

# Factors Affecting Disease Compliance in Adolescents with Cystic Fibrosis: A Qualitative Study

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**Cite this article as:** Dönmez H, Taş Arslan F. Factors affecting disease compliance in adolescents with cystic fibrosis: A qualitative study. *Arch Health Sci Res.* 2021;9(2):75-80.

## ABSTRACT

**Objective:** Adolescence is a period when there is a tendency for a decrease in pulmonary function in cystic fibrosis as well as a decrease in adherence to treatment plans for cystic fibrosis. The aim of this study is to evaluate the compliance experiences in adolescents with cystic fibrosis.

**Methods:** The participants of the study consisted of 8 adolescents with cystic fibrosis aged 14-21 years who were followed in the cystic fibrosis outpatient clinic of a university hospital. The case study method, one of the qualitative research methods, was used in the study, and the data were collected with a semi-structured interview form consisting of questions aimed at obtaining data on disease experiences. Voice recorder was used in the interviews. The content analysis and interpretation of the data were done by 2 researchers, adhering to Colaizzi's 7-step procedure.

**Results:** In the present study, we identified 3 main and 9 sub-themes related to disease compliance of adolescents with cystic fibrosis: disease experiences, barriers, and facilitators.

**Conclusion:** As a result of the study, a series of perceptions, behaviors, and attitudes that can help in completing and adapting to the time-consuming, complex regime in cystic fibrosis were identified. The effects of body perception and the relationships with parents and society, which are among the unknown factors related to cystic fibrosis, on disease compliance were demonstrated. Future research will focus on evaluating interventions and their effectiveness aimed at promoting better compliance in adolescents with cystic fibrosis.

**Keywords:** Disease compliance, adolescents, cystic fibrosis, qualitative study

## Introduction

Cystic fibrosis (CF) is a chronic disease with autosomal recessive inheritance, characterized by dysfunction of exocrine glands and involves multiple systems.<sup>1</sup> Care in CF focuses on increasing and preserving the respiratory functions of the child, providing optimal nutrition, and ensuring growth and development suitable for the age of the child.<sup>2</sup> Knowledge of disease and compliance with the treatment process are of vital importance in order to obtain the desired results.<sup>3</sup> In order to increase the quality of life in the treatment of CF, the requirements of chest physiotherapy, enzyme treatments, prophylactic antibiotics, mucolytics, vitamins, and increased fat should be met. At the same time, perfect individual hygiene rules that must be followed are an integral part of the treatment process. Compliance with the treatment of CF decreases by 50%, especially in the adolescence period, due to both the treatment burden and the planning of daily life according to the treatment.<sup>4</sup> It is observed that adolescents with CF have difficulty in determining their healthcare needs and the interventions applied to parents are ineffective in improving the compliance with disease management and quality of life of adolescents.<sup>5</sup> Adolescence is a period when there is a decline in pulmonary function in CF and also a tendency to decrease adherence to treatment plans for CF.<sup>6</sup> Patient compliance is an integral part of the effectiveness of pharmacotherapy, but adolescents with CF often have less than optimal compliance.<sup>7</sup> Difficulties of compliance in adolescents with CF include reduced parental involvement, time management and significant treatment burden, and adolescents' perceptions of the necessity and value of prescribed treatments.<sup>6</sup>

When determining appropriate strategies to optimize compliance for adolescents with CF, it is important to first review the barriers to compliance, as well as the evidence that affects adolescent compliance. The aim of this study was to qualitatively investigate the factors affecting

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Received: August 2, 2021  
Accepted: December 25, 2021

disease compliance and patient experiences in adolescents with CF, via in-depth interviews.

## Methods

### Design

The study was planned and conducted as a qualitative research study using a phenomenological approach. Phenomenology is a research design used in cases that we are aware of but that need to be examined more in depth. The data of the research are collected through in-depth interviews with the groups that can reflect their experiences about the phenomenon under investigation and through the answers to the questions of why and why.<sup>8-9</sup> The purpose of the interview was to explore in-depth the feelings and perspective of the interviewee with open-ended and exploratory questions.<sup>10</sup>

### Research Questions

(1) What are the opinions of adolescents with CF about the factors affecting the disease compliance process?

### Participants

Purposeful sampling method was used in this study. Purposeful sampling is a technique that is widely used in qualitative research to select appropriate cases and provide in-depth information about the situation under study, which allows for the most effective use of resources with clear boundaries.<sup>11</sup> Participants consisted of adolescents who were followed up with a diagnosis of CF at the pediatric chest diseases outpatient clinic of a university hospital in an urban center in Turkey. This clinic was chosen because it is the only center for adolescents with CF, with regular follow-up, and interventions for healthcare needs are planned in this clinic. Inclusion criteria of the study were determined as follows: adolescents who were diagnosed with CF at least 6 months ago and started treatment, those aged 12 years and over, and those who agreed to participate in the study. Those with a forced expiratory volume in 1 second value of below 40% since it is the terminal period<sup>12</sup> and those under 12 years of age were not included in the study. Although there is no definite rule for determining the sample size beforehand in qualitative studies, it is recommended to select individuals until a level of saturation and repetition is reached in the expressions of the interviewees.<sup>13</sup> Of the 18 adolescents followed up in the outpatient clinic, 12 met the inclusion criteria, and 8 adolescents verbally agreed to participate in the study, and written consent was obtained from their parents. The study was completed with a total of 8 participants. Four of the participants were girls and 4 were boys, and the mean age was  $17 \pm 6$  years. Five of the adolescents continued their high school education and two continued their university education. One participant was a high school graduate. All of the adolescents

lived in the city center and received routine treatment consisting of aerosol therapy and other treatments. There was no adolescent in the terminal period who received oxygen support.

### Data Collection

The data of the study were collected using semi-structured forms and in-depth interview methods between December 2019 and January 2020. The opinions of 3 experts, 2 academicians, and a clinical nurse were taken for the interview form. Each interview lasted for 30-45 minutes. In-depth interviews began with questions aimed to obtain data on the participants' disease experiences: "What practices do you do daily during the treatment process of your illness? What are your responsibilities? What do you think of the interventions?" (Table 1). The participants were encouraged to be honest in their experiences and express their feelings as deeply as possible. The researchers took a neutral stance and avoided influencing the participants. The interviews were conducted with the note-taking technique using a voice recording device. The recordings and the reporter notes were combined in the first 48 hours after the interview. During the interviews, one of the researchers acted as the moderator and the other as the reporter. The researchers, 1 professor, and 1 assistant professor were academicians in the field of nursing.

### Methodological Rigor

In this study, dependability and confirmability were provided for reliability, and credibility and transferability were provided for validity. In order to ensure confirmation, an external expert audit technique was used by obtaining audit permission and expert opinion. In order to ensure dependability, investigator triangulation was carried out. Three experts, 2 academicians, and a clinical nurse analyzed the transcripts independently, reached a view on the perceptions of the adolescents and determined themes and subthemes. A tape recorder was used to record all interviews, thereby increasing reliability.

The participants consisted of volunteers aged 12 and over, who were followed up with the diagnosis of CF in the pediatric chest clinic of a university hospital in Konya, and who accepted the study. Interviews with each participant lasted approximately 30-45 minutes. Study results cannot be generalized to all age groups followed up with a diagnosis of CF since CF is a disease that progresses with age.<sup>14</sup>

### Ethical Considerations

Ethics committee approval (November 27, 2019, 2019/14488 decision number) and written permission from the relevant institution (decision no: 2019/14488) were obtained to conduct the study. Written consent was obtained from the parents before the interview, and verbal consent was obtained from the adolescents after necessary explanations were made about the study.

**Table 1.** Main Questions in the Semi-structured Interview Guide

Topics	Questions
Disease compliance in CF	What responsibilities do you have in the treatment process?
	What is your opinion about the treatment?
	What do you think about your adaptation to the treatment process?
Factors complicating disease compliance in CF	What do you think about the problems you encounter while performing the interventions during the treatment process?
	What do you think about the other factors that make interventions difficult?
Factors facilitating disease compliance in CF	What do you think about the factors that increase your compliance with the treatment process?
	What do you think about support from your family in compliance with the treatment process?
Body perception in CF	Do you think there is a relationship between CF and your physical appearance? What do you think about this topic?
	How does it feel to live with CF?

CF, cystic fibrosis.

**Table 2.** The Steps of Colaizzi’s Phenomenological Data Analysis

1.	Description of all participants’ answers by careful reading*
2.	Defining the expressions directly related to the researched phenomenon**
3.	Formulation of key expressions identified**
4.	Creating theme sets from formulated expressions**
5.	Making a broad definition of the researched phenomenon**
6.	Determining the basic structure of the researched phenomenon
7.	The researcher giving feedback to the participants regarding the phenomenon determined***

\*In order to avoid data loss, the interview texts written by the reporter were read and combined by both researchers within the first 48 hours after the interviews.

\*\*The Miles and Huberman formula was used to reach a consensus on the statements and to make sense of and group them.

\*\*\*When the researchers were unsure about the meaning of a statement, they contacted the related participant and requested a verification without adding their own comments.

**Data Analysis**

Coaizzi’s phenomenological analysis method was used to analyze the data (Table 2). The Miles and Huberman formula was used to evaluate the consensus between the researchers on the themes.<sup>15</sup> The researchers had different opinions only on one of the 9 sub-themes, while they did not disagree on the main theme. The Miles and Huberman coefficient of the agreement was calculated as 0.916. After the data analysis, a consensus was reached on the 3 main themes and 9 sub-themes. In order to clarify some concepts in the data analysis process, the opinions of 1 faculty member, who is an expert in qualitative research, were obtained.

Participants were coded as P1, P2, etc.

**Results**

In the study, it was determined that adolescents with CF have many factors affecting disease compliance. As a result of data analysis, 3 main themes and sub-themes emerged: experiences of illness and emotions, barriers, and facilitating factors (Table 3).

**Experiences of Illness and Emotions**

**Despair and Anger**

It was determined that the inability to plan for the future in relation to CF and uncertainties related to the prognosis of the disease caused feelings of anger in the majority of adolescents. It was determined that the feeling of despair and hopelessness that developed due to the unmet expectations for new treatment methods and transplants decreased treatment compliance. In adolescents who stated that the care burden on their parents would increase in the terminal period and therefore they wanted to die alone, it was determined that the thought of being separated from loved ones in the last moments of life resulted in feelings of anger toward the disease.

*I cannot plan for the future, I want to be alone when I die, but I also want my mother to be with me at this most special moment and why me? [(P6)]*

**Table 3.** Theme and Sub-themes

Themes	Sub-themes
Experiences/emotions	*Despair, anger *Fear of death
Barriers/obstacles	*Body perception *Routines take too much time *Not believing in the disease and treatment *Limitation of social life
Facilitators/supports	*Strong parent–child communication *Emotional attachment to the opposite sex *Seeing him/herself as someone special

*This illness is not an obstacle for me, but I cannot look to the future with hope, will my lungs be able to withstand it? [(P2)].*

*Will we have enough time for new treatments? [(P1)].*

**The Fear of Death**

It was determined that the fear of death due to the disease positively affected treatment compliance in some of the adolescents, while the despair caused by the fear of death decreased compliance with the treatment in others. In all adolescents, the expected death due to illness was frightening. However, some of them used this situation positively and lived in a way that supported compliance with the treatment process.

*I’m afraid of dying. I felt good and did not use my medications much. However, I think that I should stick with the treatment because I heard the news of the death of some children of my age who stopped taking treatment [(P3)].*

*I do not believe in the effectiveness of the treatments, I stick to the treatment but I still can’t get enough air, but dying scares me too [(P2)].*

*When I apply the nebulizer, I feel terminally ill and I don’t want to use them, it reminds me that I will die no matter what [(P4)].*

**Body Perception**

In interviews with adolescents, male participants stated that they did not establish a relationship between body perception due to CF and disease compliance. However, female participants stated that there was a direct link between body perception and CF. For example, it was determined that finger clubbing or weight loss during active infection periods caused them to lose their belief in treatment and decreased compliance.

*I think CF is damaging my appearance, I could have been more beautiful without CF [(P4)].*

*The changes in my fingers make me think that I have reached the end of my life and my confidence in the treatment decreases [(P6)].*

*When I get sick, I lose weight very quickly, which is very disturbing [(P5)].*

**Barriers/Obstacles**

**Routines Take Too Long**

All adolescents reported that treatments took a lot of time, and aerosol administration, in particular, kept them very busy. The frequency and amount of aerosol applications increase, especially during infection periods. This prolongs the time allotted to treatment on a daily basis and they have to wake up earlier in order to comply with the

treatment. They reported that increased treatment intensity during the infection periods and getting up early in the morning tired them and therefore they had difficulty in applying some treatments. Adolescents reported that another time-related problem occurred during routine checks. They stated that they had problems with transportation due to the distant CF centers in their area of residence and that they waited for long hours at the outpatient clinics because it was the only center, and this situation caused a decrease in the frequency of going to the clinic for routine checks.

*Nebulizer applications, getting up early in the morning, takes a lot of time, especially during the infection periods, we apply much more medication [(P-3)].*

*Treatment and checkups take a lot of time. If I can get my checks done more easily, I will probably come to the hospital more often [(P-5)].*

### Not Believing in Disease and Treatment

Some of the participants stated that the information that they were sick was not correct and they did not see themselves as different from their peers. It was determined that some of the adolescents had an opinion that the treatment for CF did not work.

*I don't think the drugs work, if I did, I would use them. I'm having dyspnea all the time [(P-5)].*

*I do not believe that I am sick, I do not feel different from my peers [(P8)].*

### Limitation of Social Life

Adolescents stated that fulfillment of treatment routines for CF, practices such as wearing masks, coughing, and physiotherapy were seen as an obstacle to the continuity of social life. They reported that some of them could not go to school for education and that teachers coming home prevented them from making friends and therefore they led a more asocial life.

*I don't wear a mask or use my nebulizer because the people around me look at me like I have an infectious disease. Maybe everything would have been easier if they also accepted my illness [(P4)].*

*Bronchitol makes me cough a lot so I don't want to use it when I'm meeting with my girlfriend [(P3)].*

*Going to school and crowded environments are scary for my mother, I am homeschooled. But I miss my friends so much, when I am with them, I feel like a normal person [(P1)].*

### Facilitators/Supports

#### Parent–Child Communication

In the interviews with adolescents, it was determined that the positive relationship between the parent and the child increased the child's compliance with the disease and treatment protocol. It was determined that good parent–adolescent communication caused the adolescents to perceive the disease as a lifestyle and to look to the future with hope.

*My parents reminding me of my medications makes it easier for me to take my treatments[(P-7)].*

*When the school, teachers, relatives and most importantly my family accept Cystic Fibrosis, I feel better and it becomes easier for me to apply my treatments [(P-1)].*

### Emotional Attachment to the Other Sex

In the interviews with adolescents, it was determined that those who had emotional interactions with the opposite sex in their lives had higher disease compliance, adhered to treatment better, and had no difficulty in performing the interventions. The opposite sex was found to be a driving force in adolescents with CF that increased compliance to treatment and holding on to life and preserving lung function until new treatment modalities were available.

*My boyfriend always supports me to attend check-ups and take my medication regularly. I can do it without difficulty with his support [(P-3)].*

*I had a bad marriage because of CF. Maybe if my spouse supported me and accepted my illness, I wouldn't have to divorce. I was sticking with my treatment more regularly because of my spouse [(P4)].*

### Feeling Him/Herself as Someone Special

In the interviews with adolescents, it was determined that perception of CF as a special condition for the adolescent and seeing the treatment protocol as a necessity of life had a facilitating effect on disease compliance.

*When I think that treatment in CF is a necessity of life and I am special, it is not difficult for me to administer my medications [(P-5)].*

### Discussion

The aim of this study was to examine the views of adolescents with CF on life with CF and disease compliance. In the thematic analysis that emerged in line with in-depth interviews with adolescents, 3 main themes were determined as “experiences of illness/emotions, barriers/obstacles, and facilitators/supports.”

#### Experiences of Illness/Emotions

While the development of new treatments for CF has led to a significant improvement in survival, routine daily treatment has become complex, burdensome, and time-consuming,<sup>16</sup> but it is emphasized that the psychosocial support to be applied is more important.<sup>17</sup> The delay in expected changes in the adolescent period and the accompanying low self-esteem negatively affect disease compliance in CF, causing inadequate problem-solving skills, immature personality development, and anger.<sup>18</sup> However, the psychological problems experienced by adolescents with CF are often overlooked during the treatment process, and this results in reduced compliance with the disease and the treatment process.<sup>19</sup> In the present study, adolescents stated that the inability to plan for the future, expectation of transplant and uncertainties in the prognosis of the disease, and an increase in the expected care burden in the terminal period caused anger. The findings obtained are consistent with the literature, and deviations from normal experienced in adolescents due to CF caused anger and deterioration in disease compliance.

The concept of death in adolescents with CF is not always considered as the death of a living thing. It is sometimes described as the death of a career or the death of a relationship. This situation may manifest itself in adolescents sometimes as a positive power to hold on to life and sometimes as nonchalance.<sup>20</sup> Another theme related to the experience of illness in our study was the fear of death. The fact that CF is a life-limiting and progressive disease revealed the fear of death in our study and it was observed that although it negatively affected disease compliance in some cases, the treatment was applied more regularly in other adolescents due to this fear. All of the adolescents experienced

the fear of death due to the disease. We think that the discussion of the usually ignored concept of death in routine controls performed by pediatric nurses can be used as a driving force for adolescents with CF and as a tool to increase treatment compliance.

Daily life for people with life-threatening diseases such as CF and the problems encountered due to them have a negative effect on body perception in some adolescents.<sup>21</sup> In the present study, it was reported that CF damages body perception, especially in female adolescents with CF, and the resulting anger reduces treatment compliance. In addition, the present study showed the intensity of emotions created by body perception, especially in female adolescents. There are limited studies on this subject in the literature. Although the findings obtained are consistent with the literature, we believe that integrating body perception as a step of routine follow-up in female adolescents with CF and allowing them to express their feelings will contribute to compliance with the treatment.

### Barriers/Obstacles

Adolescents with CF stated that the time-consuming treatments negatively affected compliance with treatment. They reported that the increased treatment burden especially during the infection periods when pulmonary exacerbations are experienced, negatively affects the duration of sleep and school attendance and leads to a decrease in their compliance with the treatment protocol. Increasing the life expectancy in CF and the accompanying increase in treatment burden is a fact emphasized in many studies.<sup>17,22,23</sup> In the present study, another finding that made compliance with treatment difficult in adolescents with CF was the sub-theme of accepting the disease and believing in the treatment. Some of the adolescents with CF stated that the information about their illness was not correct, they did not see themselves as different from their healthy peers, they did not believe in the curative effect of the treatment and therefore, their treatment compliance was low. It has been reported that there is a relationship between self-efficacy and spiritual values, and that spiritual values and acceptance of disease should be evaluated in terms of school, family, relatives and social environment within the context of life with CF.<sup>24</sup> Another finding expressed as a barrier to compliance with treatment in our study was that CF limits social life. It has been reported that daily treatment routines such as wearing a mask, coughing, applying physiotherapy or applying aerosol drugs in CF limit social life and therefore, decreases compliance with treatment. Living an unpredictable life in CF and conflicts between freedoms and restrictions cause a feeling of stigma and inability to express oneself in adolescents with CF.<sup>25</sup> From this point of view, supporting socialization in young people with CF brings less psychosocial problems and increased treatment compliance.<sup>26</sup> Creating and increasing social awareness on this issue is important.

### Facilitators/Supports

It was determined that strong communication between parents and adolescents resulted in the disease being perceived as a lifestyle and led to an increase in treatment compliance. In chronic diseases such as CF, the emotional relationships of family members are affected more than their physical condition. The strong conduction skills of parents resulted in increased compliance with treatment for both the child and parents and for better protection of lung functions.<sup>27,28</sup> It is a well-known fact that parents have a strong role in maintaining the continuity of the treatment.<sup>4</sup> The findings obtained in the present study regarding the communication between parents and adolescents are supported by the literature.<sup>20,27</sup> In addition, it was concluded that creating awareness among family, friends, teachers, and society would reduce the barriers related to the disease and facilitate compliance.

Another sub-theme facilitating compliance with treatment was determined as emotional relationships with the opposite sex. It was

determined that those who had emotional relationships with the opposite sex in their lives were more compliant with treatment and had no difficulty in performing their treatment routines. In adolescents with CF, the continuity of physical, emotional, and social functionality is directly related to quality of life and disease compliance.<sup>29</sup> Positive experiences of adolescents with CF shared with the opposite sex regarding the disease are not reported to be a source of motivation in increasing treatment compliance.<sup>30</sup>

Another sub-theme facilitating disease compliance in our study was feeling special and seeing the disease as a necessity of life. In a study examining compliance in adolescents with CF, it was reported how the individual with CF perceives him/herself and how his/her perception of his/her social environment affects compliance with treatment.<sup>31</sup> It is suggested that attempts to increase treatment compliance in adolescents with CF should be aimed at increasing self-control over the disease.<sup>6,7,32</sup>

### Study Limitations

There are 2 limitations of our study. The first limitation is that due to the risk of opportunistic infection caused by *Pseudomonas aeruginosa* infections, which are frequently encountered in patients with CF, individual interviews were conducted; however, focus group interviews could not be conducted by bringing the participants together. Second, CF is a progressive disease due to the degeneration of the lungs with age. Therefore, the results obtained from our study cannot be generalized to all children followed up with a diagnosis of CF in Turkey.

### Conclusion

This study identified the disease compliance experiences of adolescents with CF and barriers and facilitating factors. A range of perceptions, behaviors, and attitudes were identified that can assist in complementing and adapting to this time-consuming, complex regime. This study revealed the effects of body perception and relationships with the other sex, which is among the unknowns under the iceberg, on disease adaptation. On the other hand, it was observed that emotions such as anger, despair, and the fear of death were experienced intensely and were important problems in performing daily routines. The new concepts introduced in this study will shed light on the updates to be made in patient follow-up protocols in CF with new studies to be planned in the future.

### Implications for Practice

In our study, the adolescents with CF conceptualized CF-related disease compliance based on 3 main themes: disease experiences/emotions, factors that facilitate and support the treatment process, and factors that complicate or block the treatment process. In order to increase disease compliance, pediatric nurses, who encounter adolescents with CF most frequently during the care process, should adopt multidisciplinary care approaches, through which adolescents can express themselves. In addition, due to the positive effects of parental support on treatment, it may be recommended to use family-centered approaches in the care process.

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**Ethics Committee Approval:** Ethics committee approval was received for this study from the ethics committee of Selçuk University (Date: November 27, 2019, Decision Number: 2019/14488).

**Informed Consent:** Written informed consent was obtained from all participants who participated in this study.

**Peer-review:** Externally peer-reviewed.

**Author Contributions:** Concept – H.D., F.T.A.; Design – H.D., F.T.A.; Supervision – F.T.A.; Resources – H.D.; Data Collection and/or Processing – H.D., F.T.A.; Analysis and/or Interpretation – H.D., F.T.A.; Literature Search – H.D.; Writing Manuscript – H.D.; Critical Review – F.T.A.

**Declaration of Interests:** No potential conflict of interest was reported by the authors.

**Funding:** The authors declared that this study has received no financial support.

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