient clearance of the mucus (Chaudary & Balasa, 2021). A CF patient must spend more than

100 min each day clearing poorly ventilated lung zones. Every day the patient has to do conventional chest physiotherapy, postural drainage with percussion/vibration, active cycle of breathing technique and so forth (Chaudary & Balasa, 2021).

Late adolescence and early adulthood are challenging times for adherence to the treatment required to clear the airways (Lanzkron et al., 2018). The challenges associated with CF care tend to be exacerbated during adolescence, a high-risk lifespan for both physical and psychological status (Muther et al., 2018). Parent-child interactions, family functioning, socioeconomic status, and family stress are also important variables in adherence to treatment (Hommel et al., 2019). Mental health comorbidities, including depression and anxiety, are higher among adolescents with CF than in the general population. A high risk of infection in CF patients further limits their lifestyle and may lead to social isolation and anxiety. A recent qualitative study reported that the children and adolescents with CF felt rejected when others avoided them because of differences in appearance or persistent coughing (Jamieson et al., 2014).

CF patients are highly susceptible to infections (Jamieson et al., 2014). Viral respiratory tract infections and the risk of complications and adverse effects on lung function in patients with CF are more severe than in the general population. In 2009, during the H1N1 flu epidemic, many CF patients were infected leading to respiratory failure and death (Colombo et al., 2020). The UK government initially advised CF patients to be “shielding” during COVID—that is, to stay home at all times and have no face-to-face contact with anyone outside their home, except for medical reasons (Ladores, 2020).

The National CF Foundation of Iran was established in 2019 in Markaz Tebi Hospital, an educational hospital under the coverage of ***** University of Medical Sciences. So far, 2300 patients have been registered in the National CF system of Iran, and this number is increasing. According to the center, the number of CF patients over 18 in Iran has now risen from 3% in 2007 to over 20%. The center has established a particular protocol for CF patients on outpatient and inpatient visits. In this protocol, to reduce the risk of disease transmission, all CF patients, regardless of throat or sputum culture results, maintain a distance of at least six steps (two meters) from other CF patients in all units and common areas in the CF clinic.

Moreover, assessment and examination of the patients are performed in a private room. The hospitalized patients with CF are kept in private rooms. It is mandatory to use masks in common areas, and emphasis is placed on frequent hand washing. This guideline was also implemented during the COVID-19 pandemic and was not changed.

Many of these patients and their families are members of a Telegram group where healthcare providers answer the patients' and their families' questions regarding the disease and protocols related to COVID 19. At the National CF Foundation website, information on COVID 19 is constantly updated, and the patients and their families receive guidance on infection prevention, vaccination and lockdown.

The general population in Iran is not very aware of CF disease. It seems that teachers and school officials, and even some healthcare professionals do not have sufficient information about CF. One of the applied objectives of our larger project is to enhance the knowledge and awareness of the people, health care providers and teachers about this disease.

The COVID-19 pandemic and lockdown experience have significantly disrupted the lives of adolescent patients with CF and their parents. It has had subsequent negative effects on their psychological health (Collaço et al., 2021). This outbreak has had global impacts on social life, economy, and health care. People have experienced quarantines, reduced their communication in society, and avoided infected people. Continuous cough is one of the three symptoms described by the UK Government as the “main symptoms” of COVID-19. The general public was advised to stay away from people with symptoms of fever and cough (Mukhtar & Mukhtar, 2020). The situation is worse for individuals with chronic coughs due to an underlying illness (Won & Song, 2021). The clinical manifestations of cough and shortness of breath in CF are similar to those of COVID-19 (Ladores, 2020). Cough is a significant concern in CF,

and it creates feelings of discomfort and embarrassment in the patient (Patterson, Wall, Berge, & Mill, 2008). This situation can be especially distressing in adolescents with CF, because based on the characteristics of their age, they are more sensitive to their appearance and the impact they have on those around them (Withers, 2012). In such unusual circumstances that the public is fearful of the highly contagious disease, COVID; adolescents with CF cannot hide their cough. As a result, such condition has made the lives of these teenagers much more difficult.

Although cough is recognized as the most common symptom of CF, research has not focused on patients' experiences of cough and any associated challenges regarding this manifestation, especially during the pandemic of COVID-19. Continuous cough is a classic symptom of both covid-19 and CF. Thus there is a need to focus on people's experiences with CF coughs during this global pandemic. This qualitative study was conducted to explore the experience of Iranian adolescents with CF about their cough during the pandemic.

Design and methods

Participants and procedures

This study was part of a larger research project exploring “identity formation of adolescents with CF”. Twenty-one adolescents with CF were interviewed between September 2020 and February 2021. Purposeful sampling was employed to recruit participants with different socioeconomic backgrounds and varying disease severity to maximize variation in the sample. The classification of mild, moderate and severe disease, based on Forced expiratory volume (FEV1) has been used internationally as a classification of disease severity in medical and psychosocial texts. It has been used as a standard for epidemiological study in CF (ESCF) (Gee et al., 2003).

Participants were recruited through a referral CF clinic at an educational pediatric hospital. To be eligible for the study, adolescents needed to be between 12 and 19 years old and have had a definite diagnosis of CF since their early years of life. Purposive sampling was carried out according to inclusion and exclusion criteria. The researcher (LT) introduced herself to parents and adolescents and explained the aim of the study. Face-to-face semi-structured interviews were conducted by the first author in a quiet room. Questions aimed to explore study participants' experiences of CF coughs during the pandemic. They were asked to answer questions such as: *Can you tell me about a routine day of your life after the COVID outbreak?*, *What were the main challenges you encountered after COVID outbreak?*, *Please describe any specific conditions you encountered recently with your cough?* and *What are you doing to overcome these issues?*. Participants' consent and contact information were obtained to coordinate further interviews if necessary.

Ethics

Our larger qualitative research study received ethical approval from the Ethics Committee of ***** University of Medical Sciences. The participants were given a summary description of the research before the interview. Written consent was obtained after informing the participants and their parents about the study aims, and they were informed about the recording of the interviews. They were told that participation was voluntary, and their right to withdraw at any stage of research. They were assured about confidentiality and anonymity. For participants under 18 yr old, informed consent was also received from parents or guardians. Participants were advised that they could refrain from answering. Patients were reassured that their treatment would not be affected in any way, even if they decided to withdraw from the study.

Qualitative data analysis

Inductive thematic analysis was conducted to understand and explore the experiences of adolescence with Cystic Fibrosis about their

cough. The purpose of thematic analysis is to identify important and interesting patterns in the data and use these themes to make sense of an issue (Maguire & Delahunt, 2017), rather than simply summarizing the data (Braun & Clarke, 2006). Interviews were transcribed verbatim and analyzed using MAXQDA software (v. 10.0). The interviews continued until data saturation, that is when themes emerged repetitively, and sufficient information was obtained to answer the research question.

Following Braun and Clarke's (Braun & Clarke, 2016) six-phase approach to thematic analysis, to achieve *familiarization* with the data, two authors (LT&JM) listened to the audio recordings and read the full transcripts several times to develop an in-depth understanding of the contextual details of adolescents' broader narratives and to generate initial ideas about the data. This *repeated reading* process immerses the researcher in the data and develops familiarity with both the depth and breadth of the content. In the second step, the transcripts were coded by two authors (LT&JM) independently. Afterward, they systematically highlighted interesting features that were deemed to be relevant. Then they labeled the units based on their content, and a list of codes was created. In the next step, patterns in the codes across the whole data set were identified, and related codes were grouped into potential themes by the development of a thematic map.

We refined the identified themes during a recursive process in the fourth phase. At this stage, any themes that were not sufficiently supported or were too diverse were discarded. The researchers also returned to the raw data to ensure that the themes reflected the participant's voice. Phase five involved defining and naming the themes and describing their content in relation to research aims. We conducted a detailed analysis for each theme, identifying the story that each individual theme tells. The last phase was to produce a report which included selecting samples of the transcript to illustrate elements of the theme. These extracts illustrate the themes and provide a clear example of its content.

Disagreements were discussed with the corresponding author (JM). The authors reviewed the themes to ensure that the codes were appropriate and coherent within each theme and could be clearly distinguished from the codes in other themes.

We used the widely accepted four criteria introduced by Lincoln and Guba (1985) (Lincoln et al., 1985) to demonstrate trustworthiness in our research: transferability, credibility, confirmability, and dependability. We applied various techniques to address credibility, including prolonged engagement and debriefing with other research team members (peer check and experts check). Also to verify the credibility of the data, quotes and the themes were reviewed by three study participants (17 and 18-year old girls and a 16-year old boy). Feedback from the adolescents was used to modify or revise the identified themes as appropriate. This member checking helped the researchers to establish the fit between the researcher's representation of the theme and participants' views. The use of field notes, memos, parallel analysis, and data collection increased the study's validity.

In order to achieve confirmability, all steps were performed under the coordination and supervision of the supervisor, and project consultants. Moreover, all steps of data collection, analysis, coding, and theme generation were documented and were reviewed by the supervisor and the research team. Maximum variation in sampling was a way to increase the transferability of the findings in the present study. Therefore, participants with diverse socioeconomic backgrounds, ethnic groups and different levels of educations were chosen.

Since interviews were conducted in Farsi, the manuscript was translated into English before submission.

Results

A total of 32 interviews were conducted with 21 participants (10 males, 11 females). Interviews lasted between 35 and 80 min. Due to some of the participants' physical condition, consecutive short interviews were conducted with a few individuals (one to ten months after

Table 1
The demographic data of participants.

Characteristic		value
Age	years; mean (range)	16 (12–18)
Sex	Male	10
	Female	11
Disease severity*	Mild	4
	Moderate	14
	Severe	3
Other family member with CF	Yes	2
	No	19
Educational status	Primary school	6
	High school	11
	Diploma	3
	dropped out of school	1
Residence	Urban	18
	Rural	3

* The disease severity was divided into three groups based on FEV1: mild disease (FEV1 > 70%), moderate disease (FEV1 41–69%) and severe disease (FEV1 < 40%).

the first interview). The demographic data of participants are shown in Table 1. We generated over 600 codes during the analysis, and then they were organized into three overarching themes and seven sub-themes. We identified three main themes among adolescents with CF in relation to coughing: 1. Cough is a permanent companion; 2. Coughing raises fear and concerns about stigma; 3. Patients create individualized coping strategies to deal with coughing. Table 2 summarizes the subthemes.

Main theme 1: cough is a permanent companion

CF patients with lung involvement considered cough as their *permanent companion*. They reported frequently coughing during the day and nights and also while receiving treatments with nebulizer and physical therapy. This theme consisted of two subthemes: *cough, the fixed, inevitable, and obvious symptom of CF, and perpetual nightmare*.

Subtheme 1.1 Cough the fixed, inevitable, and obvious symptom of CF

Most participants started their day with a cough and had a cough of varying severity throughout the day. Many of these adolescents stated that although they did not want others to know about their illness, the distinctive, persistent coughs caught everyone's attention and raised questions in their minds. Cough is an obvious sign of disease that cannot be hidden. In this regard, a 17-year old girl mentioned that:

Table 2
Inductive Thematic Analysis and Code Examples.

Themes	Subthemes	Code examples
Cough is a permanent companion	Cough the fixed, inevitable, and obvious symptom of CF	the obvious feature of CF
	A Perpetual Nightmare	sleepless nights with Persistent coughs
Coughing raises fear of double stigma	The stigma of contagious diseases	The stigma of COVID-19
	Negative reactions of others to patients' coughs	Staying away from the patient
	The stigma of being labeled as an addict	Fear of the stigma of addiction to narcotics
Patients' individualized coping strategies to deal with coughing	Constructive Coping Strategies	Adherence to treatment
	Destructive Coping Strategies	Restriction of physical activity

“These coughs are always present, only increase or decrease; it's a constant sign of CF.”

Similarly, a 15-year old girl said”

“I do not tell anyone that I am sick, but they will finally realize my sickness from my constant coughs.”

Other participants said *“Haniyeh is my best friend. We have been friends for twelve years. She does not know exactly that I have CF. She knows I have a disease but does not know it's name. I will not let her know. But I can't hide my cough, so far I have not let her know the details of my illness”* (17 yr old girl).

Subtheme1.2 Perpetual nightmare

Coughing is not only a problem during the day; coughing interferes with adolescents' sleep. At the beginning of the night, coughing may prevent a teen with CF from sleeping, or it may wake them up during sleep. Four teenagers referred to cough as their constant nightmare, which they are afraid of happening before going to sleep and during sleep. A 14-year-old girl described:

“Sometimes when I cough a lot and can't sleep, I cry during the midnight.”

Another participant also said:

“I cough a lot. It comes to me mostly at night. It's a nightmare day and night ... with coughs, I have to take a nebulizer because the coughs are bursting and intense. When I wake up with a cough, it takes a long time for me to fall asleep again ...” (16 yr old boy).

One 18-year-old boy stated: *“When I am very sick, I can't sleep at all. I fall asleep and wake up again. Sometimes when I have an infection, I may not even sleep for a minute till morning “.*

Main theme 2: coughing raises fear of double stigma

Participants were concerned about the stigma associated with coughing in the community and even among their relatives and friends. We chose the Double Stigma theme because teenagers were afraid of both stigmas of addiction and spreading contagious diseases. Three sub-themes develop this theme further: *the stigma of contagious diseases, negative reactions of others to patients' coughs, and the stigma of being labeled as an addict.*

Subtheme2.1 The stigma of contagious diseases

Within their families, study participants' coughing raised fears that the teen might have an infectious or viral disease, including the flu. Since the outbreak of COVID-19, even relatives who were aware of the adolescents' chronic cough distanced themselves from the patients and severely limited their contact with them. This avoidance led to unpleasant reactions, such as opening doors and windows or keeping their children away from other family members. A 15-year old girl who lives with her father's family said:

“My uncle's wife does not know what exactly my illness is and does not let her children play with me; she thinks it is dangerous and contagious.”

A 16-year-old girl added: *“Since I was a child when I was coughing in the park, mothers used to keep their kids away. I did not understand why, but now I know that they were afraid of getting sick. That's why I tell others I have asthma because everyone knows asthma and don't afraid of asthma coughs.”*

Another participant commented that:

“After corona outbreak, I follow the protocols a lot, and I am afraid of getting sick, but when I see that others think I have corona, I get upset.” (17-year old boy).

Our participants were concerned about people opinions regarding their continuous coughing and were also worried that they might be getting avoided due to concerns about COVID-19:

“I rarely go out due to Covid outbreak. I worry about what others think about me when I cough a lot. I think they see me as a huge Covid virus and stay away from me.” (15 yr old boy).

Subtheme2.2 Negative reactions of others to patients' coughs

One of the most common challenges adolescents with CF reported was the reaction of others to their cough. According to the participants, friends, family and the public sometimes distanced themselves from the teenager or covered their nose and mouth if the teen started coughing. This behavior intensified during the Covid-19 pandemic. Being stigmatized by the possibility of having Covid-19 was hurtful for these teenagers. The quotes below are examples of how this was described in the participants' interviews:

“I was coughing in the subway. Several people asked me, 'Oh, you've got a bad cough, do you have Corona?'. In fact, many people think I have corona.” (16 yr old girl).

Another participant said: *“We were in science class, one of my friends showed the body parts on manikin and said that it is Shiva's lung which is damaged. That's why she always coughs. Everyone mocked me. I got upset too and left the classroom.”* (17 years old girl).

Similarly, a 14-year old girl said, *“When our family and friends come to our house, and I cough while playing with their children, they take them away from me, but in the COVID outbreak, not only our family and friends but also strangers on the street after hearing my cough, they think I'm infected by corona.”*

“One day, I was shopping in a big store, and I was coughing all the time. A man and a woman were near me, hearing these coughs; they tightened their masks, walked away from me, and went to another part of the store. I was very embarrassed by their behavior. When I left the store, I saw them returning to the same place” (A 19 yr old girl).

Subtheme2.3 The stigma of being labeled as an addict

In addition to the stigmatization arising from possibly carrying an infectious disease, some adolescents were also concerned about coughing, raising the stigma of addiction, especially boys. They stated that they were afraid of being judged by others, especially their friends and relatives because coughing is associated with drug addiction by some people. A 16 year old boy living in a small town mentioned:

“A person who is addicted to drugs is thin and coughs a lot just like us; someone who has CF is thin and coughs, and wherever he goes, everyone thinks he is an addict. It is difficult to prove that he is not a drug user.”

Another participant reported that their cough raised questions about tobacco use: *“Sometimes while I'm coughing, my customers do tell me: “don't you want to give up the cigarettes??” that has always worried me.”* (18 yr old boy working in a cloth shop).

Main theme 3: patients' individualized coping strategies to deal with coughing

Based on the participants' experience, it has been revealed that participants used different individualized strategies concerning their coughing. Positive and negative coping strategies were adopted by the

participants. Therefore, his theme consisted of two subthemes: *constructive coping strategies*, *destructive coping strategies*.

Subtheme3.1 Constructive coping strategies

Although treatment is a time-consuming and sometimes annoying process, patients use adaptive strategies such as planning, self-care, and timely taking medication to prevent worsening symptoms, including coughing. The majority of the participants reported performing regular chest physical therapy, daily nebulizer therapies, or positive expiratory pressure when they woke up. Even two teens preparing for college entrance exams reported devoting most of their daily planning to breathing exercises and using nebulizers. For instance, one of them, who was an 18-year-old girl, stated:

"If I want to start studying at 7 in the morning, I have to wake up at 5 o'clock to take my medicine and nebulizer and become ready. I still can't begin at 7. But my classmates who want to start studying at 7 can wake up at 6:45 and begin studying at 7. This bothers me a lot."

Another participant said:

"Every time I cough hard to clear sputum. This is like a war, so I escape positively. I cough harder to get rid of the sputum, and I am tormented and annoyed. But ten minutes of annoying is better than coughing in the middle of the night." (15 yr old boy).

A 17-year-old boy stated: *"I decided not to smoke because of the information I had about its negative effect on my disease and because I knew it would lead to more cough. As far as I remember, cough always was with me. Coughs rise when I don't use the nebulizer. It starts and gets worse when I ride a motorbike or am exposed to the wind. I think about the coughs all the time, and to prevent more coughs, I decided to ride the motorbike less than before and always try to keep my distance from tobacco smokers. Because that smoke itself is harmful"*.

"I have rarely been out of the house since the disease became widespread. I used to go hiking alone or with my mom or biking in the park with my friends. But now, due to Corona, my physical activity is limited, I do not exercise at home too, and this has made me cough less, and my sputum accumulates in my lungs ..." (18 yr old girl).

Subtheme3.2 Destructive coping strategies

Several participants also stated that they avoid exercise or chest physical therapy because the activities seemed to increase their cough. We call this theme *destructive coping strategies* because of the impact of these decisions on exacerbating the symptoms of the disease. Because these personal strategies lead to poor adherence to the treatment, they can cause serious consequences. These destructive coping strategies are illustrated by the following quotes:

"I like running very much, but when I run, I start coughing, and I do not like to cough because my friends say, 'How much do you cough? What's the matter with you...? Enough'" (13 yr old girl).

"I had a bicycle, and I loved riding. One of the factors that made me leave the bike was the cough which made me tired." (18 yr old boy).

Another participant said: *"sometimes we go on vacation with family and friends and sleep there at night. I prefer not to take physiotherapy and nebulizers in the morning. Because my cough will start, and I do not want others to find out about my illness"* (14 yr old girl).

A 19-year-old girl mentioned: *"When I coughed a lot in the subway, the old lady walked away from me, and I tried to stop my cough and hold my breath because of her and the others who stared at me, but after that, I suffered from severe lung pain and I felt bad"*.

Discussion

The COVID-19 pandemic changed everyday living conditions dramatically for everyone around the globe, even healthy people. A number of key challenges emerged during the COVID-19 outbreak for adolescents with chronic health conditions, such as disrupted routines, heightened anxiety regarding health and well-being, increased risk of family stress, abuse and domestic violence, reduced access to physical and psychosocial support, and social stresses associated with school closure (Serlachius et al., 2020). Through this study, we wanted to explore the specific experiences of adolescents with CF about their cough, which itself was a public concern during the COVID outbreak. Coughing and shortness of breath are common symptoms of both CF and COVID-19.

In addition to their everyday challenges with cough, CF patients had different experiences in this outbreak. The similarity of the main manifestation of COVID and CF has further isolated these adolescents and created more psychological burdens for them and their families. During the interviews, the continuous cough often prevented them from continuing our conversation. Sometimes, they had to clear their sputum, which made them embarrassed in some cases. The interviewer had water and paper towels available, and in some cases, the interview was postponed. The participants were urged to remind the interviewer if they felt uncomfortable. Our study suggests that the felt stigma of addiction or infectious diseases was a concern and fear of the majority of participants, which was in turn a substantial factor in not disclosing the disease or trying not to cough in public. This concern was heightened since the outbreak of COVID-19, as study participants had to deal with the widespread public fear of cough, a common symptom of CF and COVID-19, and the inappropriate reactions of some people. Collaco and colleagues (2021), based on a qualitative study, found that most parents, children, and adolescents are worried about the COVID-19 and their health (Collaço et al., 2021). Although spreading the virus is a major concern in CF patients, these patients faced other challenges in the COVID-19 pandemic. Since some features of CF mimic the manifestations of COVID-19 (Ladores, 2020), people who do not know about CF or that the study participant is a CF patient may be worried or scared when encountering any shortness of breath or cough. Cough is a symptom that may have a considerable social impact following a cough-related stigma (Ward et al., 2017). Adolescents in this study were disturbed by how people behaved in public and labeled as COVID patients. People with CF reported that because of their cough, they were verbally attacked, including being told to go home and not spread COVID-19 (Ladores, 2020). Therefore in addition to physical problems, CF patients faced psychological challenges (Muther et al., 2018). The CF patients also have faced social stigmas before the COVID-19 pandemic. Researchers conducted a focus group to develop a CF-specific Stigma Scale. Their findings showed that most CF patients noted that CF symptoms (e.g. coughing) negatively affected the general public's reactions and extreme reactions such as sent home from school for CF cough were reported (Pakhale et al., 2014).

As we found out in our interviews, it seems that not only does each adolescent experience a "CF cough" differently from others, but also each adolescent encounters a variety of challenges toward coughing in different situations throughout their lives. Almost all participants complained about coughing and considered it an annoying experience, though three participants considered it normal and mentioned that they did not feel embarrassed about it. However, one of these participants changed her mind in a subsequent interview, which took place about ten months later. By that time, she was studying for the university entrance exam and preparing herself for an important competition. She complained that unpredictable coughing led to a loss of concentration.

For adolescents with CF, a distinctive and persistent cough that was usually made more intense during respiratory infections had always been with them, and they had to deal with it all the time. Cough is a complex and common symptom in patients with CF, which interferes with sleep and is sometimes referred to as a *nightmare*. Reports of

sleep disruption are an alarming and significant concern. Stenekes et al. (2009) investigated the frequency and self-management of symptoms in Cystic Fibrosis in Canada. They reported that 83% of participants experienced cough. Sixty-three percent said that cough always or sometimes affects their sleep (Stenekes et al., 2009). In another study which has been conducted in Melbourne, Australia, 33% of CF children reported awakenings on more than three nights per week. Coughing was one of the most common reasons for waking (Vandeleur et al., 2017). Van der Giessen and colleagues. Assessed nocturnal cough frequency in children with clinically stable CF during two nights in The Netherlands. They also found that more than 80% of the children experienced coughing, which was considerably more severe in the first hour of sleep but can significantly vary throughout the night and from night to night. They reported that nocturnal cough and age were correlated; the older the child, the more she/he coughed (van der Giessen et al., 2009). The results of their study align with our findings; our participants also stated that their coughs had increased in recent years, compared to their childhood.

Low body weight and clubbing fingers were two other prominent bodily appearances of CF that most participants identified. During the interview, the interviewer often saw the participants hiding their clubbing fingers under the sleeves of their clothes or fisting their hands. Later in their interviews some of the same participants expressed their concerns regarding the changes in their appearance caused by the disease. However, study participants seemed to consider coughing as a more important barrier to concealing their illness from others in casual encounters than such physical characteristics. In other qualitative studies that explored the experience of patients with CF, participants have also reported challenges with their cough. Jamison and colleagues. Summarized some of these challenges by conducting a systematic review of the experiences of CF patients. In one of the included studies, participants reported that while CF patients cough, it sounds like they are choking, which may scare other children; Therefore they reported not having many friends (Jamieson et al., 2014). A qualitative study referred to *private coughs and social coughs* in children and adolescents with CF, meaning that they refrained from coughing or taking medication in the presence of others in order to appear normal. Further, some patients were afraid that their peers, who thought illness was spread by coughing, would leave them, so they felt worried and embarrassed about it (Jamieson et al., 2014).

Patients with chronic and long-term conditions use various coping strategies to maintain their psychological health; these practices can affect their treatment adherence (Askew et al., 2017). CF is one of the most challenging long-term pediatric diseases with regard to adherence to treatment (Hommel et al., 2019). To date, there is no definitive cure for CF, but several therapies have been introduced to alleviate the symptoms of CF in the last two decades, such as CF medication, as well as exercise and nutritional recommendations (Narayanan et al., 2017). Exercise is a particularly important part of CF management (Ward et al., 2019). It is defined as the purposeful movement of the lower or upper extremities or both. Exercise interventions might include periodic huffing and coughing to clear secretions (Ward et al., 2021). The results from this study suggest that since patients started to cough following exercise, most of them reduced physical activities such as running, biking, playing football, or climbing, despite their interest in those activities.

At CF Clinic, we frequently encountered parents complaining that their teens do not adhere to their treatment. This problem existed before the COVID-19 pandemic, but isolating adolescents at home during pandemic led to a significant reduction in physical activity. Adolescence is also a time to improve adherence behaviors as a key part of adult-focused transitional care (Sawicki et al., 2015). Researchers investigated the motivating adherence in adolescents with CF in Boston. They realized that adherence to chest physical therapy and nebulizer treatments were the most challenging aspects of self-care for both adolescents and their parents (Sawicki et al., 2015). The adolescents in our study had

varying perceptions of these treatments. One participant described the nebulizer as a way to fight cough. He mentioned that he preferred to cough frequently during the day after using the nebulizer and chest physical therapy rather than interrupting his sleep in the middle of the night. But some participants also refused these treatments or did not use them properly to prevent coughs. Patients missed their treatment for a variety of reasons. Researchers conducted research on the challenges and coping mechanisms of CF patients; they found that patients missed their treatment due to interruptions in daily life, waking up late, time pressures, or discomfort about taking medication in front of others (Askew et al., 2017). While management of CF rests in the hands of the parents in childhood, adolescents must gradually assume responsibility for self-care. Nurses, physicians, physiotherapists and so forth. Should identify barriers to adherence in adolescents with CF, such as poor patient-provider communication, polypharmacy, and lack of knowledge regarding CF. They can strengthen constructive individualized coping strategies and reduce adolescents' destructive coping strategies through multidisciplinary teamwork.

Practice recommendations

Lack of public awareness about CF, widespread fear, and constant scrutiny when in public creates a potentially threatening and discriminatory situation for adolescents with CF. Multidisciplinary teams can inform and support stigmatized groups such as teens with CF. They also play an important role in actively communicating with patients with CF and their parents to identify patients who have a severe and ineffective cough due to exacerbation of the disease and refer them to a specialist.

Limitations

This study is one of the few studies conducted with adolescents with cystic fibrosis during the COVID-19 outbreak. Our study provided first-hand information about adolescents' experiences with cough, which is a common and shared symptom between COVID and CF. However, the present study had some limitations, of which the most important was the impossibility of using other methods of collecting qualitative data, such as group discussion. CF patients are susceptible to infections and must keep their distance from other CF patients, and the COVID-19 pandemic prevented the formation of such a group.

Conclusions

Coughing is a bodily defense mechanism in CF patients but, patients report that it is annoying and disrupts their daily activities and sleep. Adolescents with CF used constructive adaptive strategies to reduce these challenges, including timely use of medications, regular nebulizers, and breathing exercises. However, some teens also used destructive strategies to reduce the frequency of coughing, such as reducing physical activity, holding their breath, or rejecting chest physiotherapy.

As patients reported preferring to keep their illness secret, frequent coughing sometimes led them to disclose their illness. In the COVID-19 pandemic, cough caused major problems in social encounters and even with their peers and relatives. The stigma of COVID and keeping distance from the patients were bitter experiences for the CF patients in our study.

Conflicts of interest

The authors declare no conflicts of interest.

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Credit authorship contribution statement

JM and LT collected data. All authors participated in thematic analysis. LT and JM wrote up the final report with feedback and contribution from all authors.

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