# Effect of Compliance Educational Protocol on Parents' Adherence Caring for their Children with Cystic Fibrosis

**Fatma Ismael Mohammed[1], Seham Mohammed Abd Elaziz[2] & Doaa E, Abo zaid[3]**
[1]Lecturer of Pediatric Nursing, Faculty of Nursing, Benha University, Egypt
[2]. Assistant Professor of Pediatric Nursing, Faculty of Nursing, Benha University, Egypt.
[3]. Lecturer of Pediatric Nursing, Faculty of Nursing, Menoufia University, Egypt

**Abstract**

**Background**: Cystic fibrosis (CF) is a genetic disorder caused by mutations in the CFTR ion channel leading to abnormal secretions in multiple body systems and eventually respiratory failure. This study aimed to evaluate the compliance of educational protocol with parents' adherence to caring for their children with cystic fibrosis. A quasi-experimental design was utilized to conduct study. All available (40) parents accompanying their children with cystic fibrosis and attending the genetics outpatient and pediatric intensive care unit at El-Demerdash Hospital, affiliated with Ain Shams University Hospitals during study period (6 months). Five tools were used, namely Tool I: Personal and medical data sheet, Tool II: Self-reported practice questionnaire, Tool III: Care adherence scale, Tool IV: Barriers to treatment adherence scale and Tool V: Cystic Fibrosis Self Efficacy-Questionnaire. Study results shows that; less than three-quarters of the studied parents had poor levels of adherence to educational protocol, which improved to most of them had good levels of adherence at post and follow-up compliance educational protocol implementation. Study concluded that implementation of compliance educational protocol improved parents' adherence to caring for their children with cystic fibrosis. Study recommended similar studies on larger samples and regions to generalize the results.

**Keywords:** Adherence, Caring, Children, Compliance, Cystic Fibrosis, Educational Protocol, Parents

## Introduction

In children with cystic fibrosis, mutations in the CFTR gene result in a faulty CFTR protein. This defective protein is unable to facilitate the movement of chloride to the cell surface. Consequently, without chloride to attract water to the cell surface, the mucus in various organs thickens and becomes adhesive. This thickened mucus obstructs the air passages in the lungs, trapping bacteria and causing infections, inflammation, respiratory issues, and other complications. Moreover, the accumulation of mucus in the pancreas interferes with the production of digestive enzymes crucial for the body's food absorption, leading to malnutrition and impaired growth. Thick mucus in the liver can obstruct the bile duct, leading to liver disease. ***(Cystic Fibrosis Foundation, 2023)***.

In children diagnosed with CF, different bodily components are affected, and some organs appear to be more sensitive than others. The main risk factor for morbidity is the effect on the lungs and gastrointestinal tract. Children with cystic fibrosis commonly experience symptoms like chronic persistent cough, frequent bouts of pneumonia, difficulty gaining weight, fatty stools, intestinal obstruction at birth, and occasionally, liver and gallbladder issues. The sweat chloride test is a crucial diagnostic tool for cystic fibrosis. Managing the nutritional health of these children is a vital aspect of their long-term care, particularly when they face challenges in growing and developing properly, which is a significant concern for Egyptian children with CF. Obtaining their dietary needs in calories, macronutrients, and micronutrients presents a challenge to their long-term maintenance ***(El Falaki et al., 2021)***.

Additionally, glucose issues have been identified in young children with cystic fibrosis through the oral glucose tolerance test (OGTT). It is suggested that glucose tolerance worsens over time in childhood due to permanent harm to the function of the endocrine pancreas, which impairs insulin secretion and interferes with glucose metabolism until diabetes manifests ***(Nguyen et al., 2021)***. Even among children with the same CFTR genotype, there is a

significant diversity in how the condition develops. ***(Oates et al., 2020).***

Chronic MRSA infection worsens the health outcomes and death rates in children with cystic fibrosis. Children with CF who have enduring MRSA infections experience reduced lung capacity and struggle to recover lung function following exacerbations, necessitating elevated maintenance and antibiotic treatments ***(Oates et al., 2019).***

Cystic fibrosis is a long-term and worsening condition that needs consistent care. This care includes various treatments like physiotherapy, respiratory medications, and dietary supplements to prevent further lung damage and nutrient issues. More recently, CFTR modulators have been created to significantly enhance lung function, nutritional health, and even the lifespan of individuals, especially children with cystic fibrosis. CFTR modulators increase the amount and activity of the CFTR protein in children with CF with specific CFTR genetic mutations ***(Poore et al., 2022).***

Effective management of CF involves a range of care and treatment that prioritize maintaining lung function close to normal levels by managing respiratory infections and offering nutritional support through pancreas enzyme supplements and a balanced diet to ensure proper nutrition. Additionally, it involves strategies to promote growth and prevent, detect and treat complications. In order to accomplish these objectives, it is necessary to have a diverse team of skilled health professionals and for parents to be aware and follow the recommended care guidelines ***(Millana et al., 2019).***

Adherence refers to how well a child follows the healthcare provider's recommendations and is acknowledged as a multifaceted behavior that differs among individuals. Poor compliance with treatment is a widespread issue in healthcare that has been associated with worse results like higher rates of illness, death, and expenses in various medical conditions, including chronic diseases like (CF). ***(O'Toole et al., 2019).***

Adherence shifts the focus from making value judgments about good (compliant) or bad (noncompliant) behavior, highlighting the child's autonomy to decide whether to adhere to the prescriber's suggestions. Yet, there is a foundational belief that child and parents are encouraged to adhere to treatment guidance as it is logically beneficial for maintaining good health. This sets a standard expectation that child and parents will likely comply with the treatment regimen unless there is a valid reason for non-adherence. Failure to adhere to this assumption could lead to doubts about the child and parents' reputation as upstanding individuals with solid morals, as well as their status as a "good patient." ***(Kronish & Moise, 2017).***

In research on adherence, non-compliance is frequently categorized as either intentional or non-intentional. Intentional non-adherence happens when a child chooses not to follow their treatment on purpose, showing a lack of motivation to adhere. Inadvertent non-adherence happens when individuals unintentionally miss their treatments due to factors beyond their control, despite their desire to follow through. ***(Choudhry et al., 2017).***

**Operational definitions:**

**Cystic Fibrosis:** Cystic fibrosis is an inherited condition where specific glands produce unusually thick secretions, leading to harm in tissues and organs, particularly affecting the lungs and digestive system.

**Adherence/Compliance level:** In the healthcare field, adherence (also known as compliance) pertains to how well a pediatric patient adheres to medical and nursing recommendations. This typically relates to following medication instructions but can extend to using medical devices, self-care routines, prescribed exercises, or attending therapy sessions. Both the pediatric patient and the healthcare provider play a role in influencing adherence, with a strong nurse-pediatric patient-parent relationship being crucial in enhancing adherence levels.

**Protocols:** Organized procedures that facilitate effective and purposeful discussions,

foster mutual comprehension, and offer essential backing for teamwork, feedback, and project-oriented learning are essential for enabling collaboration to thrive.

## Significance of the study

The incidence rate of CF differs based on ethnic background, with rates ranging from 1 in 2,000 to 1 in 3,500 for Caucasians in Europe, the United States, and Canada, and lower rates observed in Hispanics (1 in 8,400 births), African Americans (1 in 15,000 births), and the Asian community in Hawaii (1 in 89,000 births). Within Egypt, approximately 3500 children were sent for evaluation of possible CF between 2007 and 2019 from various locations in the country ***(El Falaki et al., 2021).***

Adhering to care and treatment is crucial for preserving the well-being and extending the lifespan of children with CF. Yet, adherence to the treatment regimen, particularly in aspects like diet, exercise, and chest physiotherapy, proves to be challenging. Many CF children struggle to follow prescribed pancreatic enzyme replacement therapy (PERT), vitamin regimens, and respiratory exercises due to factors such as lack of motivation, time constraints, and disinterest. A key element of CF therapy is nutrition, where a high-fat diet serves as a fundamental aspect of treatment. Nonetheless, most children with CF struggle to follow the dietary guidelines, resulting in malnutrition, poor growth, decreased lung function and higher susceptibility to respiratory infections ***(Poulimeneas et al., 2020).***

## Aim of the study:

Through the following objectives, this study aimed to evaluate the effect of compliance educational protocol on parents' adherence to caring for their children with cystic fibrosis.

1.Assessing parents' knowledge and self-reported practice regarding care for their children with cystic fibrosis.

2.Assessing parents' care adherence level, barriers to treatment adherence and self-efficacy level regarding care for their children with cystic fibrosis.

3.Design and implement a compliance educational protocol to improve parents' adherence to caring for their children with cystic fibrosis.

4. Evaluate effect of implementing compliance educational protocols on parents' adherence to care for their children with cystic fibrosis.

**The research hypotheses**:

1.Parents receiving compliance educational protocol will expect improved knowledge and self-reported practice scores at the post and follow-up compliance educational protocol than pre-compliance regarding care for their children with cystic fibrosis

2.Parents receiving a compliance educational protocol will expect an improved adherence care level and self-efficacy score at post- and follow-up compliance educational protocol regarding care for their children with cystic fibrosis than at pre-compliance.

3.Parents receiving a compliance educational protocol will expect a decrease in barriers related to treatment adherence at post- and follow-up compliance educational protocol regarding care for their children with cystic fibrosis than at pre-compliance.

## Subjects and Method

### I. Technical design:

The study's technical design involves the study design, setting, subject, and tools for data collection.

### Study design:

The study employed a quasi-experimental design for its execution (pre-post and follow- up)

### Setting:

The study took place at the genetics outpatient department and (PICU) within El-Demerdash Hospital, which is associated with Ain Shams University Hospitals.

### Subjects:

All available (40) parents accompanying their children with cystic fibrosis and visiting the previously mentioned facility during study

period (6 months) after meeting the following criteria

**Inclusion criteria:** Parents had children diagnosed with cystic fibrosis, conscious and willing to participate in the study.

**Exclusion criteria:** Parents' inability to read and write and limited mental abilities.

**Tools of data collection:** Five tools were used for data collection:

**Tool (I) Personal and medical data sheet:** The researchers formulated this tool by taking into account existing pertinent literature and research to evaluate the personal and medical information of the participants (parents and children) under study. The tool was written in Arabic and consisted of three primary sections.

**Part (1): Personal characteristics of studied parents:** age, gender, academic qualification job, channels through which they obtain information about cystic fibrosis, consanguinity relationship, residence and income.

**Part (2): Personal characteristics and medical data of children:** age, gender, educational level, family history of the disease, regular attendance school days, commitment to treatment and follow-up, previous hospitalization related to cystic fibrosis and main complaints from cystic fibrosis.

**Part (3): Parents' knowledge about cystic fibrosis:**

The questionnaire consists of (8) multiple-choice questions covering various aspects : defining CF, causes, symptoms, diagnosis, treatment, complications, home care for CF children, and precautions during oxygen therapy.

**Scoring system:**

The responses provided by the parents were matched against a model key answer, where a fully correct response was awarded 2 points, a partially correct response received 1 point, and an unknown or incorrect answer was scored 0. The total knowledge scores varied from 0 to 16 points. Based on this, the level of parents' knowledge was classified into two categories: a satisfactory knowledge level (60-100%), corresponding to scores ranging from 9 to 16 points, and unsatisfactory knowledge level (<60%), with scores falling between 0 and 9 points.

**Tool II: Self-reported practice questionnaire :** Adapted from **Rajgor (2022), Datta (2022), and Cystic Fibrosis Foundation 2023,** to evaluate parents' self-reported practices in caring for children with cystic fibrosis. It consisted of 69 actions grouped into 8 main categories, including steps related to monitoring breathing patterns and symptom tracking (6 steps), oral medication administration (8 steps), nebulizer usage (11 steps), chest physiotherapy (12 steps), nutritional support (5 steps), weight measurement (10 steps), height measurement (9 steps) and infection control practices (8 steps).

**Scoring system:**

The responses provided by the parents were evaluated against a model key answer, where "done" was scored 1 and "not done" was scored 0. Total practice scores ranged from 0 to 69 points. Accordingly, the level of reported practice by parents was classified into two categories: satisfactory practice level (70% to 100%), with scores between 48 and 69 points, and unsatisfactory practice level (<70%), with scores ranging from 0 to 48 points.

**Tool III: Care adherence scale:**

It was adapted and modified based on ***(Bregnballe et al., 2011)*** to assess the level of parents' adherence to care regarding CF; it consisted of a three-option Likert scale

it includes **Reactions from parents, (6) statements** (Saying to a child you are good at taking medication, scolding the child for missing medication, reminding the child to take medication while multitasking, negotiating with the child about medication, commending the child's diligence in taking medication and verifying that the child has taken medication. **Communication about CF in family (5) statement:** (parents communicate freely about CF, parents offering strong support to their

children, parents discuss their feelings toward CF, parents discuss everything related to CF, and parents can talk about their anxiety toward CF.

**Scoring system:**

The scoring system involved rating parents' responses against a standard answer key. Consistent responses were awarded 2 points, sometimes scored 1 point, and never scored 0 points. Total adherence scale scores ranged from 0-22. So, the level of adherence was categorized as poor- adherent (< 50%) varied between 0 < 11 points; intermediate adherent (50% to < 70%) varied between 11 < 15 points and good adherent (70-100%) varied between 15-22 point.

**Tool IV: Barriers to treatment adherence scale:**

It was adapted and modified by researchers based on (***Bregnballe et al., 2011)*** to assess the level of parents' barrier to treatment adherence; it consisted of a three-option Likert scale

It includes 5 statements: difficulty finding time to give CF treatment to a child, neglecting to administer CF treatment, opting to spend time with friends instead of administering CF treatment, feeling too exhausted to administer CF treatment, and failing to administer CF treatment in public.

**Scoring system:**

The parents' responses were assessed against a benchmark answer key, with scoring as follows: consistently scored 2 points, sometimes scored 1 point, and never scored 0 points. Total barriers to treatment adherence scale scores ranged from 0-10. So, the level of barriers to treatment adherence was categorized as minor barriers (< 70%), which ranged from 0 < 7 points, and significant barriers (70-100%), which ranged from 7-10 points.

**Tool V: Cystic Fibrosis Self Efficacy-Questionnaire:**

It was adapted and modified by researchers based on ***Patel (2010***) to evaluate parents' self-efficacy concerning caring for children with CF; it consisted of a three-option Likert scale. It includes 11 items: parents feel capable of overcoming challenging situations with sufficient effort; they believe they can navigate obstacles when faced with opposition; parents can find it manageable to adhere to their objectives and successfully achieve their desired outcomes, parents are assured in their ability to handle unforeseen circumstances effectively, parents feel well-equipped to address unforeseen events by utilizing their problem-solving skills, parents receive the necessary support to tackle difficulties, with the right amount of effort invested, parents can typically find solutions to most problems they encounter, parents have the capacity to maintain composure during challenging times by drawing on their coping skills, in situations where parents encounter a problem, they typically can identify multiple solutions, parents generally feel valued for their opinions and have the capability to manage whatever obstacles they face and finally; parents typically feel respected for their viewpoints and possess the ability to navigate through any challenges that arise.

**Scoring system:**

Parents' response categories from exactly authentic scored 3 points, hardly faithful scored 2 points, and not authentic scored 1 point. Total self-efficacy scale scores ranged from 11-33. So, the level of self-efficacy was categorized as positive-self-efficacy, ≥ 75% was ≥ 25 points and negative-self-efficacy, < 75% was < 25 points.

**II. Operational design:**

The operational design incorporated a preparatory phase, content validity, tool reliability, pilot study and fieldwork.

**The preparatory phase:**

This step involved examining past and current literature at a national and international level on cystic fibrosis, along with studying theoretical concepts related to the research using various sources like textbooks, online articles, and journals to better understand different aspects of the study.

**Content validity:**

A panel consisting of three experts (professors) specializing in pediatric nursing from Benha university and Menoufia University assessed the tools' validity. This panel evaluated the instruments' content validity based on criteria including clarity, comprehensiveness, relevance, simplicity, and accuracy. All feedback provided

by the panel was taken into account, leading to some items being rephrased to reach the final version of the tools. The experts deemed the tools valid based on their evaluation.

**Reliability:**

The researchers used reliability tests to assess how consistently the tools performed by giving the same tool to the same subjects in similar situations. Cronbach's alpha coefficient was used to evaluate the internal consistency reliability of all the items in the tools. This was (0.82.) for the parents' knowledge assessment sheet. Parents' self-reported practices were deemed to have a reliability value of 0.89. The parents' barriers to care adherence scale showed a reliability of 0.88 and the reliability of the parents' cystic fibrosis self-efficacy questionnaire was (0.78).

**Ethical Considerations:**

The researchers obtained ethical approval from the scientific research ethical committee at Benha University's faculty of nursing code; REC-PN-P 45 on March 12, 2023and from the directors of the pediatric intensive care unit at Demerdash hospital. Prior to data collection, informed consent was obtained from the parents involved in the study. Parents and their children were briefed on the study's objectives and anticipated outcomes. Additionally, parents were reassured about the study's harmlessness to their children, the voluntary nature of their participation, and their right to withdraw without explanation at any point. Anonymity, confidentiality and the exclusive research use of collected data were guaranteed. The ethical principles, values, culture and beliefs of the parents and their children were respected throughout the study.

**Pilot study:**

A preliminary study was conducted with 10% of the overall participants (4 parents with children affected by cystic fibrosis). These participants were excluded from the main study to prevent any sample bias or contamination due to adjustments made in the statements. Following this, the final version of the tools was refined and the duration required to complete each tool was established.

**Fieldwork:**

The study's data collection spanned a period of six months, commencing from December 2023 and concluding in May 2024. Researchers were present two days per week for data collection during morning hours at the planed location. The data collection process involved sequential stages of assessment, planning, implementation, and evaluation as outlined below:

**Assessment phase:**

During the assessment phase, interviews were conducted with parents and their children to gather foundational data. Researchers visited the genetics outpatient and pediatric intensive care unit at Demerdash hospital on a rotational basis two days per week from 9 AM until 1:30 PM. At the start of each interview, researchers greeted the parents and children, elucidated the study's objectives, duration and procedures and obtained verbal consent before commencing data collection. Information regarding children with cystic fibrosis was sourced from both medical records and parents, lasting approximately 15 minutes, then, the researchers asked the parents to fill out a tool in by the researchers to assess the their knowledge, which took nearly 15- 20 minutes. Then, the researchers completed the parents self-reported practice questionnaire, which took nearly 25- 30 minutes. Finally, the researchers assessed the parents' adherence to treatment and its barriers; it took nearly 25- 30 minutes.

**Planning phase**

The compliance educational protocol for parents of children with cystic fibrosis was developed based on initial assessment data and research findings. This compliance protocol was tailored to meet the specific needs of parents caring for children with cystic fibrosis. It was created by adapting existing literature and ensuring that the content was clear and understandable in simple Arabic. Various teaching methods, including lectures, group discussions, demonstrations and role-playing were utilized in a dedicated teaching space. Additionally, materials like booklets, photos, presentations and other visual aids were employed to enhance parents' understanding of the information provided.

**Implementation phase:**

During the implementation phase, sessions

were conducted with a structured approach. Each session began with a review of the previous session and an outline of the goals for the current one. Arabic was used to ensure the content was accessible to parents with varying educational backgrounds. Motivation and reinforcement strategies were employed throughout the sessions to encourage active participation and engagement in the study.

The researchers developed and executed an educational protocol for parents aimed at empowering them with knowledge and guidance regarding CF. The main goal of this compliance educational intervention was to equip parents and their children with information and confidence about managing cystic fibrosis. Specific objectives of the protocol were outlined and implemented to address the actual needs of children and their parents. The parents and children involved in the study were grouped into eight groups, each comprising five parents and their children. The implementation phase involved eight sessions, with two theoretical sessions and six practical sessions conducted over two days per week, with two sessions per day, each theoretical session lasted approximately 30 minutes, while each practical session lasted around 45 minutes. The theoretical sessions, including the initial session, covered an introduction to the compliance protocol, objectives and an overview of cystic fibrosis, including its definition, causes, symptoms and diagnosis. Subsequent sessions delved into topics related to treatment, complications, home care, practical sessions including; oral medication administration, nebulizer use, chest physiotherapy, nutritional support, growth measurements and infection control practices.

**Evaluation phase:**

Following the implementation of the compliance educational protocol, a post-test was conducted to evaluate parents' knowledge and self-reported practices. This assessment took place right after the empowerment sessions were completed. Additionally, a follow-up assessment was conducted four weeks after the final session. Researchers contacted each participant via telephone and invited them to the hospital to confirm the acquired skills and ensure confidence in utilizing the provided materials. The follow-up assessment utilized the same format as the pretest to maintain consistency.

**III- Administrative Design:** The Dean of the Faculty of Nursing at Benha University provided official approval to the director of El-Demrdash hospital, which is associated with Ain Shams University, to conduct the study. In order to proceed smoothly, a detailed explanation of the study's purpose, significance, and anticipated results was presented to ensure minimal resistance.

**IV- Statistical Design:**

The gathered data was structured, arranged in tables, and analyzed statistically using Statistical Package for Social Science (SPSS) version 21 on a Windows-operating IBM-compatible computer. Descriptive statistical methods such as frequency, percentages, mean, and standard deviation were utilized. To assess significance, the Chi-square test ($\chi 2$) was employed for qualitative variables, while the correlation coefficient (r) was used for quantitative variables that were normally distributed or when one variable was qualitative. The paired t-test is used to measure the significance of the mean scores of the variables. These tests were applied to test the study hypothesis. The reliability of the study tools was assessed using Cronbach's Alpha. A significant level value was considered when $p < 0.001$, and a significant level value was considered when $p < 0.05$. No statistical significance difference was considered when $p > 0.05$.

## Results

**Table (1)** shows that; less than half (40.0%) of parents were in the age group 35- <40 years, with a mean age of 31.67 ± 4.68 years. About gender, more than two-thirds (70%) of studied parents were females. Regarding academic qualification, less than half (47.5) had a secondary certificate. Meanwhile, half (55%) of them do not work, and less than half (42.5) of them, their channels to obtain information about cystic fibrosis is from doctors and nursing staff. Moreover, 62.5 of parents had a consanguinity relationship. Also, 60% were from rural areas, and half (50.0) of parents had average income.

**Table (2):** explains that; 30% of studied children were in the age group from 5-<8 years with a mean age of 8.07± 3.84 years, more than half (57.5 %) of them were male, 52.5 of them were in primary school stage of education, and the majority (80 %) of them did not have a family history of cystic fibrosis. Also, 65.5% from children going to school had irregular attendance

to school day and 62.5 of them not committed to taking treatment and follow up. Moreover, more than two-thirds, 70% of children obtained from genetic outpatient clinics and the majority of them 82.5 had previous hospitalizations related to CF.

**Figure (1):** Shows that (87.5%, 52.5%, 70%, and 75%) of studied children their main complaint from cystic fibrosis are recurrent chest infection, failure to thrive, rhinosinusitis and cough, respectively.

**Table (3):** This table indicates that; majority (90%) of the studied parents had unknown/wrong answers regarding causes of CF at pre-program, which improved significantly to (92.5& 70.0%) of them had a complete, correct answer at post and follow up program implementation respectively. Moreover, there was a highly statistically significant difference (p <0.000) in favor of post and follow-up compliance educational protocol implementation.

**Figure (2):** Illustrates that, a significant proportion (95.0% and 82.5%) of the parents involved in the study exhibited a satisfactory level of knowledge following the post and follow-up phases of the compliance educational protocol, in contrast to the pre implementation phase.

**Table (4):** Outlines that; vast majority (97.5%) of the parents had unsatisfactory level of self-reported practice related to monitoring breathing patterns and symptom tracing at a pre-educational protocol .This improved significantly, with 82.5% and 67.5% achieving satisfactory levels during the post and follow-up phases, respectively. Additionally, there was a markedly significant improvement (p < 0.000) in favor of the post and follow-up phases of the compliance educational protocol implementation.

**Figure (3):** Demonstrates that; a significant proportion (95.0%) of the parents exhibited unsatisfactory level of self-reported practice in caring for their children with cystic fibrosis at pre phase. This percentage improved notably, with 85% and 72.5% reaching satisfactory levels during the post and follow-up phases of the compliance educational protocol respectively.

**Table (5):** Presents that; three quarter (75.0 %) of the studied parents never discuss their feelings regarding CF during a pre-compliance educational protocol, which improved to be (80%, and 72.5%) of them always discuss their feelings regarding CF during the post and follow-up compliance educational protocol implementation respectively. Moreover, there was a highly statistically significant difference (p <0.000) in favor of post and follow-up phases.

**Figure (4):** Demonstrates that, less than three quarters (72.5 %) of parents had poor levels of adherence at a pre-compliance educational protocol, which improved to be (90% and 70%) of parents had a good level of adherence at the post and follow-up compliance educational protocol implementation respectively.

**Table (6):** Presents that; three quarter (75.0 %) of the studied parents always had difficulty finding time to give their child CF treatment at a pre-compliance educational protocol, which improved to be (87.5%, and 70%) of them never had difficulty finding time to give their child CF treatment, at the post and follow up compliance educational protocol phases respectively. Moreover, there was a highly statistically significant difference (p <0.000) in favor of post and follow-up compliance educational protocol implementation.

**Figure (5) :**Shows that; three quarter (75.0%) of parents had major level of barrier to care adherence for children suffering from cystic fibrosis at a pre-compliance educational protocol, which improved to be majority (95.0% and 82.5%) of them had a minor level of barrier at the post and follow up compliance educational protocol implementation respectively.

**Table (7):** Mentions that; the mean score of the studied parents regarding feeling capable of overcoming challenging situations with sufficient effort at pre-compliance educational protocol (1.62±.867), which improved to be (2.87±.334 & 2.72±.452), at the post and follow up phases respectively. Furthermore, there was a notably significant statistical variance (p <0.000) in favor of the post and follow-up phases of the compliance educational protocol implementation

**Figure (6):** Illustrates a significant percentage (92.5%) of the parents had negative self-efficacy levels in caring for children with cystic fibrosis at pre compliance educational protocol. This percentage improved notably, with 85% and 75% exhibiting positive levels of self-efficacy during the post and follow-up phases of the compliance educational protocol, respectively

**Table (8):** Reflects that there is a statistically significant positive correlation between studied parents' total knowledge, self-reported practice, adherence care and self-efficacy pre and post-compliance educational protocol implementation (P <0.000); on contrary, there is a statistically significant negative correlation between studied parents' total level of care adherence and total barriers level pre and post compliance educational protocol implementation (P <0.000).

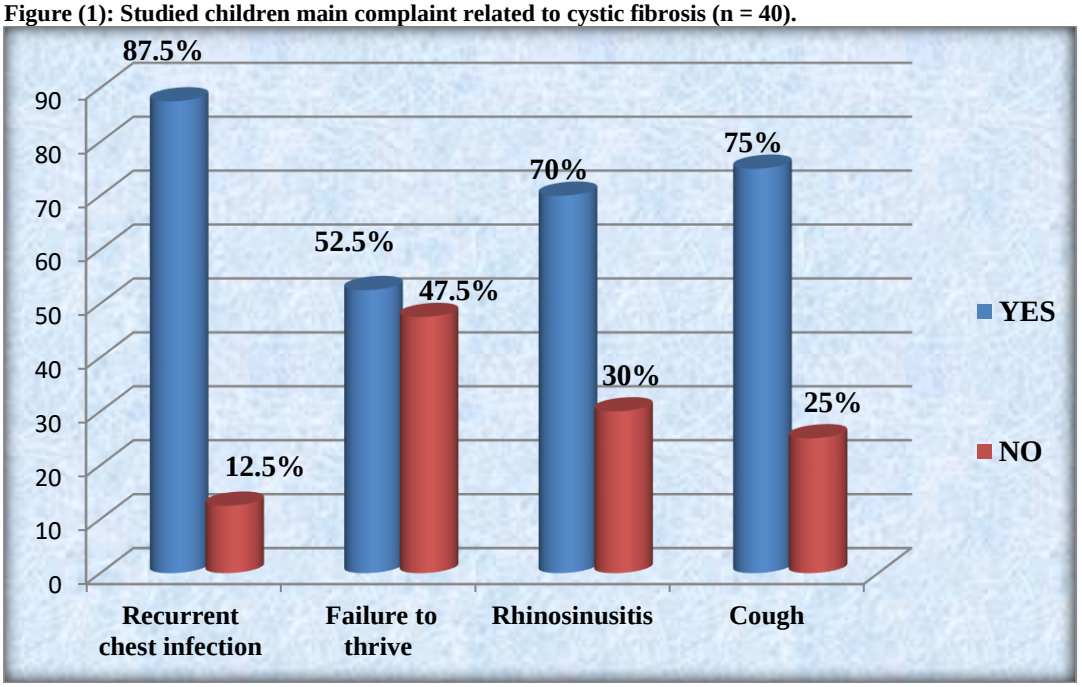
**Table (1): Distribution of the studied parents regarding their personal characteristics (n= 40)**

| Items | No. | % |
|---|---|---|
| **Age/ years** | | |
| 25- <30 | 2 | 5.0 |
| 30- <35 | 13 | 32.5 |
| 35- <40 | 16 | **40.0** |
| ≥ 40 | 9 | 22.5 |
| **Mean ± SD** | **31.67± 4.68 years** | |
| **Gender** | | |
| Male | 12 | 30.0 |
| Female | 28 | **70.0** |
| **Academic qualification** | | |
| Primary | 6 | 15.0 |
| Secondary | 19 | **47.5** |
| University | 12 | 30.0 |
| Post-graduate studies | 3 | 7.5 |
| **Job** | | |
| Work | 18 | 45.0 |
| Not work | 22 | **55.0** |
| **Channels through which parents obtain information about cystic fibrosis** | | |
| Doctor and nurse staff | 17 | **42.5** |
| Social media | 15 | 37.5 |
| Previous experience with CF | 8 | 20.0 |
| **Consanguinity relationship** | | |
| Yes | 25 | **62.5** |
| No | 15 | 37.5 |
| **Residence** | | |
| Rural | 24 | **60.0** |
| Urban | 16 | 40.0 |
| **Income** | | |
| High | 5 | 12.5 |
| Average | 20 | **50.0** |
| Low | 15 | 37.5 |

**Table (2) Distribution of the studied children according to their personal characteristics and medical data (n =40).**

| Items | No. | % |
|---|---|---|
| **Age /years** | | |
| 2-<5 | 8 | 20.0 |
| 5-<8 | 12 | **30.0** |
| 8-< 11 | 11 | 27.5 |
| 11 to 15 | 9 | 22.5 |
| **Mean ± SD** | **8.07 ± 3.84 years** | |
| **Gender** | | |
| Female | 17 | 42.5 |
| Male | 23 | **57.5** |
| **Educational stage** | | |
| Preschool | 11 | 27.5 |
| Primary school | 21 | **52.5** |
| Preparatory | 8 | 20.0 |
| **Family history of cystic fibrosis** | | |
| Yes | 8 | 20.0 |
| No | 32 | **80.0** |
| **Regular attendance on school day (n=29)** | | |
| Yes | 10 | 34.5 |
| No | 19 | **65.5** |
| **Committed to taking treatment and follow-up** | | |
| Yes | 15 | 37.5 |
| No | 25 | **62.5** |
| **Setting** | | |
| Genetic outpatient clinics | 28 | **70.0** |
| Pediatric ICU | 12 | 30.0 |
| **Previous hospitalization related to CF** | | |
| Yes | 33 | **82.5** |
| No | 7 | 17.5 |

**Figure (1): Studied children main complaint related to cystic fibrosis (n = 40).**



**Part II: Parents' knowledge regarding cystic fibrosis (n =40)**

**Table (3): Distribution of the studied parents according to their knowledge regarding the care of children suffering from cystic fibrosis through compliance educational protocol phases (n =40)**

| Items | Pre compliance educational protocol (n =40) | | | | | | Post compliance educational protocol (n =40) | | | | $X^2$ FET | P(1) value | Follow up compliance educational protocol (n =40) | | | | $X^2$ FET | P(2) value |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Complete correct answer | | Incomplete correct answer | | Unknown or wrong answer | | Complete correct answer | | Incomplete correct answer | | | | Complete correct answer | | Incomplete correct answer | | | |
| | NO. | % | NO. | % | NO. | % | NO. | % | NO. | % | | | NO. | % | NO. | % | | |
| Definition of CF | 2 | 5.0 | 5 | 12.5 | 33 | 82.5 | 35 | 87.5 | 5 | 12.5 | 62.43 | 0.000** | 25 | 62.5 | 15 | 37.5 | 57.59 | 0.000** |
| Causes of CF | 1 | 2.5 | 3 | 7.5 | 36 | **90.0** | 37 | **92.5** | 3 | 7.5 | 70.10 | 0.000** | 28 | **70.0** | 12 | 30.0 | 66.53 | 0.000** |
| Manifestation of CF | 2 | 5.0 | 4 | 10.0 | 34 | 85.0 | 38 | 95.0 | 2 | 5.0 | 67.06 | 0.000** | 32 | 80.0 | 8 | 20.0 | 61.80 | 0.000** |
| Diagnosis of CF | 0 | 0.0 | 5 | 12.5 | 35 | 87.5 | 33 | 82.5 | 7 | 17.5 | 68.33 | 0.000** | 28 | 70.0 | 12 | 30.0 | 65.88 | 0.000** |
| Treatment of CF | 4 | 10.0 | 0 | 0.0 | 36 | 90.0 | 33 | 82.5 | 7 | 17.5 | 65.73 | 0.000** | 27 | 67.5 | 13 | 32.5 | 66.06 | 0.000** |
| Complications of CF | 5 | 12.5 | 0 | 0.0 | 35 | 87.5 | 35 | 87.5 | 5 | 12.5 | 62.5 | 0.000** | 29 | 72.5 | 11 | 27.5 | 62.9 | 0.000** |
| Home care for a child suffering from CF | 6 | 15.0 | 0 | 0.0 | 34 | 85.0 | 37 | 92.5 | 3 | 7.5 | 59.34 | 0.000** | 31 | 77.5 | 9 | 22.5 | 59.89 | 0.000** |
| Precaution should be taken during oxygen therapy administration. | 1 | 2.5 | 8 | 20.0 | 31 | 77.5 | 38 | 95.0 | 2 | 5.0 | 69.70 | 0.000** | 31 | 77.5 | 9 | 22.5 | 59.18 | 0.000** |

**** A highly statistically significant difference (P <0.001) --Fisher exact test ''FET''-- P (1): between pre and post-test -- P (2): between pre and follow-up test**

**Figure (2): Total level of parents' knowledge regarding the care of children suffering from cystic fibrosis through compliance educational protocol phases (n= 40).**

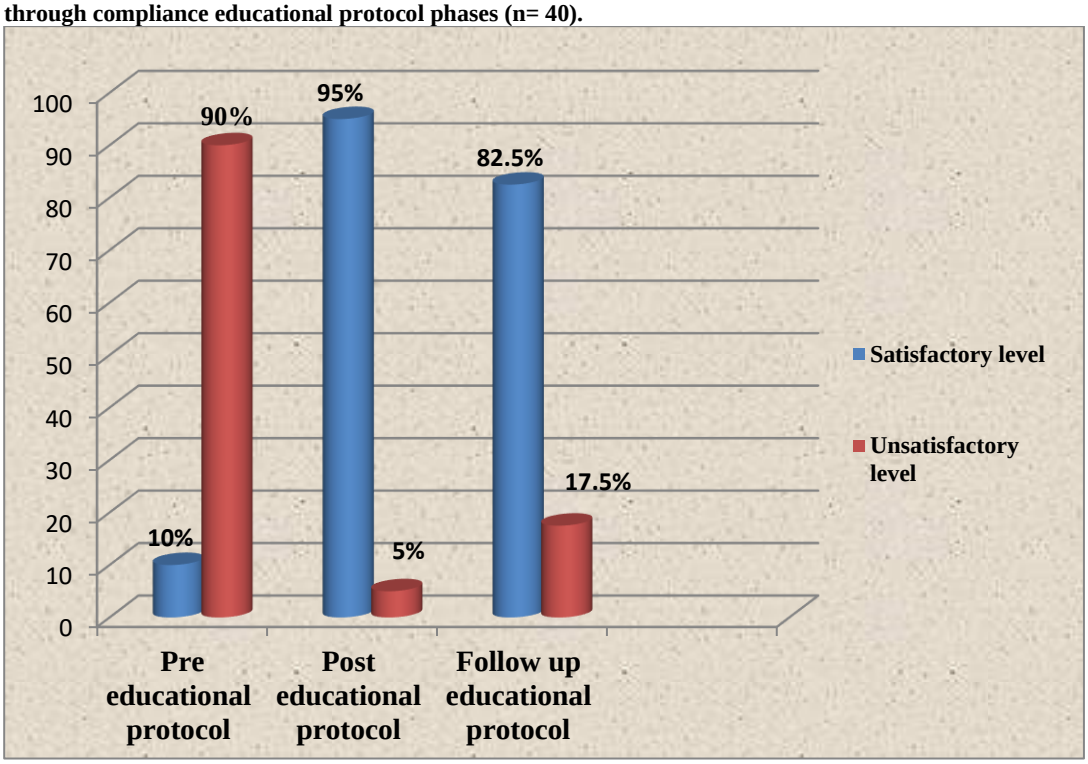


**Table (4): Distribution of the total level of the studied parents' self-reported practice regarding care of children suffering from cystic fibrosis through compliance educational protocol phases (n =40).**

| Procedure | Pre-compliance educational protocol (n =40) | | | | Post- compliance educational protocol (n =40) | | | | $X^2$ FET | P value | Follow-up compliance educational protocol (n =40) | | | | $X^2$ FET | P value |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Satisfactory ≥85% | | Unsatisfactory< 85 % | | Satisfactory ≥85% | | Unsatisfactory< 85 % | | | | Satisfactory ≥85% | | Unsatisfactory < 85 % | | | |
| | No. | % | No. | % | No. | % | No. | % | | | No. | % | No. | % | | |
| Monitoring breathing patterns and symptom tracking | 1 | 2.5 | 39 | **97.5** | 33 | **82.5** | 7 | 17.5 | 52.3 | 0.000** | 27 | **67.5** | 13 | 32.5 | 37.14 | 0.000** |
| Oral drug administration | 1 | 2.5 | 39 | 97.5 | 37 | 92.5 | 3 | 7.5 | 64.9 | 0.000** | 30 | 75.0 | 10 | 25.0 | 44.29 | 0.000** |
| Administering a nebulizer setting | 4 | 10.0 | 36 | 90.0 | 39 | 97.5 | 1 | 2.5 | 61.59 | 0.000** | 33 | 82.5 | 7 | 17.5 | 42.28 | 0.000** |
| Chest physiotherapy | 5 | 12.5 | 35 | 87.5 | 38 | 95.0 | 2 | 5.0 | 54.75 | 0.000** | 32 | 80.0 | 8 | 20.0 | 36.65 | 0.000** |
| Nutritional support | 2 | 5.0 | 38 | 95.0 | 36 | 90.0 | 4 | 10.0 | 57.94 | 0.000** | 30 | 75.0 | 10 | 25.0 | 40.83 | 0.000** |
| Weight measurement | 3 | 7.5 | 37 | 92.5 | 38 | 95.0 | 2 | 5.0 | 61.28 | 0.000** | 32 | 80.0 | 8 | 20.0 | 42.71 | 0.000** |
| Height measurement | 2 | 5.0 | 38 | 95.0 | 36 | 90.0 | 4 | 10.0 | 57.94 | 0.000** | 30 | 75.0 | 10 | 25.0 | 40.83 | 0.000** |
| Infection control practices | 4 | 10.0 | 36 | 90.0 | 37 | 92.5 | 3 | 7.5 | 54.48 | 0.000** | 27 | 67.5 | 13 | 32.5 | 27.86 | 0.000** |

**** A highly statistically significant difference (P <0.001) --Fisher exact test ''FET''-- P (1): between pre and post-test -- P (2): between pre and follow-up test**

**Figure (3): Total level of parents' self-reported practice regarding care of children suffering from cystic fibrosis through compliance educational protocol phases (n =40).**

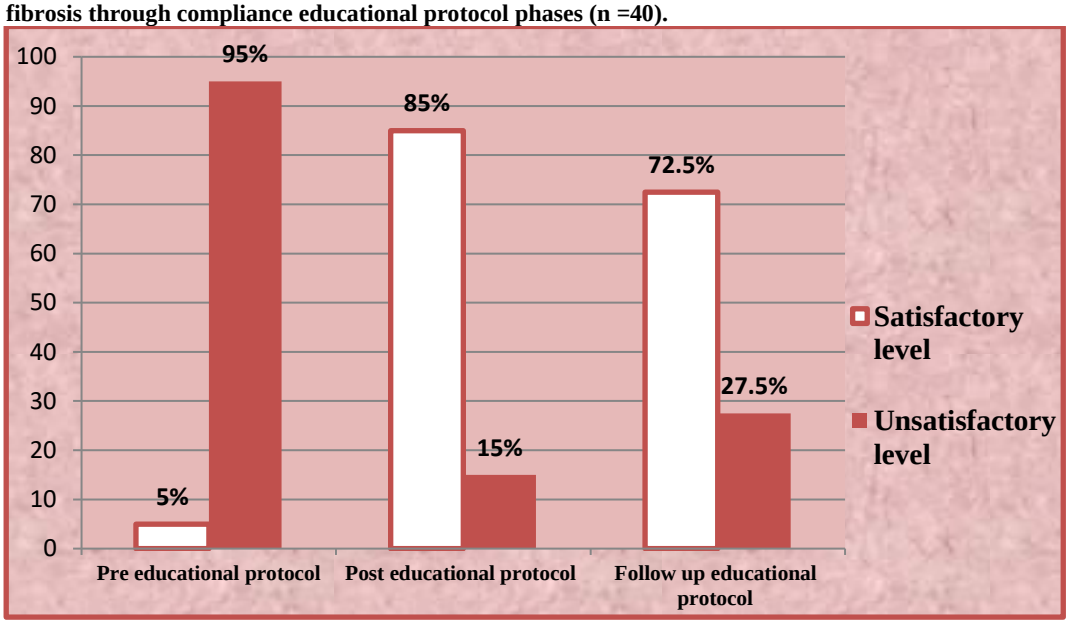


**Table (5): Distribution of the studied parents' adherence regarding the care of children suffering from cystic fibrosis through compliance educational protocol phases (n =40).**

| Items | Pre-compliance educational protocol (n =40) | | | Post- compliance educational protocol (n =40) | | | X2 FET | P (1) value | Follow-up compliance educational protocol (n =40) | | | X2 FET | P (2) value |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Always | Sometimes | Never | Always | Sometimes | Never | | | Always | Sometimes | Never | | |
| | % | % | % | % | % | % | | | % | % | % | | |
| **I-Reactions from parents** Saying to a child you are good at taking medication | 17.5 | 25.0 | 57.5 | 90.0 | 10.0 | 0.0 | 45.13 | 0.000** | 75.0 | 25.0 | 0.0 | 37.29 | 0.000** |
| Scolds child for missing medication | 7.5 | 35.0 | 57.5 | 90.0 | 7.5 | 2.5 | 55.20 | 0.000** | 72.5 | 25.0 | 2.5 | 41.95 | 0.000** |
| Reminding the child to take medication while multitasking | 55.0 | 17.5 | 27.5 | 100.0 | 0.0 | 0.0 | 23.22 | 0.000** | 80.0 | 20.0 | 0.0 | 12.91 | 0.002** |
| Negotiating with the child about medication | 17.5 | 17.5 | 65.0 | 90.0 | 10.0 | 0.0 | 46.37 | 0.000** | 75.0 | 25.0 | 0.0 | 40.82 | 0.000** |
| Commending the child's diligence in taking medication | 7.5 | 47.5 | 45.0 | 90.0 | 10.0 | 0.0 | 55.70 | 0.000** | 72.5 | 27.5 | 0.0 | 41.25 | 0.000** |
| Verifying that the child has taken medication | 35.0 | 37.5 | 27.5 | 95.0 | 5.0 | 0.0 | 32.01 | 0.000** | 75.0 | 25.0 | 0.0 | 17.81 | 0.000** |
| **II-Communication about CF in the family** Parents communicate freely about CF | 2.5 | 30.0 | 67.5 | 92.5 | 7.5 | 0.0 | 66.50 | 0.000** | 75.0 | 25.0 | 0.0 | 54.31 | 0.000** |
| Parents offering strong support to their children | 5.0 | 37.5 | 57.5 | 82.5 | 15.0 | 2.5 | 51.48 | 0.000** | 72.5 | 25.0 | 2.5 | 44.68 | 0.000** |
| Parents discuss their feelings toward CF | 12.5 | 12.5 | **75.0** | **80.0** | 20.0 | 0.0 | 50.39 | 0.000** | **72.5** | 27.5 | 0.0 | 49.19 | 0.000** |
| -Parents discuss everything related to CF | 12.5 | 25.0 | 62.5 | 87.5 | 12.5 | 0.0 | 49.16 | 0.000** | 77.5 | 22.5 | 0.0 | 43.83 | 0.000** |
| Parents can talk about their anxiety concerning CF. | 17.5 | 22.5 | 60.0 | 90.0 | 10.0 | 0.0 | 45.48 | 0.000** | 80.0 | 20.0 | 0.0 | 40.08 | 0.000** |

**** A highly statistically significant difference (P <0.001) --Fisher exact test ''FET''-- P (1): between pre and post-test -- P (2): between pre and follow-up test**

**Figure (4): Total level of studied parents' adherence related to care of their children suffering from cystic fibrosis through compliance educational protocol phases (n =40).**

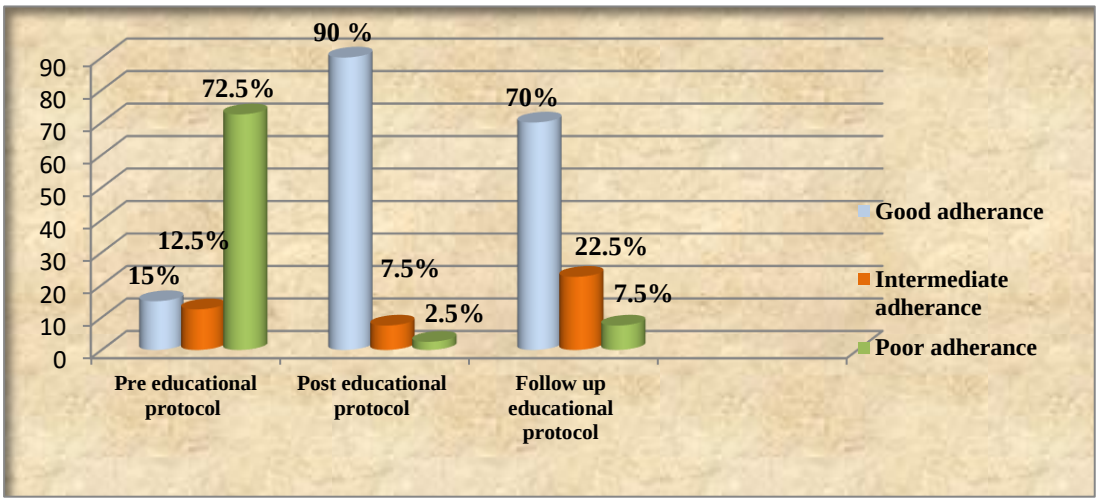


**Table (6) Distribution of the studied parents' barriers to care adherence for children suffering from cystic fibrosis through compliance educational protocol phases (n =40).**

| Items | Pre-educational protocol (n =40) | | | Post-educational protocol (n =40) | | | X2 FET | P (1) value | Follow-up educational protocol (n =40) | | | X2 FET | P (2) value |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Always | Sometimes | Never | Always | Sometimes | Never | | | Always | Sometimes | Never | | |
| | % | % | % | % | % | % | | | % | % | % | | |
| Difficulty finding time to give CF treatment to a child | **75.0** | 17.5 | 7.5 | 7.5 | 5.0 | **87.5** | 51.81 | 0.000** | 7.5 | 22.5 | **70.0** | 42.50 | 0.000** |
| Neglecting to administer CF treatment | 67.5 | 20.0 | 12.5 | 5.0 | 5.0 | 90.0 | 48.5 | 0.000** | 5.0 | 20.0 | 75.0 | 39.40 | 0.000** |
| Opting to spend time with friends instead of administering CF treatment | 62.5 | 27.5 | 10.0 | 5.0 | 15.0 | 80.0 | 42.84 | 0.000** | 5.0 | 27.5 | 67.5 | 36.65 | 0.000** |
| Feeling too exhausted to administer CF treatment | 62.5 | 32.5 | 5.0 | 7.5 | 5.0 | 87.5 | 54.7 | 0.000** | 10.0 | 22.5 | 67.5 | 37.4 | 0.000** |
| Failing to administer CF treatment in public | 75.0 | 17.5 | 7.5 | 7.5 | 10.0 | 82.5 | 47.90 | 0.000** | 7.5 | 20.0 | 72.5 | 43.28 | 0.000** |

**** A highly statistically significant difference (P <0.001) --Fisher exact test ''FET''-- P (1): between pre and post-test -- P (2): between pre and follow-up test**

**Figure (5): Total barrier level of studied parents to care adherence for children suffering from cystic fibrosis thorough compliance educational protocol phases (n =40).**

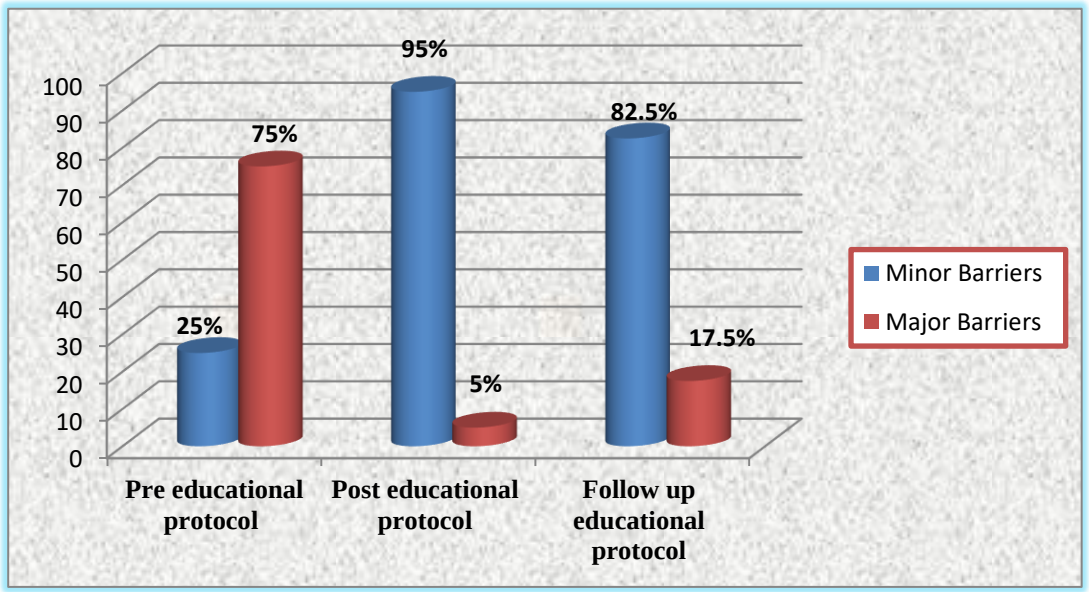


**Table (7): Mean score of the studied parents' self-efficacy regarding the care of children suffering from cystic fibrosis through compliance educational protocol phases (n =40).**

| Items | Pre compliance educational protocol (n =40) | Post compliance educational protocol (n =40) | Paired t-test | P (1) value | Follow up compliance educational protocol (n =40) | Paired t-test | P (2) value |
|---|---|---|---|---|---|---|---|
| | Mean ± SD | Mean ± SD | | | Mean ± SD | | |
| Parents feel capable of overcoming challenging situations with sufficient effort. | **1.62±.867** | **2.87±.334** | 9.14 | 0.000** | **2.72±.452** | 8.42 | 0.000** |
| Parents believe they can navigate obstacles when faced with opposition. | 1.65±.764 | 2.77±.422 | 9.81 | 0.000** | 2.52±.505 | 6.41 | 0.000** |
| Parents can find it manageable to adhere to their objectives and successfully achieve their desired outcomes. | 1.67±.693 | 2.65±.483 | 10.69 | 0.000** | 2.47±.501 | 8.32 | 0.000** |
| Parents are assured in their ability to handle unforeseen circumstances effectively | 1.70±.648 | 2.70±.464 | 9.30 | 0.000** | 2.53±.503 | 7.32 | 0.000** |
| Parents feel well-equipped to address unforeseen events by utilizing their problem-solving skills. | 1.67±.615 | 2.67±.474 | 10.55 | 0.000** | 2.50±.506 | 8.20 | 0.000** |
| Parents receive the necessary support to tackle difficulties | 1.69±.615 | 2.62±.490 | 10.06 | 0.000** | 2.40±.496 | 7.66 | 0.000** |
| With the right amount of effort invested, parents can typically find solutions to most problems they encounter. | 1.72±.684 | 2.60±.496 | 9.63 | 0.000** | 2.42±.495 | 6.44 | 0.000** |
| Parents have the capacity to maintain composure during challenging times by drawing on their coping skills. | 1.74±.598 | 2.57±.506 | 10.07 | 0.000** | 2.45±.496 | 6.50 | 0.000** |
| In situations where parents encounter a problem, they typically can identify multiple solutions. | 1.70±.516 | 2.62±.490 | 11.13 | 0.000** | 2.40±.486 | 6.82 | 0.000** |
| Parents generally feel valued for their opinions and have the capability to manage whatever obstacles they face. | 1.72±.597 | 2.50±.504 | 7.91 | 0.000** | 2.32±.474 | 5.64 | 0.000** |
| Parents typically feel respected for their viewpoints and possess the ability to navigate through any challenges that arise. | 1.77±.576 | 2.55±.503 | 9.24 | 0.000** | 2.40±.496 | 6.93 | 0.000** |

**** A highly statistically significant difference (P <0.001) -- P (1): between pre and post-test --P (2): between pre and follow-up**

**Figure (6): Total self-efficacy levels of the parents under study regarding care of children with cystic fibrosis across different phases of the compliance educational protocol (n = 40).**

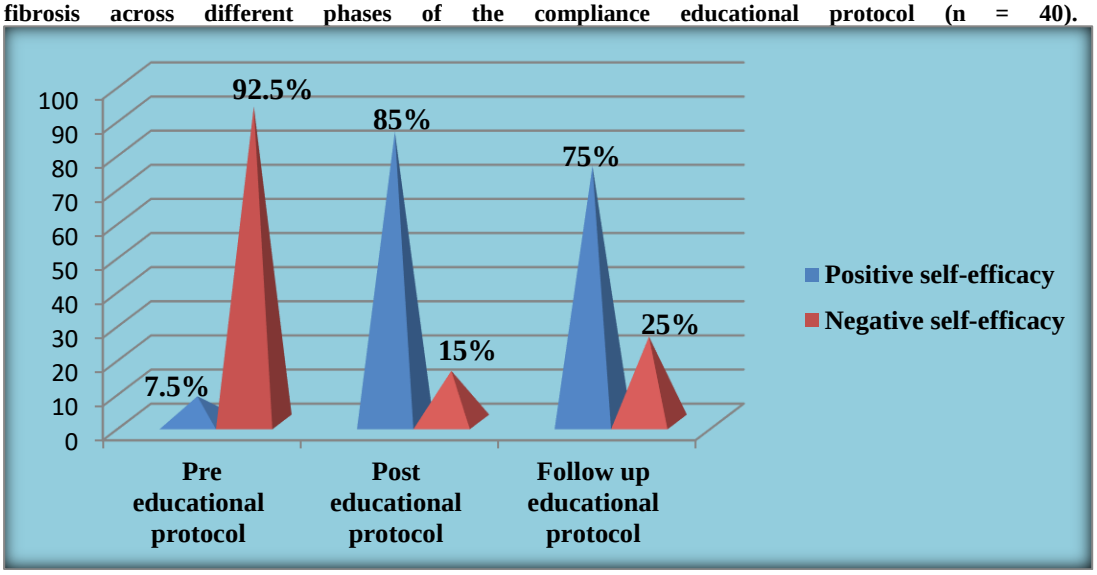



**Table (8): Correlation between the parents' overall knowledge, self-reported practice, adherence to care, self-efficacy, and barriers scores pre and post the implementation of the compliance educational protocol (n=40).**

| Items | Pearson correlation coefficient | | | |
|---|---|---|---|---|
| | Pre- implementation of the compliance educational protocol | | Post- implementation of the compliance educational protocol | |
| | r | P-value | r | P-value |
| Knowledge – self-reported practice | .901 | .000** | .972 | .000** |
| Knowledge – self-efficacy | .708 | .000** | .883 | .000** |
| Knowledge- adherence care | .845 | .000** | .931 | .000** |
| Self-reported practice- self-efficacy | .631 | .000** | .870 | .000** |
| Self-reported practice- adherence care | .795 | .000** | .920 | .000** |
| Adherence care- total barriers | -.973 | .000** | -.959 | .000** |

**** The correlation is deemed statistically significant at the 0.01 level with a 2 tailed analysis.**

## Discussion

Cystic fibrosis is a disease that shortens life and is burdensome, necessitating intricate knowledge for its management. There is a lack of understanding among parents that could result in their inability to properly follow through with treatment and adequately pass on care responsibilities to their children. Properly taking care of a child with cystic fibrosis (CF) is intricate and requires a significant amount of time. The daily routine for CF generally starts in the morning, finishes at bedtime and can demand more than an hour a day for both parent and child. Treatment plans typically involve taking oral and nebulized drugs, practicing chest physiotherapy, participating in exercise, and following a high fat and calorie diet. It could also involve using extra enzymes, getting

nutrients through an IV and finishing treatment (**ShanthiKumar et al., 2021)**.

About gender of the studied parents, the study results revealed that more than two-thirds of them were females. This result agreed with **Richards et al. (2022)** who implementing adherence MAP for care of children with cystic fibrosis and revealed that majority of mothers responsible for caring of their children with cystic fibrosis.

Regarding gender of children under study, the study findings indicated that more than half of the them were males; this result agreed with **Bonfim et al. (2020)** who study treatment adherence between children and adolescents in reference center of cystic fibrosis and found that more than half of children with cystic fibrosis were males.

Toward children main complaint related to cystic fibrosis; the study results showed that; majority of studied children had recurrent chest infection and more than half suffer from failure to thrive, this finding supported by **El Attar et al., (2017):** who assess growth of Egyptian children diagnosed with cystic fibrosis and found that one third of studied children suffer from failure to thrive and less than three quarter of them had recurrent chest infection as the main complaint.

Also; the study finding clarified that; less than three quarter of studied children had rhinosinusitis. This finding supported by **Jayawardena, et al., (2020):** who study management of rhinosinusitis in pediatric patient with cystic fibrosis, and reported that; occurrence of rhinosinusitis is nearly 100% among children with cystic fibrosis (CF).

Regarding parents' knowledge toward care of children with cystic fibrosis, the study's findings indicated that majority of the parents involved in the study exhibited a satisfactory level of knowledge following the post and follow-up phases of the compliance educational protocol, in contrast to the pre implementation phase. From the researcher's point of view, this might be because of compliance educational programs succeeded in enhancing parents' knowledge and the ability of the researchers to improve parents' motivation to know more about their child's health condition to prevent complications and due to using various teaching methods as group discussions and lectures. This study results was supported by **Bishay and Sawicki., (2016),** who studied treatment strategies to increase adherence in adolescent with cystic fibrosis, and reported that; increased knowledge of intervention group about airway clearance and improved self-reported adherence about aerosol medications.

On the same line; this results congruent with **Ali et al., (2024):** who assess designed nursing intervention program to improve awareness of parents had children with cystic fibrosis and founded that; most of the studied parents had satisfactory level of knowledge post program.

Regarding parents' reported practice in administering a nebulizer setting, the study findings indicated a significant statistical difference across the pre-, post- and follow-up phases of the compliance educational protocol. Initially, many parents exhibited inadequate practice, which notably improved to a majority demonstrating adequate practice during the post- and follow-up stages of the compliance educational protocol. The researchers speculate that this improvement could be attributed to heightened awareness among parents regarding the significance of nebulizer care in reducing contamination with pathogens. This result congruent with **Loukou et al. (2020),** who study care of nebulizer and inhalation technique in children with cystic fibrosis and reported that only one-third of children and their families achieved high scores for their inhalation technique and nebulizer disinfection/maintenance so that; regular review and ongoing education are still necessary for them.

In relation to parents' reported practice regarding chest physiotherapy, the study results indicated a significant statistical variance across the pre-, post-, and follow-up phases of the compliance educational protocol. Initially, most parents demonstrated inadequate practice, which notably improved to most parents exhibiting adequate practice during the post- and follow-up phases. This might be because

the compliance educational protocol made refreshments in parents' knowledge, which in turn led to an improvement in their practice level. This finding was supported by Al-**Masry et al. (2018),** who compared practices of pediatric nurses and mothers with children having respiratory problems toward chest physiotherapy and finding that; all mothers were incapable in performing chest physiotherapy.

Regarding total level of parents' self-reported practice toward care of children suffering from cystic fibrosis through compliance educational protocol the study finding demonstrated that; a significant proportion of the parents exhibited unsatisfactory level of self-reported practice at pre phase. Then this percentage improved notably, to majority reaching satisfactory levels during the post and follow-up phases. This result congruent with **Ali et al., (2024):** who reported that; the majority of parents had unsatisfactory hand hygiene practices, cleaning and evaluating the condition of the skin before program, which improved to, most of them reported satisfactory level of practice post program.

Concerning the total level of studied parents' adherence regarding the care of children suffering from cystic fibrosis through compliance educational protocol phases, the study results showed that; less than three-quarters of the studied parents had a poor level of adherence at pre- phase, which improved to majority of them had a good level of adherence at post and follow up compliance educational protocol implementation. From the researcher's point of view, this might be attributed to the improvement of parents' knowledge and practice level. These results context with **Goodfellow et al. (2015),** who study treatment adherence in children and adolescents diagnosed with cystic fibrosis and identified that; less than three quarter of studied children had low adherers to enzyme supplements, less than two third of them exhibited low adherence to vitamins, and half of them were categorized as low adherers to chest physiotherapy.

In relation to the total level of studied parents' barrier to care adherence regarding care of children suffering from cystic fibrosis through compliance educational protocol phases, the study results shows that three-quarters of parents under study had major level of barrier at a pre- phase which improved to be majority of them had a minor level of barrier at post and follow up compliance educational protocol implementation, this might be attributed to improve parents' awareness about the importance of care adherence to reduce fatal complications and improve health outcomes of children with cystic fibrosis. This result context with **(Durkin et al., 2022)** who studied nutritional recommendations adherence for adolescents with cystic fibrosis and revealed that; parents perceived more obstacles related to enzyme and medication usage. Parents highlighted substantial hindrances associated with enzyme use due to the frequent dosages required throughout the day.

On the same line; **Helms et al., (2017)** also reported that; children with chronic illnesses rely on their caregivers for assistance in managing their health condition. Hence, obstacles within the family environment can negatively impact a child or teenager's adherence to their medical routines. Family-related challenges may encompass inadequate health literacy or understanding of treatments, medication shortages, limited access to healthcare information, and financial constraints hindering the affordability of medications. So that caregivers' identified obstacles to adherence need to be assessed and dealt with to enhance health status of children with cystic fibrosis.

Also **Jackson et al., (2020)** explained that, barriers to adherence in various systems tend to remain constant. Without intervention, they are likely to continue negatively impacting adherence. It is essential to create effective strategies to tackle and lessen potential long-lasting obstacles, decrease ongoing negative consequences, improve compliance and encourage favorable health results.

Regarding parents' self-efficacy toward care of children suffering from cystic fibrosis through compliance educational protocol phases, the study finding mentions that; majority of parents had negative self-efficacy levels in caring for children with cystic fibrosis

at pre compliance educational protocol. This percentage improved notably, to majority of them exhibiting positive levels of self-efficacy during the post and follow-up phases of the compliance educational protocol. These results agreed with **Mussaffi et al. (2021), who** researching the effectiveness of interventions to enhance compliance in teenagers and adults with cystic Fibrosis, discovered that a problem-solving approach can enhance adherence to medical regimens by addressing obstacles specific to the children' requirements and aspirations. **More over** ; **Benedetto and Ingrassia (2018)**: reported that; parents' self-belief in their abilities becomes an important factor in understanding the differences in the level of care they provide to their children.

Toward correlation between the parents' overall knowledge, self-reported practice, adherence to care, self-efficacy, and barriers scores pre and post the implementation of the compliance educational protocol; the study finding mentioned that; there is a statistically significant positive correlation between studied parents' total knowledge, self-reported practice, adherence care and self-efficacy pre and post-compliance educational protocol implementation on contrary, there is a statistically significant negative correlation between studied parents' total level of care adherence and total barriers level pre and post compliance educational protocol implementation . This could be because of the favorable impact of the compliance program, which leads to motivating the parent to adhere to the treatment plan following the closure of the knowledge gap.

## Conclusion:

Based on this study's findings, the majority of parents had satisfactory knowledge and adequate levels of self-reported practice at post and follow-up compliance educational protocol implementation, furthermore; majority of parents had good adherence and minor barriers at the post and follow-up compliance educational protocol implementation. A favorable relationship was observed among the parents' knowledge, self-reported practice, adherence levels, and barriers influencing their commitment to caring for children with cystic fibrosis. Additionally, the compliance educational protocol enhanced parents' adherence to the care of their children with cystic fibrosis.

## Recommendations:

- Availability and dissemination of handouts and pamphlets for parents with cystic fibrosis to raise their level of knowledge and self-reported practice, level of adherence and decrease of level barriers for parents' adherence caring for their children with cystic fibrosis.

-Similar studies are encouraged on larger samples and regions to generalize the results.

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