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The Health-Related Stigma, Self-Efficacy and Treatment Adherence in Children with Cystic Fibrosis in the West Bank, Palestine

Fida Jaser Aqel Turkman

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Prepared by:

Fida Jaser Aqel Turkman

BSc. Nursing Science/ Al-Quds university/ Palestine

Supervisor:

Dr. Kawther Shaban Alayasa.

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Student name: Fida Jaser Aqel Turkman

Registration No: 21811276

Supervisor: Dr. Kawther Shaban Alayasa.

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The names and signatures of the examining committee members are as follows:

1- Head of Committee:	Dr. Kawther Alayasa	Signature:
3- Internal Examiner:	Dr. Maysa' Al Austa	Signature:
4- External Examiner:	Dr. Mohammad Mer'ie	Signature:

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Dedication

To my mother who stays by me and supports me in every step.

To my father who lives in the sky, but still, I believe he will always be with me in the depth of my heart.

To my family, they are my backbone in this life, thanks for your presence in my life.

To my love, the one and only person, who supports, believes and pushes me up.

To my family at work, thanks for helping me, especially my head nurse Samar, thank for everything, you are my role model.

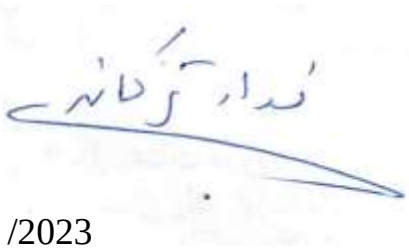
To Dr. Nasreen Roman, thank you for supporting me, you are the best.

To my friends who still believe in me and support me, you are very special for me.

Declaration

I certify that this thesis submitted for the degree of master is the result of my own research, except where otherwise acknowledged, and that this thesis (or any part of the same) has not been submitted for a higher degree to any other university or institute.

Name: Fida Jaser Aqel Turkman

Signature: 

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To my family who supports me

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To my indeed friends who haven’t let me down

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To Dr. Nisreen Rumman who helped me to reach out to the patients, thank you for supporting and believing in me

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List of Abbreviations

ADL	Activities of daily living
CF	Cystic fibrosis
CFTR	Cystic fibrosis trans-membranous conductance regulator
NSB	Newborn screening
SD	Standard deviation
KMO	Kaiser-Meyer-Olkin

Abstract

Background: Cystic fibrosis (CF) is a genetic autosomal recessive disease that affects several systems such as the respiratory, the digestive, the urinary and the reproductive systems. Children who have CF face many challenges due to the consequences of CF such as difficulties in doing activities like their peers in community, due to the roles of taking the treatment of CF and side-effects that may happen due to CF or the treatment. These challenges affect the well-being state of children on the physical, emotional, psychological and social domains. Due to these challenges, stigma from disease may happen to children who could affect the level of adherence to treatment and the self-efficacy of the child.

Objectives: This study was conducted to assess self-reported treatment adherence and self-efficacy that children with CF have, assessing level of perceived stigma for children with CF, assessing factors influencing adherence, self-efficacy and stigma for children with CF. In addition, the study aims at examining correlations of adherence (taking medications, diet, and exercise routines) with perceived stigma for children with cystic fibrosis, examining correlations of adherence and self-efficacy (taking medications, diet, and exercise routines) with sociodemographic characteristics and to examine potential correlation between perceived stigma in children with CF and sociodemographic characteristics.

Methodology: a cross-sectional quantitative design was used to assess level of stigma, adherence and self-efficacy of children aged from 8-16 years who have CF in West Bank-Palestine. A structured interview was done with each child and parents using a questionnaire containing demographic data for the child and the parent, stigma scale, adherence scale and self-efficacy scale.

Results: Fifty-two children were interviewed A questionnaire containing stigma, adherence and self-efficacy scales was used which each scale has variables, each variable

range from 1-4. According to the data analysis, results were displayed as mean, SD and range, stigma (2.13, 0.35, 1.25-2.88), adherence (2.97, 0.55, 1.42-3.8) and self-efficacy (2.48, 0.6, 1.33-3.83). when children and parents' characteristics were analyzed, there was a relation between stigma in children with CF and place of residence and work state of father with p-value (0.56, 0.2).

Conclusion: children who have CF in west-banks has moderate level of health-related stigma, self-efficacy and treatment adherence. With no relation between these variables. Also, place of residency and economic state for child's parents paly and important role in perceived stigma, adherence to treatment and self-efficacy.

وصمة العار المتعلقة بالصحة والكفاءة الذاتية والالتزام بالعلاج لدى اطفال مرضى التليف الكيسي في الضفة الغربية في فلسطين.

إعداد: فداء جاسر عقل تركمان.

المشرف: د. كوثر العيسى.

الملخص:

التليف الكيسي هو مرض وراثي متنحي يصيب عدة أجهزة مثل الجهاز التنفسي والجهاز الهضمي والبنكرياس والكبد والكلى والجهاز التناسلي. يواجه الأطفال المصابون بالتليف الكيسي العديد من التحديات بسبب مضاعفات التليف الكيسي مثل صعوبة القيام بأنشطة مثل اقرانهم من حولهم، وذلك بسبب روتين تناول علاج التليف الكيسي والآثار الجانبية التي قد تحدث بسبب المرض أو علاجه. تؤثر هذه الصعوبات على حياة الأطفال من الناحية الجسدية والعاطفية والنفسية والاجتماعية، وقد يواجه الاطفال الوصمة بسبب هذه الصعوبات، وقد يضعف الالتزام بالعلاج وتنخفض الكفاءة الذاتية للطفل.

الهدف: أجريت هذه الدراسة لتقييم الالتزام بالعلاج الذاتي والكفاءة الذاتية لدى الأطفال المصابون بالتليف الكيسي، وتقييم مستوى الوصمة عندهم، وتقييم العوامل التي تؤثر على الالتزام والكفاءة الذاتية، وكذلك الوصمة عند اولئك الأطفال، وايضا تهدف الدراسة الى بحث الرابط بين الالتزام (تناول الأدوية، والنظام الغذائي، وإجراءات التمارين الرياضية) مع الوصمة لدى الأطفال المصابين بالتليف الكيسي، واللعلاقة بين الالتزام والكفاءة الذاتية (روتين تناول الأدوية والنظام الغذائي والتمارين) مع الخصائص الاجتماعية والديموغرافية وفحص الرابط المحتمل بين الوصمة لدى الأطفال المصابين بالتليف الكيسي والخصائص الاجتماعية الديموغرافية.

المنهجية: استخدم تصميم كمي مقطعي لتقييم مستوى الوصمة والالتزام والكفاءة الذاتية لدى الأطفال الذين تتراوح أعمارهم بين 8–16 سنة والذين يعانون من التليف الكيسي في الضفة الغربية في فلسطين. إجريت مقابلات شبه منظمة مع كل طفل وأولياء الأمور باستخدام استمارة تحتوي على بيانات ديموغرافية للطفل والوالدين، ومقياس الوصمة ومقياس الالتزام ومقياس الكفاءة الذاتية.

النتائج: قابلت الباحثة 53 طفلاً لتعبئة استبيان يحتوي على مقاييس الوصمة والالتزام والكفاءة الذاتية، ولكل مقياس متغيرات من 1–4 ، بمشاركة 30 ذكرًا و 23 أنثى. لدى الأطفال مستوى معتدل من الوصمة والالتزام والكفاءة الذاتية .

الخلاصة: لدى الأطفال المصابون بالتليف الكيسي مستويات معتدلة من الوصمة والالتزام والكفاءة الذاتية وفقًا لتحليل الاستبيان.

Chapter One:

Introduction

1.1 Background

Cystic fibrosis (CF) is a genetic autosomal recessive disease that affects several systems such as the respiratory system, the digestive system including the pancreas and the liver, the urinary and the reproductive systems (Ong et al., 2017). The severe effects of cystic fibrosis on lung increase morbidity and mortality to children with cystic fibrosis (Brown et al., 2017).

Chronically ill children are mostly dependent on family members for care and treatment because they spend all the time at home (Jessup et al., 2018). Environment is an important factor in making cystic fibrosis a challenging disease for children's families, a matter that threatens the well-being of children, as well as the well-being of their families. This effect reflects on family functioning and adherence for treatment (Muther et al., 2018) .

The treatment of CF aims at relieving its signs and symptoms. This can be achieved by managing diet, air way , physiotherapy and medications such as anti-inflammatory drugs and antibiotics (Narayanan et al., 2017); (Jones et al., 2015).

Several remedies are currently available for managing CF, such as inhaled medications, oral, and intravenous antibiotics, anti-inflammatory therapies, pancreatic enzymes, and

supplemental nutrients and vitamins. The inhaled medication include bronchodilators that dilate and clean airway from secretions, supplemental oxygen, cystic fibrosis transmembrane regulator CFTR modulators (Narayanan et al., 2017).

Due to the nature of CF and its long-term effect on both the child and the family, emotional, physical and cognitive development are affected . (McDonald et al., 2013).

Considering the physical aspect, parents feel anxious due to their child's limitation in doing physical activity, so the child will fear from enrolling in any physical activity even if it is simple and easy (Prieur et al., 2021).

The stress of parents on how their child can be accommodated with his colleagues at school may make parents decide to delay enrolling their child in school, which will delay the cognitive and social skills of the child, and lower self-esteem will be the yield from this delay (Prieur et al., 2021).

For children who have CF and their families, it is important to consistently adhere to treatment over time, in order to improve health outcomes, quality of life and survival rate (Hommel et al., 2019). Adherence to treatment is important to prevent worsening of the disease (Goodfellow et al., 2015). Low adherance is related to poor health outcomes, such as decreasing lung effciency and exacebration of pulmonary disorders, increasing risk of hospitalization as well as the increasing the costs on health care systems (Faint et al., 2017). The rate of adherence to medications is higher in adolescence than in toddlerhood therefore this study was conducted to demonstrate the rational of low adherence in toddlers than teenagers (Zindani et al., 2006).

Adherence to treatment is affected by self-efficacy (self-efficacy is a person's faith in their ability to execute the action needed to finish a certain task). In addition, self-efficacy has a close relationship with self-management, including activities and skills implemented to

control signs and symptoms of a chronic disease and to improve quality of life for patients with CF (Faint et al., 2017).

The results of a qualitative study that aimed to describe the factors affecting children with CF adherence to treatment have shown that nine main factors affected adherence, they are "social support, community support, organizational strategies, intrinsic characteristics, combining treatments with pleasurable activity, flexibility, easier or faster treatment, prioritizing treatments, and negative effects of non-adherence (Nicolais et al., 2019).

Health-related stigma is defined as a personal experience with specific characteristics including: exclusion, rejection, blame, or devaluation resulting from the anticipation of a negative judgment (Pakhale et al., 2014).

CF can be considered a stigmatizing disease because it marks those who have it. There is body abnormal introduce by the complication of the disease, which marks the body in a characteristic way, including producing a barrel chest and clubbing of the feet (Pizzignacco et al., 2010). The impact of the stigma related to CF is especially critical during childhood and adolescence because these are periods when social relationships and the individuals' identity are formed. Because CF is a congenital disease and is most often diagnosed during childhood, many children with CF start to know that they are different from their peers. For example, they realize, only by being in contact with their peers, that they are smaller and thinner, that they cough and become tired easily, thus the school environment is frequently the landmark of their experience with their chronic disease. The fear of not being accepted leads to anxiety and fear of social interactions (Pizzignacco et al., 2010).

1.2 Problem statement:

Living with a chronic condition such as CF can impact various daily life aspects, including psychological issues such as stigma. Previous qualitative studies reported that the

sociocultural and religious beliefs can influence how people perceive their illness. Stigma can have negative outcomes on children with CF such as impaired psychosocial wellbeing and avoiding self-care activities, with an effect on physical health. Stigma also can interfere with a patient's adherence to the intensive treatment regimens required for chronic conditions such as CF. Low adherence is linked to poor health outcomes, such as reduced lung function and increased pulmonary edema, increased hospitalization risk, and increased health-care costs (Faint et al., 2017).

While development of new treatments for cystic fibrosis (CF) has led to a significant improvement in survival age, routine daily treatment for CF is complex, burdensome, and time intensive. Treatment routines often consist of bi-daily chest physiotherapy, daily inhaled therapies and large amounts of oral medications including digestive enzymes, nutrient supplements and antibiotics. The burden of adhering to this kind of treatment by children, adolescent and their family affect every aspect of life. Another factor that affect adherence to treatment in children with CF is Self-efficacy. Increased self-efficacy is associated with better adherence and health behavior. Therefore, the aim of the study is to assess the relationship between self-efficacy, health-related stigma and treatment adherence among Palestinian children with CF.

1.3 Significance of the study:

Most of the studies about adherence and self-efficacy that children with cystic fibrosis have been conducted in Western countries. In addition, studies about the stigma that children with chronic illnesses such as CF have, are conducted qualitatively within various cultural contexts. Previous studies have reported the impact of stigma on daily life of children with chronic illnesses such as physical and mental illnesses.

There is little existing information about adherence and self –efficacy and impact of stigma on children with CF in the West Bank, Palestine.

To date, no quantitative studies have been published about impact of stigma on Palestinian children with CF. Consequently, assessing adherence to treatment, self-efficacy and self-perceived stigma and associated factors of children with CF can help in identifying children who are at risk for intervention. It could also provide health care providers with information that contributes to help improve the health care services which improves the quality of physical, psychological, and social life. Furthermore, the results of this study will also increase knowledge of health care providers who will be better able to recognize the complexity of living and coping with chronic illness in the West Bank. They will also be better equipped to provide appropriate interventions, strategies, and support to children with chronic illness in order to improve health of children with CF in the West Bank, Palestine.

1.4 Purpose of the study:

The main purpose of the study is to assess the relationship between self-efficacy, health-related stigma and treatment adherence among Palestinian children with CF.

1.5 Objectives of the study:

1. To assess the level of self-efficacy and health-related perceived stigma among Palestinian children with CF.

2. To assess self-reported treatment adherence among Palestinian children with CF.

3. To assess factors that related to treatment adherence, self-efficacy and health-related stigma for children with CF.

4. To examine correlations of treatment adherence (taking medications, diet, and exercise

routines) with health-related stigma for children with cystic fibrosis

5. To examine correlations of treatment adherence and self- efficacy (taking medications, diet, and

exercise routines) with sociodemographic characteristics.

6. To examine potential correlation between health related stigma in children with CF and

sociodemographic characteristics.

1.6 Research questions:

1. What is the level of self-efficacy and health related stigma among Palestinian children with CF?
2. What is the level of self-reported treatment adherence among Palestinian children with CF?
3. What are the factors that related to treatment adherence, self-efficacy and health-related stigma for children with CF?
4. Is there a correlation between health related stigma and treatment adherence among Palestinian children with CF.?
5. Is there correlations between treatment adherence and self- efficacy (taking medications, diet, and exercise routines) with sociodemographic characteristics among Palestinian children with CF
6. Is there a significant difference between socio-demographic characteristics in terms of health related stigma among children with CF.?

1.7 Hypothesis of the study:

1. There is no significant differences between socio-demographic characteristics in terms of self-efficacy, treatment adherence and health related stigma among Palestinian children with CF
2. There is no correlation between health related stigma and treatment adherence among children with CF.?
3. There is no correlation between self- efficacy and treatment adherence among children with CF.
4. There is no a correlation between health related stigma and self-efficacy among children with CF.

1.8 The following are the assumption of this study:

- Older children are more capable of self-treatment than younger children.

- Children with lower socioeconomic status have less resources for treatment than children with higher socioeconomic status.

- Younger children have poor ability to self-exercise to improve self-efficacy.

- Sometimes parents of children who have CF tend to hide the truth that their child has CF on society

- Children and adolescents are afraid from spreading the word about their condition.

1.9 Summary:

In this introduction chapter, CF is defined as a genetic autosomal recessive disorder that affect multisystem. There is no cure from CF and children must have an adherence to

treatment to reduce signs and symptoms of CF. In addition, adherence affect self-efficacy of CF children.

CF is considered as a stigmatizing disease. The impact of the stigma related to CF is especially critical during childhood and adolescence. So, in this chapter, an overview of the proposed study has been presented including the background of the study, the statement of the problem, the aim and objectives as well as the importance of the study. In addition, the research assumptions were defined.

Chapter Two:

Literature review:

2.1 Introduction:

Cystic fibrosis is a chronic health disease that is considered one of the chronic health conditions that can affect children. There are many studies around the world conducted about CF. On the other hand, there is poor evidence-based literature about CF in the Middle East. CF is not curable, but the target of treatment is to enhance lifestyle for children by increasing adherence to medication, improving children's self-efficacy and decreasing children's and families' perceived health-related stigma.

2.2 Childhood chronic health conditions:

A chronic disease is a long-term progressive, non-contagious disease, which could happen due to genetics, environmental factors or poor lifestyle. Studies showed that a chronic disease decreases life expectancy for the future generation. Moreover, it has an impact on the emotional, psychological and social aspects of patient's life such as sedentary lifestyle and social isolation (Anderson & Durstine, 2019). Examples of chronic diseases are Diabetic Meletus, hypertension, and CF.

Nowadays, medical technology helps the health system in early diagnosis and treatment of chronic health conditions, which can slow down the progression of chronic disease. Moreover, modern technology has an impact on parental participation, where when using the new technology it helps children and parents to understand the process of CF and how to deal with the consequences of this disease and this yield to increase the awareness about CF and this enhance the perception of the chronic disease for the parents. (Wonggom et al., 2019)

By using these technologies, the communication between patient, parents, family, and the health care becomes easy and the confusion can be avoided. All of these benefits enhance the life style of the patient and slow the progression of the disease.

2.3 Cystic fibrosis:

Cystic fibrosis (CF) is a progressive, single-gene disease with autosomal recessive inheritance in the Caucasian population, occurring in approximately 1 to 3500 births. CF affects the lungs, pancreas and other organs. CF is caused by a mutation in a protein named CFTR protein. The CFTR protein plays a vital role in transporting mucus by forming chloride channels. Mutations in CFTR disrupt chloride secretion, sodium reabsorption, and water transport, which leads to increasing mucus concentration and decreasing mucociliary clearance. Concentrated mucus secretions lead to endobronchial infection with a narrow spectrum of bacteria which the most bacteria that may be colonized are Pseudomonas aeruginosa, Burkholderia cepacia and Achromobacter xylosoxidans and a powerful inflammatory response, which results in the development of severe bronchiectasis rather than fibrosis and, eventually, respiratory failure (Turcios, 2020).

CF was first described as a specific disease in 1938 , and the CFTR gene was discovered first in 1989 with multiple mutation, including the common one F508del(Sui et al., 2022).

The diagnosis of cystic fibrosis (CF) is straight forward in the majority of patients, and the clinical picture includes signs and symptoms of chronic respiratory disease and malabsorption, the sweat chloride test value is > 60 mmol/L , and two known disease causing CFTR mutations are identified which are recurrent pancreatitis and bronchiectasis (De Boeck et al., 2017).

The newborn screening (NBS) is an early diagnosis for CF, and it is the most preferred strategy in most countries because it increases health outcome and better survival for CF patients. the CF NSB started with measuring serum immunoreactive trypsinogen in a dry blood spot, but this criteria has a low positive predictive value of around 10% and patients has to be recalled for a second test (De Boeck, 2020).

in addition, the discovery of CFTR gene helps researchers to understand the pathophysiology and the genotype-phenotype relationships of this clinical variable disease, that produce CFTR modulator therapies to address the basic defect of CF. This have been remarkable and the field is rapidly improving, but this modulators are highly expensive (Wang et al., 2019).

The CF affect the lungs, the pancreas and other organs. In the lung, the mucus clogs the airway that leads to frequent lung infection like first with Staphylococcus aureus and later with Pseudomonas aeruginosa, persistent coughing at times with phlegm, wheezing and shortness of breath. In the pancreas, the accumulation of mucus prevents the release of digestive enzymes that help the body to digest food and absorb key nutrients, which leads to malnutrition, poor weight gain, frequent greasy, bulky stools or difficulty with bowel movements. In the liver, the thick mucus blocks the bile ducts that cause liver disease, which causes male infertility for men (cystic fibrosis foundation, also CF patient has varied salty tasting skin and clubbing or enlargement of the fingertips and toes. 2022).

CF is a chronic lethal multi-system condition; however, most of the morbidity and mortality is dependent on the status of the respiratory system. Progressive respiratory decline is mediated by chronic infection and inflammation, punctuated by important acute events known as pulmonary exacerbations which can lead to accelerated decline (Schwarz et al., 2018).

CF survival is the median age of survival which is the age at which 50% of patients are expected to live beyond .The median age of survival rate in CF has increased greatly in the last decade and is expected to continue due to CFTR modulator and NBS secerning (Corriveau et al., 2018). The survival rate of people with CF has improved over recent decades due to the improvement in the care and treatment, for instance, 48 years for males and 43 years for females in the UK (Keogh et al., 2018).

2.4 Epidemiological data of CF

According to the annual report for CF cases in united states there was an increase in the case of CF of 2% in 2021 than 2020 from 31534 to 32100 cases where adults with CF 58.3% and 41.7 for children, the increase in adult was more than children where from 1991 to 2021 the percentage of adults who have CF from total population of CF was 32.7% and in 2021 become 58.3% form Cf population where in children in 1991 percent of children was 67.3% and in 2021 become 41.7%. (Wang et al., 2020)

Worldwide, the prevalence of CF is varying from region to region, the incidence of cystic fibrosis annually is as high as 1:377 in parts of England and as low as 1:90 000 among Asian people in Hawaii. In Europe, the rate of cystic fibrosis is between 1:2000 and 1:3000 births. In Southern Africa, the incidence of 1 in 7056 births. The incidence in Latin America ranges from 1:3900 to 1:8500. Estimates for the Middle East are between 1:2560 and 1: 5,876 (Riquena et al., 2019)

In the Middle East, the incidence is estimated at 1 in 2000–5800 live births (Hammoudeh et al., 2021).

A study was conducted in 2020 the average annual incidence rate of CF disease through the last ten years (2009-2019) in the Gaza strip was one case per 3952 live births. The average prevalence of CF disease through the last ten years in Gaza strip was 7.52 cases per 100,000 population with no significant difference in incidence through the last ten years (ElShanti) . However, there are no evidence-based data and statistics about the prevalence of CF in West Bank.

2.5 Treatment of CF:

Because childhood is a key time that determines future health, the target of treatment for CF children is to decrease signs and symptoms that affect multiple systems in the body, and to improve health outcomes. This treatment is day to day treatment that needs compliance from children as well as time management. First, to promote clearance of the airway secretion, one needs to do airway clearance technique, like twice daily physiotherapy, increase in physical activity, nebulized dorsnase alfa once daily, nebulized hypertonic saline or inhaled mannitol twice daily, if the child has an infection in sputum culture, or to prevent acute exacerbations need to take nebulized or inhaled antibiotic and oral antibiotics, influenza vaccination annually prior to each winter season. To monitor CF symptoms, the child has to take high fat, high calorie diet, pancreatic enzyme replacement with every meal and liposoluble vitamins (Bell et al., 2020).

If the child has a respiratory insufficiency, then needs admission for hospitalization to take their treatment. Sometimes children need recurrent admission to hospital depending on their health condition. They might need oxygen therapy, non-invasive ventilation and pulmonary rehabilitation. When the child has anxiety or depression, he/she needs

nonpharmacological therapy like cognitive behavioral therapy and anti-depressant therapy (Bell et al., 2020) .

In addition, for treatment of CF, insulin is used for CF-related diabetes, and most recently CFTR modulators (Bishay & Sawicki, 2016) . CFTR modulators have several modes of action, they aim to improve or even restore the function of defective CFTR protein and are effective for people with only certain CFTR variants (or mutations) (Clancy et al., 2019).

The CF treatment requires every day compliance, that becomes a routine and time management throughout the life to promote health outcome, and most of the treatments is complicated as well as time consuming, need several hour to be completed (Narayanan et al., 2017).

2.6 Stigma related to cystic fibrosis:

The first author that defined stigma was Goffman in 1963 as an embarrassment due to reactions or events, alters lifestyle either physical , emotional , social and spiritual beliefs that makes society member self-shamed (Goffman, 1963).

Because CF is a congenital disease and is most often diagnosed during childhood, many children with CF start to observe their differences. The differences in these children's daily routine caused by the disease symptoms and treatment also contribute to making them different and consequently stigmatized. Also, the fear of not being accepted from their peers leads to anxiety and fear of social interactions. The fact that the disease has a visible symptom, such a cough and expectoration, has an immediate impact on interpersonal relationships and is related to the issue of being transmittable, feeling shame and fear of stigma(Pizzignacco et al., 2010).

Families of children and adolescents with CF also share the feeling of being different when they compare their lives with those of other families with healthy children. In addition to children and adolescents with CF, their families can also become socially isolated due to the specific care they have to deliver to their children (Pizzignacco et al., 2010) .

People living with CF have difficulties with psychological adjustment , they may experience emotional disturbances , low self-esteem , feeling of helplessness and also depression (Berge & Patterson, 2004).

Health-related stigma is defined as an individual experiences with specific characteristic including exclusion, rejection, blame resulting from inception of a negative judgment. Stigma has an important impact on overall health outcome (Cataldo et al., 2011).

For people who are living with CF, stigma can be associated with low adherence to their treatment regimen. In CF patient stigma could be associated also with decreased social contact , impaired relationship and worsening of disease and deterioration in lung function, weight and physical function (Pakhale et al., 2014).

People who live with CF may feel different from other peers as a result of the time consuming in daily treatment, they may experience increase in social isolation and social anxiety in social settings, they may also choose to be noncompliant with their treatment as perception to feel similar to their peers. some CF people may choose to hide their diagnosis from others by attempting to minimize symptoms or hide medication usage (Oliver et al., 2014).

A mixed-method design with two phases (Pakhale et al., 2014) was carried out. First phase was a qualitative study that aimed to understand the experience of patients with CF, which included a focus group with 11 participants include adult CF and informal caregiver, second phase was a quantitative cohort study to measure stigma for CF by using cystic

fibrosis stigma scale, participants were 45 adults with CF. It has been shown that stigma emerged as consistent concern for people living and caring for those with CF, affecting both patients' lives and health, there is a significant relationship between stigma and impact of live of CF. The authors of the study recommend to investigate the role of stigma in patients living with CF (Pakhale et al., 2014).

A quantitative study aimed to examine stigma and optimism among patients with CF, Participants were recruited between July 2010 and March 2011 from a large pediatric and adult CF center in the Midwest of USA. Male and female outpatients were eligible for participation if they were between the ages of 14 and 25, had a physician's diagnosis of CF, and had the capacity to give informed consent, or assent if under 18 years of age. Seventy-two patients with CF completed a self-report questionnaire assessing stigma, distress, CF-specific quality of life and optimism. Result showed greater stigma was associated with lower pulmonary function, lower levels of quality of life, and less optimism. Stigma was positively correlated with distress. Which means that stigma is related to worse lung function and psychological health in patients with CF, but higher levels of optimism may act as a protective factor (Oliver et al., 2014).

Kane et al. (2019) conducted a literature review study that aimed to discuss the relationship between stigma and health outcomes related to chronic disease in middle income countries. They used Five searches of peer-reviewed manuscripts published between 2008 and 2017 in low middle income countries. they found stigma is associated with poor health outcomes (Kane et al., 2019).

A cross-sectional study conducted by Bok (2012) ,was recruited from the Cystic Fibrosis Clinic at Nationwide Children's Hospital, Columbus, Ohio . Aimed to evaluate factors associated with self-reported treatment adherence among adolescent and young adult with

CF also examines correlations of adherence (to medications, diet, and exercise regimens/routines) with perceived stigma, anxiety/depression, and overall quality of life. The fifty adolescents and young adults (mean age = 19.2 years; age range: 15 to 25 years) with CF were recruited. The result showed Higher self- reported medication adherence was associated with better overall quality of life and more perceived stigma (Bok, 2012).

2.8 Self-efficacy related to cystic fibrosis:

Self-efficacy can be defined as the ability of performing actions that can decrease the signs and symptoms of the illness. The aspects that were assessed in self efficacy is ADL, emotional stress, doctor visit and medications adjustment.(Levy et al., 2020)

Self-efficacy is learning a new behavior due to environmental or social influence to enhance their ability to overcome certain events in future, so by using this cognitive process the patient improve the quality of life for patients who have chronic disease (Farley, 2020) .

Managing life can be done by using these three methods. Personal, proxy agency and collective, when losing control on a certain event, cloning other's behavior in handling these events this we called proxy agency. When expressing proxy agency from spiritual view, this giving a belief that self-efficacy has been strengthened(Eller et al., 2018).

Self-efficacy influences human actions, self-management is one of these actions. The belief about our capability of doing certain action influences decision making process and effort of persistence. Low self-efficacy gives a belief that it is difficult to do certain task while our actual ability can overcome this task. for children this belief weekend the ability of handling self-management tasks (Farley, 2020)

Self-management is essential to effective care of chronic illnesses, resulting in improved patient outcomes, Effective self-management of a child's chronic disease extends beyond typical parenting skills to include symptom monitoring, treatments, medications, specialized nutrition, physical and psychosocial issues, and financial planning(McDonald et al., 2013).

A systemic review study conducts by Eller et all, 2018, to explore the usefulness of the concept self-care self-efficacy, by using empirical studies across disciplines published between 1996 and 2015 were used as data number is 1130 article was conducted, they conclude that Self-care self-efficacy is associated with performance of self-care activities and positive health outcomes in diverse population.

A mixed method study conducted by McDonald et al. (2013) , conducted in pediatric cystic fibrosis center in Salt Lake city , Utah . aimed to evaluate the effect of engaging CF children's parents in developing an educational material on self-efficacy and confidence in self-management skills. A convenience sample of parents was participated in pre and post intervention survey. The sample was gathered through electronic surveys, written questionnaires, focus group and informal interviews. They found that by engaging parents in these development methods enhance self-efficacy and confidence especially if there was an electronic method such as videotaped parent education presentation. also found nominative problem-solving process identified parental issues to address first feeling isolated due to infection control concerns, second one being overwhelmed by CF care, third uncertainty about the reliability of a lot sources if CF information, last one for some families the emotional distance from cystic fibrosis center.

Another quantitative study conducted by Faint et al. (2017) conducted in the Princess Margaret Hospital in Australia for Children Respiratory Medicine outpatient clinics. Aimed to compare disease knowledge between parents and adolescent and to evaluate self-

efficacy association with disease knowledge and adherence, and to determine the relationship between adherence and disease knowledge. Forty-one Adolescents with cystic fibrosis and their parents were approached, and 39 were recruited over a 6-month period. The study had found that the disease knowledge is not associated with self-efficacy, and is sub-optimal in adolescents with cystic fibrosis associated with poor adherence to some treatments, The authors had recommended the need for educational interventions in adolescents with cystic fibrosis to optimize self-management and health outcomes.

A quantitative, descriptive study conducted by Wahl et al, at 2005, in Turkey, about self-efficacy, pulmonary function, perceived health and global quality of life for cystic fibrosis patients. A sample comprised 86 adults (48% female; mean age, 29 years; age range, 18–54 years) with cystic fibrosis, recruited from the Norwegian competence center for cystic fibrosis (83% response rate). The results had showed that self-efficacy is as important as pulmonary function for the perceived health status and global quality of life of patients. these valuable findings should be considered in the treatment and care of adult patients suffering from cystic fibrosis. The study recommend to require to extend our knowledge of the impact of living with cystic fibrosis and to test the effects of psycho educational programmers(Wahl et al., 2005) .

2.9 Adherence related to cystic fibrosis:

Adherence is defined by the World Health Organization in 2011 as "the degree to which the person’s behavior corresponds with the agreed recommendations from a health care provider. Many factors could affect adherence such as patients ability to read and understand to instruction of medication, Gender, personality, and cultural factors (Jimmy & Jose, 2011) .

Adherence to treatment has many barriers, studies indicates that lower adherence to prescribed treatment regimens may be in part due to time management, forgetting, increased complexity of regimens, decreased parental supervision, perceived doubts about the necessity of treatments, stigma and reluctance to disclose CF status, and depression in both patients and their parents . (Bishay & Sawicki, 2016).

First of treatment barrier is time management, the new available treatment of CF is causing significant treatment burden. need more time to take medication in a specific daily routine also need to do a correct performance to decrease severity of the signs and symptoms. this may consider a time consuming because to child how has CF need to take at least two or more nebulized medication and performing airway clearance treatment for over 30 minutes daily. also, the treatment is considered complexity, to family and parents play a major role in determining adherence for CF children. child cooperation was highly associated with positive family attention, instruction and avoidance negative statements. Also there is a correlation with adherence and understanding to the perception of the treatment is necessary (Bishay & Sawicki, 2016).

The consequence of non-adherence is waste of medication, disease progression, reduced functional abilities, a decrease quality of life, increased use of medical resources such as nursing homes, risk of hospital visits and hospital admissions(Jimmy & Jose, 2011) .

A literature review for studies published from January 2010 to August 2016 to capture the most up-to-date recommended therapies and current/recent care patterns for CF patients; in English language; related to human subjects; and peer-reviewed journals A total of 19 studies qualified for inclusion in the review: 12 retrospective, three randomized trials, two prospective studies, one was a combination of retrospective and prospective data, and one open-label study. Result showed adherence to current CF treatments is variable upon several factors such as age, type of medication and time of medication. adherence effect on

treatment outcome, cost and quality of life need to study especially among new oral medication , also there is a several barriers effect on adherence such like lack of time , forgetfulness, side effect of medication , polypharmacy , poor communication between patient and provider , insufficient disease , and cost of medication (Narayanan et al., 2017) .A prospective study conducted by Hommel et al. (2019) , at the children hospital of Philadelphia aimed to examine patterns of adherence to a novel dietary supplement in pediatric cystic fibrosis. Participants aged 5-17 years (N=109) were monitored monthly via supplement packet counts. Result showed four distinct trajectories best characterized adherence in this sample, with 18% of participants demonstrating near perfect adherence, 42% demonstrating good adherence (at or above 80%), 16% demonstrating poor adherence that declined over time, and 24% demonstrating significant non-adherence (< 30%). Which mean assessment of adherence to dietary supplementation over time can identify patients at risk for continued difficulty with self-management and provide opportunities for early intervention (Hommel et al., 2019).

A cross-sectional, multi-method study conducted by Goodfellow et al. (2015) at Northern Ireland Pediatric Cystic Fibrosis Centre. Aim of the study to evaluate adherence to enzyme supplements, vitamins and chest physiotherapy in children with cystic fibrosis and to determine if any modifiable risk factors are associated with adherence. A convenience sample of 100 children (≤18 years) and their parents filled out Medication Adherence Report Scale (MARS).

The results had showed that 72% of children were classified as low-adherers to enzyme supplements, 59% low-adherers to vitamins and 49% low-adherers to chest physiotherapy. Variations in adherence were observed between measurement methods, treatments and respondents. which mean Low adherence is more likely to occur in older children, whereas, better adherence to cystic fibrosis therapies is more likely in children whose

parents strongly believe the treatments are necessary. The necessity of treatments should be reinforced regularly to both parents and children (Goodfellow et al., 2015).

A prospective study conducted by Barker and quitter multicenter trial conducted between 2001 and 2007, at 3 CF centers in Florida aimed to evaluate adherence to pancreatic enzymes, by using 83 patients (1–13 years). The results had found that adherence to pancreatic enzymes was 49.4% ± 3.4% Parents reported high rates of depressive symptoms Children of parents with symptoms of depression versus those without were less adherent (34.8% ± 4.5% vs 48.5% ± 4.1%), and adherence to enzymes was significantly related to 3-month weight outcomes. Average gain in weight z scores across 3 months was 0.5 ± 0.2for children who were >50% adherent and –0.1 ± 6.1for children who were <33% adherent. Parental depression had a significant, indirect effect on weight via adherence. High rates of parental depressive symptoms, coupled with its negative effects on adherence. They suggest that measuring and treating parental depression may improve children's adherence to therapy (Barker & Quittner, 2016).

A semi-structure interview conducted by Gathercole (2019), in England . children with CF usually depends in the family home. the family play an important role in adherence for treatment in CF children, this study aimed to examine to how family manage CF. this study includes 14 participant comprising 5 children and young people with CF, 4parencts, 2 CF nurse specialist and 3 teachers. they find education is a priority for families. which they affects how their manage CF and family education play an important role to increase adherence rate to medication and daily treatment for children with CF (Gathercole, 2019).

A quantitative study conducted by Hakeem (2018) , in Saudi Arabia , to assess adherence level of respiratory treatment for CF , because its play an important elements in the management of respiratory complication associated with CF disease . the data was collected through a descriptive survey using question based on CF guidelines, the survey

was emailed to all member of the Saudi society for respiratory care. the result shows the level of adherence is low among to respiratory treatment. education equipment is necessary to improve level of awareness , knowledge and management of CF disease (Hakeem, 2018).

Self-efficacy may affect adherence to treatment with CF, the individual belief in his io her ability to perform the treatment in correct way. Self-efficacy is necessary to control signs and symptoms of the disease and to improve health outcome. increase self-efficacy has associated with better adherence , health behavior , effective pain management and chronic disease management(Faint et al., 2017).

Chapter Three:

Conceptual Framework:

3.1 Introduction

This chapter provides the framework of this study. It will assess the adherence and self-efficacy and related health stigma for children who has CF. The conceptual framework of the study is built based on the result of the literature review regarding the adherence to treatment, self-efficacy and heath related stigma in CF children among west bank.

The search strategy and main themes generated from the literature search are presented. The conceptual framework underpinning this study is the concept of CF children, which is addressed first. The main focus of this chapter addresses the concepts examined in the study questionnaire, that being to assess adherence, self-efficacy and health related stigma.

3.2 Dependent Variables:

adherence to treatment is the main independent variable which in the treatment plan child should stick to the treatment to enhance self-efficacy and reduce the health-related stigma due to CF. also adherence depends severity of disease and sociodemographic variables.

Self-efficacy and health-related stigma considered dependent based on sociodemographic data according to figure 3.1.

3.3 Study Independent Variables:

This study will display the association between the independent variables represented by the socio-demographic characteristic such as age, gender, location, educational level, economic status. however self-efficacy and health related stigma consider dependent variable, they also considered independent variables in relation to adherence to treatment.

3.4 Socio demographic data:

Gender: This refers to male and female respondents.

Age: This refers to the age of the respondent, study include children from 8 to 18 years old.

Location: This refers to the where the CF children stay, in city, village and camp.

Educational level for children: This refers to the number of class of children education.

Economic status for family: this refers to the economic outcome, it was categorized into the following: Less than 1000-shekel, 1000–2000-shekel, 2000-3000 shekel, and more than 3000 shekels.

Educational level for mother: This refers to the level of mother education obtained by respondents. It was categorized into sixth groups: not education, primary, secondary, Diploma, Bachelor Degree, Master Science of Nursing (MSN), and PhD.

Educational level for father: This refers to the level of father education obtained by respondents. It was categorized into sixth groups: not education, primary, secondary, Diploma, Bachelor Degree, Master Science of Nursing (MSN), and PhD.

Is the mother employee: this answer yes or no.

Is the father employee: this answer yes or no.

Does the family tell others that they have CF children: is answer yes or no.

Do the CF children have another disease: this is a qualitive question, answer what the name of the other disease if present?

3.5 Definition of terms

3.5.1 Operational definition:

Children with CF: the CF is an autosomal genetic disease. there is no a cure from CF(Turcios, 2020). this study includes children from 8-18 years who diagnosed with CF. this child must to adapt on this disease, children need to take the nebulizer, oral antibiotic and other medication and do performance such as chest physiotherapy to decrease severity of the disease

Adherence for CF treatment: cystic fibrosis is a daily regimen. affect multisystem in the body. to decrease sign and symptoms of this disease, children must adhere to treatment. which includes at least a twice daily nebulizer, daily physiotherapy, oral antibiotic, intake of pancreatic enzyme. children must have a adherence to medication to control the complication of this disease (Bryon, 2020).

Self-efficacy for CF: self-efficacy is an important factor to do self-performance or action to monitor severity of the disease. this is related to the believes and how capable to do specific performance behavior that lead to increase outcome and can produce a successful treatment(Di Ciommo et al., 2018).

Health-related stigma for CF: Cystic fibrous is considered a stigmatizing disease because CF is inherited, chronic, progressive and fetal. Sign and symptoms include productive

cough , repeated lung infection , change in the body , this may cause a negative perception and social rejection of the CF children(Pakhale et al., 2014).

3.5.2 Conceptual definition

Children: is a young person , especially between infancy and puberty .not yet of the age of majority (Alexander, 2010)

Family is defined by the patient and is the persons, related or not, who provide support and have a significant relationship with the patient (ANA, 2010; ENA, 2007).

Cystic fibrosis: Cystic fibrosis (CF) is a progressive, single-gene disease with autosomal recessive inheritance in the Caucasian population, CF consider fetal disease, affect multisystem in the body, has a sever sign and symptoms and chronic complication. there is no specific treatment to a cure from CF. there is some treatment to decrease severity of the disease (Turcios, 2020).

Adherence: Adherence is defined by the World Health Organization in 2011 as "the degree to which the person's behavior corresponds with the agreed recommendations from a health care provider. (Jimmy & Jose, 2011) .

Self-efficacy: Self efficacy is learning a new behavior due to environmental or social influence to enhance their ability to overcome certain events in future, so by using this cognitive process the patient improve the quality of life for patients who have chronic disease (Farley, 2020) .

Health related stigma : Health-related stigma is defined as a personal experience with specific characteristics including: exclusion, rejection, blame, or devaluation resulting from the anticipation of a negative judgment(Pakhale et al., 2014)

3.6 Framework of the study:

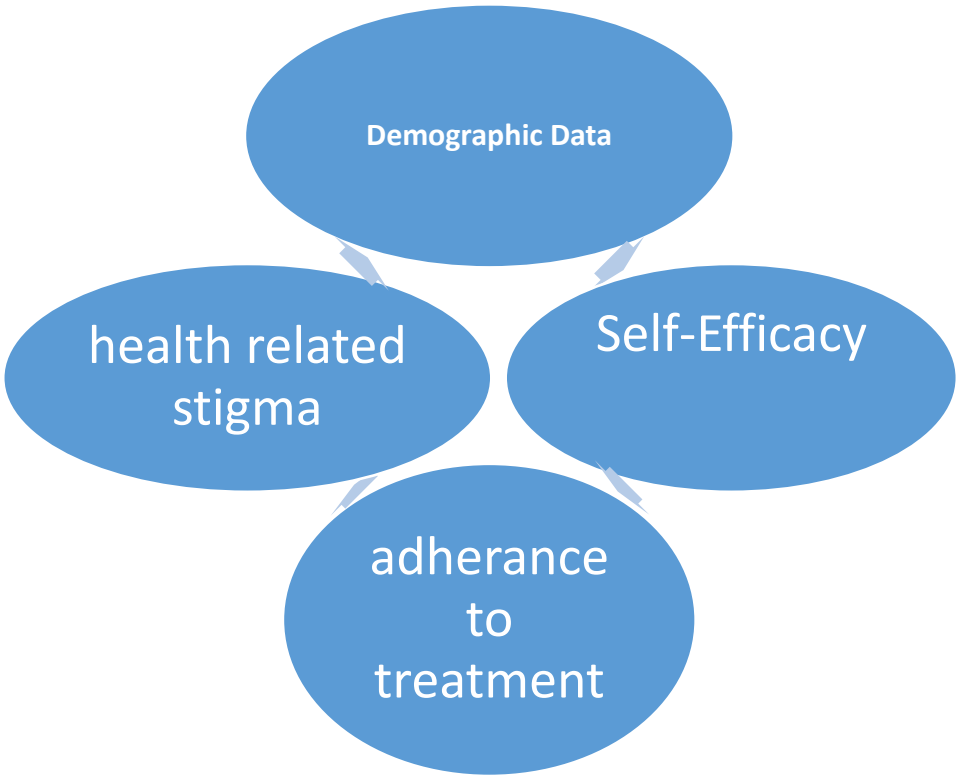

Figure 3.1: Conceptual framework model of the study

Chapter Four:

Methodology:

4.1 Introduction

This chapter describes the methodology used to assess self-adherence, self-efficacy, and stigma of Palestinian children with CF in the West Bank. The study depends on descriptive analysis and inferential analysis to answer the research aim and objectives. It describes the study design, study setting, study population, sampling frame, sample criteria, sampling process, and data collection procedures. It also reviews the selection of the study tool and how it was built, the amendments made and the procedures used to verify the validity and consistency of the questionnaire. The study has also dealt with the various statistical methods and tests used in the treatment of data.

4.2 Study Design

To examine the research hypotheses, a cross-sectional analytical study design is employed. The type of information collected and analyzed will be quantitative in order to study the relationship between variables in numerical and statistical form. Research information is collected from the study sample through a semi-structured questionnaire.

4.3 Study Settings

The setting of this study is obtained from children within home settings, some were done face to face and some via phone calls as some families refused home visits.

The addresses and contact information of children's families were obtained from the database of Dr. Nisreen Romman clinic who is a pediatric pulmonologist working in different hospitals in Palestine. Most of the cities of Palestine were included such as Ramallah, Hebron, Bethlehem, Tol-Karem, Qalqilya, Nablus, etc.

4.4 Study Population

The target population of this study has represented all children who have a diagnosis of CF. The population is children aged from 6-18 years. This age selection was determined based on who have CF and because this age is the most important one in psych-socio-spiritual behaviors. Based on the communication with Dr. Nisreen clinic, it has been acknowledged that the population consists of 69 patients.

4.5 Sampling Frame

- **Inclusion criteria**:

1. Children who are between 6–18 years of age and had a diagnosis of CF.
2. Children from the West Bank.

- **Exclusion criteria:**

1. Patients with intellectual impairments or those who have additional chronic illnesses.
2. Patients who refused to participate in the study.

4.6 Study Sample

The efficient way to choose the sample that represents the population is convenience sampling because of the medical situation of children and the uniqueness of the illness of CF as well as uniqueness of illness in Palestine. In addition, the patients were distributed all over West Bank cities.

In order to calculate and gain a more accurate result on the sample size, Slovin's Formula was used, equation (1) illustrates the basis to determine the sample size through Slovin's Formula.

$$n = \frac{N}{1 + Ne^2} \qquad eq.(1)$$

$$n = \frac{69}{1 + 69 * 0.05^2} = 58.9 \qquad eq.(2)$$

Where n is the sample size, N represents the population size, and Ne represents the desired margin of error that equal 0.05. Slovin's formula shows that the efficient sample size representing the population in this study is 69 by using a 0.05 desired margin of error (e). Slovin's formula shows that the number of 59 observations can efficiently represent the population in this study. Out of the 59 questionnaires, 56 questionnaires were filled completely and the response rate was 94.9%.

4.7 Tools for Data Collection

The construction of the research questionnaire is based on several previous studies, which relied on the stigma scale, self-efficacy scale, and adherence scale as variables which in turn are similar to the variables of this study. Data was collected by interviewing the participants using a self-administered questionnaire. The questionnaire is divided into five main sections as follows:

1. **Section One:** A consent form to be signed by the parents and it demonstrates the study protocol, objectives, researcher, supervisors, and the confidentiality of data.
2. **Section Two:** includes questions related to personal and demographic data for children and their parents such as age, gender, and educational level. Also, the family income, place of residence, educational level of parents and their jobs. Moreover, it has information about the state of illness which the child or parents tell people about, and if there is another chronic disease in addition to CF.
3. **Section Three:** it contains the stigma scale that was used to assess the socio-emotional state of the child, this section has 8 items on a four-point Likert scale ranging between strongly agree (4), agree (3), disagree (2), and strongly disagree (1).
4. **Section Four:** section four contains a self-efficacy scale and was used to assess the ability of the child to do the activities of daily living, social activity, and drug administration. This section has 8 items on a four-point Likert scale ranging between very confident (4), confidant (3), not confidant (2), and not at all confidant (1).
5. **Section Five:** section five contains an adherence to the treatment scale; this section has 8 closed-ended multiple-choice questions.

4.8 Pilot Study

A pilot study took a purposive sample of 5 children from the database and was conducted before starting the actual data collection. This aimed to be a pretest to determine the real-time needed to fill the questionnaire and identify areas of vagueness, point out weaknesses in wording, test the reliability of its items and to test validity and suitability of the questionnaire. Modifications were made accordingly and the results and data from the pilot study will not be included in the main study.

4.9 Reliability and Validity of the Instrument

The reliability of instrument tools is considered a consistency measure to indicate when the measurements are repeated twice with the same respondents, the results would essentially be the same, while the instrument validity is often defined as the extent to which an instrument measures what it purports to measure, and validity requires that an instrument is reliable (Akib et al. 2015).

To check the reliability of the instrument, Cronbach's α coefficient (CA) was used. To check the instrument validity, construct validity through convergent validity by factor loading was used. To check it out, Exploratory Factor Analysis (EFA) was used with the application of varimax rotation. Exploratory factor analysis is a "statistical technique applied to a single set of variables when the researcher is interested in discovering which variables in the set form coherent subsets that are relatively independent of one another" (Tabachnick, 2014). Hair et al. (2013) indicated that factor analysis shows whether all of the items of a construct are highly correlated and represent the same construct or not.

Kaiser-Meyer-Olkin (KMO) and Bartlett tests were applied to determine the suitability of the data sample for factor analysis. The KMO measure for the study dimensions were ranging between 0.543 and 0.744 which is more than 0.05, and that indicates the suitability of the items to measure the construct (factors). This is again confirmed by Bartlett's test with a p-value of 0.000 for each dimension, which is less than 0.05 and is considered significant, so the assumption of the factor analysis was applicable (Dziuban & Shirkey, 1974).

According to the result in table 4.1, Cronbach's α coefficients ranged between 0.541 and 0.960, indicating an excellent internal consistency among factor, which means the instrument is reliable (Hair et al., 2017).

In addition, to check the instrument validity, Hair et al. (1998) suggested that the item with a factor loading more than 0.40 can be accepted in the study. Table 4.1 indicates the factor loading of all items was between 0.371 and 0.857, which indicates all items are acceptable except item eight in adherence to the treatment scale which was deleted because the factor loading of this item was less than 0.40. This indicates that all items are acceptable, and that means the convergent validity is ensured.

Table (4.1): Results of confirmatory factor analysis of the instrument

	Items	**Factor loading**
	Stigma Scale (Cronbach's α=0.793)	
1.	I have been hurt by how people reacted to learning I have cystic fibrosis.	0.594
2.	I have stopped socializing with some people because of their reactions of me having cystic fibrosis.	0.785
3.	I have lost friends by telling them I have cystic fibrosis.	0.838
4.	I am very careful who I say that I have cystic fibrosis.	0.576
5.	I worry that people who know I have cystic fibrosis will tell others.	0.452
6.	I feel that I am not as a good person as others because I have cystic fibrosis.	0.612
7.	Having cystic fibrosis makes me feel unclean	0.684
8.	Having cystic fibrosis makes me feel that I'm a bad person.	0.622
	Self-efficacy Scale (Cronbach's α=0.908)	
1.	How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	0.763
2.	How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	0.822
3.	How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	0.857
4.	How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	0.814
5.	How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	0.500
6.	How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	0.495
	Adherence to the treatment Scale (Cronbach's α=0.541)	
1.	Do you always remember to take all your medications according to your doctor's instructions?	0.617
2.	Do you find purchasing of the medications prescribed by your doctor a significant financial burden?	0.416
3.	Do you happen to change the dosing of your medications without prior consultation with your doctor?	0.454
4.	Do you adjust the dosing of your medications according to how you feel?	0.630
5.	On the appearance of medication-related side effects (e.g., stomach pain,	0.413

	Items	Factor loading
	liver pain, rash, lack of appetite, oedema):	
6.	Do you find all your medications necessary for your health?	0.572
7.	Does your doctor inquire about medication-related problems that you might possibly experience?	0.406
8.	Do you tell truth when asked by your doctor about medication-related problems?	0.371

4.10 Ethical Consideration

Ethical approval was obtained from the ethical community of Al-Quds university. Informed consent was obtained from the parents after demonstration of the study and its objectives and for what this study was conducted for.

Confidentiality and anonymity will by assured. The data will be secured in a safe place and the allowed people who can view this data are who just enrolled in research who are researcher, and study supervisor. The participant will be presented as numbers and no one can identify the person that this information belongs to.

4.11 Data Collection Methods and Procedures

Initially, permissions from selected families were obtained to introduce their total approval to conduct this study. The researcher herself collected data using a self-administered questionnaire. The consent form was obtained from the participants in the study after clarifying the purpose of the study and confirming the anonymity and confidentiality of information. The questionnaire was filled out individually and completed by the study participants.

4.12 Data Analysis

Data analyses was performed by using version 23 of the Statistical Package for Social Sciences (SPSS). The assumption of normality needs to be checked for many statistical

procedures, namely parametric tests, because their validity depends on it, so before determining the statistical tools that the research must use, Shapiro-Wilk Test was used to check the factor distribution. Table (4.2) clarifies that the stigma scale and self-efficacy scale had non-normal distribution with p-values less than the significance level (α=0.05), while adherence to the treatment scale had a normal distribution with p-value more than the significant value (α=0.05).

Table (4.2): Shapiro-Wilk Test for Normal Distribution

Factor	Statistic	df	Sig./p-value
Stigma Scale	0.943	56	0.011
Self-efficacy Scale	0.947	56	0.016
Adherence to the treatment Scale	0.959	56	0.053

In this study, to examine the hypotheses and questions, the researcher used some parametric and nonparametric statistical tools as follows:

- Frequencies and percentages to describe the sample's characteristics and responses.
- Independent sample t-test to test the differences between the mean score of study factors (stigma scale, self-efficacy scale, and adherence to the treatment scale) with normal distributions and equal variance in two groups (e.g., gender).
- Mann-Whitney U test to examine the differences between mean scores of study factors (stigma scale, self-efficacy scale, and adherence to the treatment scale) with non-normal distributions or non-equal variance in two groups.
- One-way analysis of variance tests to examine the differences in the mean score of factors (stigma scale, self-efficacy scale, and adherence to the treatment scale), if variable distributions in all groups were not significantly different from normal and have a homogenous variance.

- Kruskal Wallis test is the non-parametric alternative one-way analysis of variance (ANOVA), which is appropriate when there is a need to compare data that have more than two groups to determine if there is a significant difference between the tested groups or not.
- spearman correlation coefficient was used to study the relationships between study variables.
- To describe the participant's response, the researcher used three main classes for easier response interpretation by dividing of response scale into the main classes which are three, table 4.3 illustrate the distribution of mean value into one of the agreement classes.

Table (4.3): Distribution of mean value into one of the agreement classes

	Stigma and self-efficacy scale		**Adherence to the treatment scale**	
Class	**Mean Range**	**Agreement class**	**Mean Range**	**Agreement class**
1	Less than 2.10	Low	Less than 3.00	Low
2	2.10 -3.00	Moderate	3.00 -3.74	Moderate
3	3.10-4.00	High	3.75-4.00	High

Chapter Five:

Results:

5.1 Introduction

This chapter includes the presentation of data analysis and testing the research hypotheses by answering the research questions and reviewing the main results of the questionnaire gained by analyzing the various variables. The SPSS program was used to obtain the results of the research that will be presented and analyzed in this chapter. The researcher presents the study results to answer the questions that appeared and were included in the questionnaire, which represent the problem of the study after collecting the data required by the study tool.

5.2 Sample Characteristics

Throughout the study, the researcher looked at certain characteristics of participants, section (5.2.1) presents children's characteristics and section (5.2.2) presents the parents' characteristics.

5.2.1 Children Characteristic

Through the questionnaire, the researcher observed certain demographic characteristics of children that included four variables as shown in Table 5.1, which contains the frequency and percentage for each variable listed according to the survey categories. According to the result in Table 5.1, 56 children responded to the questionnaire, 30 (56.6%) were males, and 23 (43.4%) were females. Regarding the place of residence, the majority of children (n=34, 63%) were living in the village, 17 (31.5%) of them were living in the city, and only 3 (5.5%) were living in refugee camps. However, 21 (37.5%) of the children were less than 11 years old, 20 (35.7%) of them between 11 and 15 years old, and 15 (26.8%) were more than 15 years old. More than 40% of the children (n=24, 44.4%) were in primary school, 19 (35.3%) of them were in high school, 9 (16.7%) of them were in secondary school, while 2 (3.6%) of them were studying at the university. Furthermore, the majority of children tell people about their states of illness (n=37, 67.3%), and 9 (16.7%) not.

Table 5.1: Children's Characteristics (N=56)

Variable	Options	Frequency	Valid Present %	Missing
Gender	Female	23	43.4	3
	Male	30	56.6	
Age categories	Less than 11 years	20	35.7	0
	11– 15 years	21	37.5	
	16– 18 years	15	26.8	
Place of residence	City	17	31.5	2
	Village	34	63.0	
	Camp	3	5.5	
Education level.	Primary school	24	44.4	2
	High school	19	35.3	
	Secondary school	9	16.7	
	College	2	3.6	

Variable	Options	Frequency	Valid Present %	Missing
Tell people about illness status	Yes	37	67.3	1
	No	18	32.7	
Other chronic dieses	Have	9	16.7	2
	Don't have	45	83.3	

5.2.2 Parents Characteristics

In this section, the researcher looked at certain demographic and characteristics of parents, which include five variables. Table 5.2 illustrate that more than half of families get a monthly income between 2001 and 3000 NIS (n=28, 54.9%), 15 (29.4%) of them get a monthly income between 1000 and 2000 NIS, and only 8 (15.7%) get more than 3000 NIS. For the parent's education level, the majority of mothers had a preparatory education (63.6%, n=35), also the majority of fathers had a preparatory education (72.7%, n=40), no one of the fathers had a college degree, and 1 (1.8%) of the mothers had a college degree (BA, master, and Ph. D), on another hand 5 (9.1%) of the mothers and 4 (7.3%) of fathers are uneducated. In addition, 6 (10.9%) of the mothers and 6 (10.9%) of the fathers are employed.

Table 5.2: Parents' Characteristics (N=56)

Variable	Options	Frequency	Valid Present %	Missing
Monthly income	Less than 1000 NIS	0	0.00	5
	1000-2000 NIS	15	29.4	
	2001-3000 NIS	28	54.9	
	More than 3000 NIS	8	15.7	
Education level of the mother	Uneducated	5	9.1	1
	Elementary	2	3.7	
	Preparatory	35	63.6	
	High school	6	10.9	

Variable	Options	Frequency	Valid Present %	Missing
	Diploma	6	10.9	
	BA Graduate	1	1.8	
	Master or Ph. D Degrees	0	0	
Education level of the father	Illiterate	4	7.3	1
	Elementary	6	10.9	
	Preparatory	40	72.7	
	High school	2	3.6	
	Diploma	3	5.5	
	BA Graduate	0	0.0	
	Master or Ph. D Degrees	0	0.0	
Work status of the mother	Work	6	10.9	1
	Didn't work	49	89.1	
Work status of the father	Work	6	10.9	1
	Didn't work	49	89.1	

5.3 Assessment of Stigma in Children With CF

The questionnaire has 8 items used to assess stigma in children with CF. Table 5.3 showed that the rank of stigma in children with CF was 2.13 with a standard deviation of 0.35, which means stigma in children with CF is moderate. In addition, participants indicate that they had a moderate agreement for all items of the stigma scale except item 7 and item 8. Participants had the highest agreement with item 4, which states "I am very careful who I say that I have cystic fibrosis" (mean=2.55, SD=0.76) with a moderate level of agreement, followed by item 5, which states "I worry that people who know I have cystic fibrosis will tell others" (mean =2.25, SD=0.61) with a moderate level of agreement, while they had the

lowest agreement for item 7, which states “Having cystic fibrosis makes me feel unclean” (mean =1.88, SD=0.47).

Table (5.3): Descriptive Statistics for Items on the Stigma Scale

No.	Items	Mean	S.D	Rang	Level of agreement
4	I am very careful who I tell that I have cystic fibrosis	2.55	0.76	1-4	Moderate
5	I worry that people who know I have cystic fibrosis will tell others	2.25	0.61	1-4	Moderate
1	I have been hurt by how people reacted to learning I have cystic fibrosis	2.21	0.51	1-3	Moderate
6	I feel that I am not as good a person as others because I have cystic fibrosis	2.13	0.51	1-3	Moderate
2	I have stopped socializing with some people because of their reactions of me having cystic fibrosis	2.09	0.51	1-3	Moderate
3	I have lost friends by telling them I have cystic fibrosis	2.07	0.50	1-3	Moderate
8	Having cystic fibrosis makes me feel that I’m a bad person	1.95	0.48	1-3	Low
7	Having cystic fibrosis makes me feel unclean	1.88	0.47	1-3	Low
	Overall score of the stigma scale	**2.13**	**0.35**	**1.25-2.88**	**Moderate**

Figure 5.1 illustrates the distribution of participants’ responses to items on the stigma scale, after calculating the mean score of stigma. Participants indicated that they strongly agreed or agree with “I am very careful whom I tell that I have cystic fibrosis”, where it represents the highest positive agreement (n=32, 57.1%) .On other hand, participants indicated that they disagreed or strongly disagree for 7 of the 8 items (5, 1, 6, 2, 3, 8, and 7), where the highest negative agreement for “Having cystic fibrosis makes me feel unclean” (n=53, 94.6%), followed by “Having cystic fibrosis makes me feel that I’m a bad person” (n=51, 91.1%), while the lowest negatively agreement was “I worry that people who know I have cystic fibrosis will tell others” (n=39, 69.6%) (see Appendix 2).

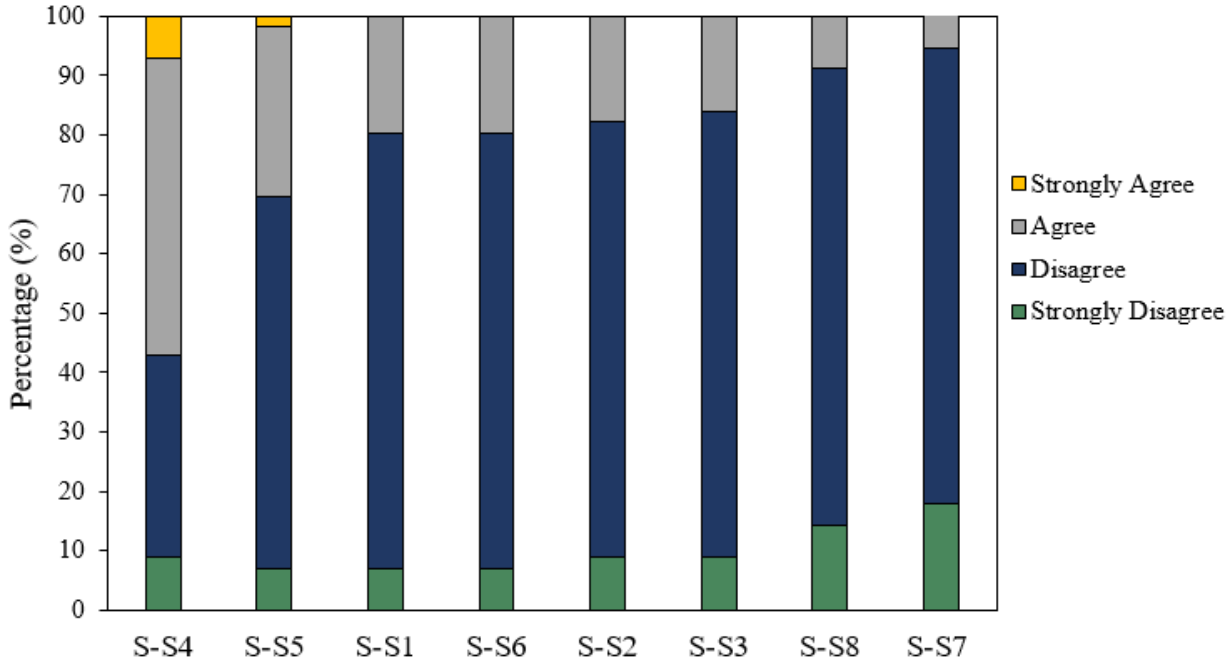

Figure 5.1: Participant's Responses Distribution of Items on the Stigma Scale (S-S)

5.4 Assessment of Self-Efficacy Scale:

This section answers the research question that states "what is the level of self-efficacy in children with CF?" The questionnaire has 6 items used to assess self-efficacy in children with CF. Table 5.4 showed that the mean score of the self-efficacy scale in children with CF was 2.48 with a standard deviation of 0.48, which means the self-efficacy level in children with CF is moderate. Furthermore, participants had moderate confidence for all items of the self-efficacy scale. Participants had the highest confidence to "How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?" (mean=2.64, SD=0.67), followed by "How confident are you that you can do things others than just taking medication to reduce how much your illness affects your everyday life?" (mean =2.63, SD=0.62), while they had the lowest nceconfide for "How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?" (mean =2.30, SD=0.60).

Table (5.4): Descriptive statistic for items on the Self-Efficacy Scale (S-E)

No.	Items	Mean	S.D	Rang	Level of confidant
5	How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	2.64	0.67	1-4	Moderate
6	How confident are you that you can do things others than just taking medication to reduce how much your illness affects your everyday life?	2.63	0.62	2-4	Moderate
4	How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	2.48	0.66	1-4	Moderate
2	How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	2.43	0.66	1-4	Moderate
1	How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	2.41	0.63	1-4	Moderate
3	How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	2.30	0.60	1-4	Moderate
	Overall score of the self-efficacy scale	**2.48**	**0.48**	**1.33-3.83**	**Moderate**

Figure 5.2 illustrates the distribution of participant's responses to items on the self-efficacy scale, participants indicated that they were confident or very confident for two items of the six items (5 and 6), where the highest positively confidant is for item 5, which states "How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?" (n=34, 54.7%), followed by item 6 which states "How confident are you that you can do things others than just taking medication to reduce how much your illness affects your everyday life?" (n=31, 55.3%).

On other hand, participants indicated that they were not very confident or not confidant for four of the six items (1, 2, 3 and 4), where the highest not confident is for item 3, which

states “How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?” (n=37, 66.1%), followed by “How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?” and “How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?” (n=33, 59%, for each of them), while the lowest confidant for “How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?” (n=32, 57.3%) (see Appendix 3).

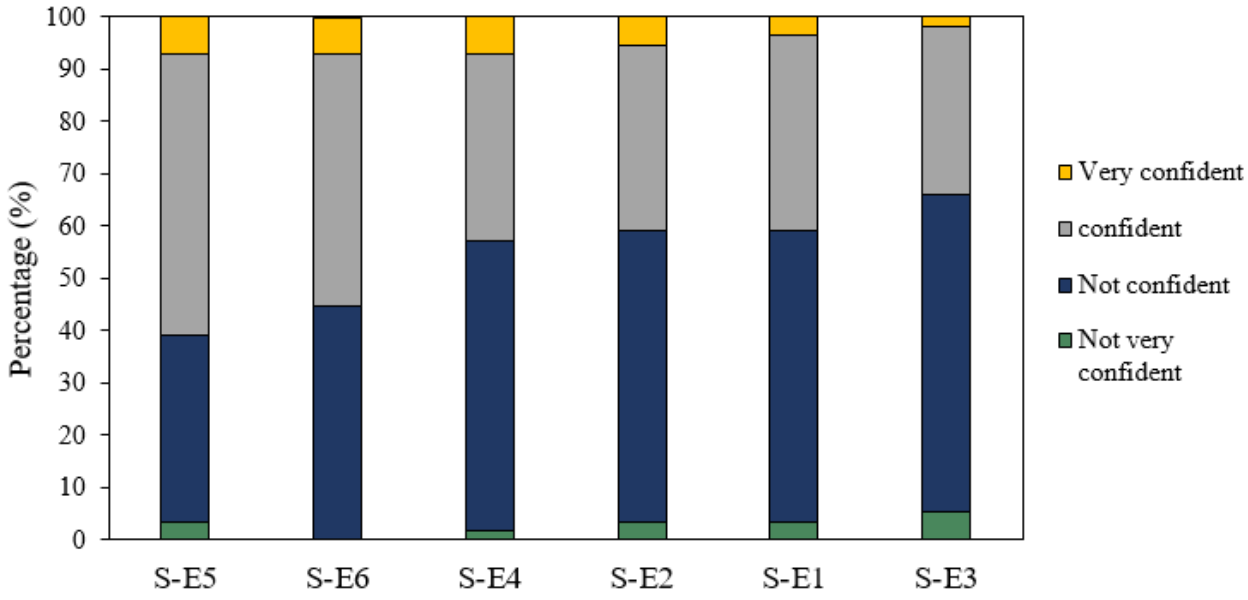

Figure 5.2: Participant’s Responses Distribution of Items on the Self-efficacy Scale

5.5 Assessment of Adherence to the Treatment Scale:

This section answers the research question that states “what is the level of adherence to the treatment of children with CF?” The questionnaire has 8 items used to assess adherence to the treatment of children with CF; one of them was deleted, so the number of items in this scale is seven. Table 5.5 showed that the mean score of adherences to the treatment of children with CF is 20.86 with a standard deviation of 3.86, which means children with CF

had low adherence. In addition, the mean score of three items (3, 6, and 7) indicates moderate adherence to the treatment and low adherence for four items (1, 2, 4, and 5). Participants had the highest adherence for item 6 and item 3, which state "Do you find all your medications necessary for your health?" and "Do you happen to change the dosing of your medications without prior consultation with your doctor?" (mean=3.55, SD=0.81 and 0.87 respectively) with a moderate level of adherence, followed by item 7, which states "Does your doctor inquire about medication-related problems that you might possibly experience?" (mean =3.21, SD=1.44) with a moderate level of adherence, while participants had the lowest adherence for item 2, which states "Do you find purchasing of the medications prescribed by your doctor a significant financial burden?" (mean =2.30, SD=0.97).

Table (5.5): Descriptive Statistic for Items on the Adherence to the Treatment Scale (S-E)

No.	Items	Mean	S.D	Rang	Level of adherence
3	Do you happen to change the dosing of your medications without prior consultation with your doctor?	3.55	0.81	1-4	Moderate
6	Do you find all your medications necessary for your health?	3.55	0.87	1-4	Moderate
7	Does your doctor inquire about medication-related problems that you might possibly experience?	3.21	1.44	0-4	Moderate
4	Do you adjust the dosing of your medications according to how you feel?	2.95	1.13	1-4	Low
5	On the appearance of medication-related side effects (e.g., stomach pain, liver pain, rash, lack of appetite, oedema)	2.66	1.05	0-4	Low
1	Do you always remember to take all your medications according to your doctor's instructions?	2.63	1.17	0-4	Low
2	Do you find purchasing of the medications prescribed by your doctor a significant financial burden?	2.30	0.97	0-4	Low
Overall score of the adherence to the treatment Scale		**20.86**	**3.86**	**10.0-27.0**	**Moderate**

Figure 5.4 illustrates the distribution of participant's responses to items on adherence to the treatment scale. The percentage of children who had high adherence with percentage more than 70% is for three items (3, 6, and 7), while 50% is for item number 4 and less than 50% for three items (5, 1, and 2). The highest percentage of children who didn't adhere to the treatment is for item 7, which states "Does your doctor inquire about medication-related problems that you might possibly experience?". (See Appendix 4).

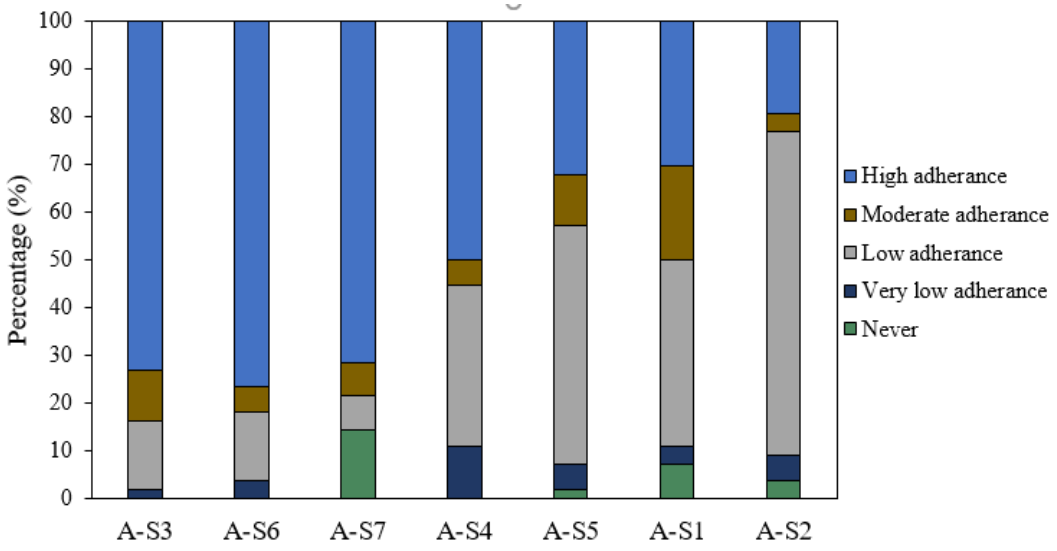

Figure 5.3: Participant's Responses Distribution of Items on Adherence to the Treatment Scale

5.6 Assessment of stigma in children with CF by Demographic Factors:

This section displays the results of the first and second main hypotheses which state:

1. **"There is no significant difference in the mean score of stigma in children with CF due to the children's characteristics (gender, place of residence, age, education level, family income, have another chronic disease)".**
2. **"There is no significant difference in the mean score of stigma in children with CF due to the parent's characteristics (level of mother education, level of father education, work status of the father, work status of the mother)".**

The result of the Mann–Whitney U-test in table 5.6 indicates that there is no statistically significant difference in the mean score of stigma in children with CF between female children and male children (p=0.617). Also, there is no statistically significant difference in the mean score of stigma in children with CF between children who have chronic diseases and others who didn't have (p=0.897). In addition, Kruskal–Wallis test showed there are no statistically significant differences in the mean score of stigma in children with CF due to children's age (p=0.602), education level (p=0.946), and family income (p=0.932). While, the result showed there is a statistically significant differences in the mean score of stigma in children with CF due to place of residence (p=0.056<0.10).

With Regard to differences due to parents' characteristics, Kruskal–Wallis test revealed there are no statistically significant differences in the mean score of stigma in children with CF due to the level of mothers' and fathers' educations (p=0.451 and 0.380 respectively). Furthermore, the results of the Mann–Whitney U-test indicate that there is no statistically significant difference in the mean score of stigma in children with CF due to the work status of the mother (p=0.803), while there is a statistically significant difference in the mean score of stigma in children with CF between children whose father is employed and other unemployed fathers (p=0.020<0.05).

Table (5.6): Result of Main Differences in the Mean Score of Stigma in Children with CF due to Children and Parents' Characteristics

Variables	Options	Mean	SD	Mean rank	Test statistic	Sig.
Gender	Male	2.16	0.36	28.20	-0.500‡	0.617
	Female	2.10	0.36	26.08		
Place of residence	City	2.29	0.25	34.94	5.777†	0.056*
	Village	2.04	0.38	23.88		
	Camp	2.13	0.25	26.33		
Age	Less than 11 years	2.18	0.30	27.33	1.014†	0.602
	11– 15 years	2.16	0.30	31.24		

Variables	Options	Mean	SD	Mean rank	Test statistic	Sig.
	16– 18 years	2.13	0.46	26.23		
Education level	Primary school	2.17	0.31	26.35	0.372†	0.946
	High school	2.11	0.35	27.79		
	Secondary school	2.14	0.44	30.00		
	Collage	2.19	0.34	27.25		
Family income	Less than 1000 NIS	0.00	0.00	0.00	0.141†	0.932
	1000-2000 NIS	2.07	0.47	26.80		
	2001-3000 NIS	2.10	0.28	25.30		
	More than 3000 NIS	2.17	0.27	26.94		
Other chronic dieses	Have	2.17	0.35	28.11	-0.129‡	0.897
	Don't have	2.13	0.36	27.38		
level of mother's education	Uneducated	1.88	0.44	18.80	4.721†	0.451
	Elementary	2.44	0.62	35.50		
	Preparatory	2.17	0.33	29.91		
	High school	2.02	0.34	24.58		
	Diploma	2.19	0.27	28.92		
	BA Graduate	1.75	0.00	7.00		
	Master or Ph. D Degrees	0.00	0.00	0.00		
level of father's education	Uneducated	2.00	0.47	24.13	4.200†	0.380
	Elementary	2.38	0.41	35.42		
	Preparatory	2.11	0.34	27.49		
	High school	1.94	0.09	12.50		
	Diploma	2.29	0.26	35.50		
	BA Graduate	0.00	0.00	0.00		
	Master or Ph. D Degrees	0.00	0.00	0.00		
Work status of the mother	Work	2.12	0.30	26.33	-0.274‡	0.803
	Didn't work	2.13	0.36	28.20		
Work status of the father	Work	1.77	0.46	13.92	-2.312‡	0.020**
	Didn't work	2.18	0.32	29.72		

†: Result obtained by Kruskal–Wallis test a
‡: Result obtained by Mann–Whitney U-test
**and *: Result significant at 5% and 10% respectively.

Figure 5.4 clarifies the sources of differences in the mean score of stigma in children with CF due to the place of residence and work status of fathers. The result indicates there is a significant difference in the mean score of the stigma of children who live in a city and others who live in the village (p=0.045) in favor of children who live in the city. In addition, the result showed there is a statistically significant difference in the mean score of

stigma in children with CF between children whose fathers are employed and others whose fathers are unemployed.

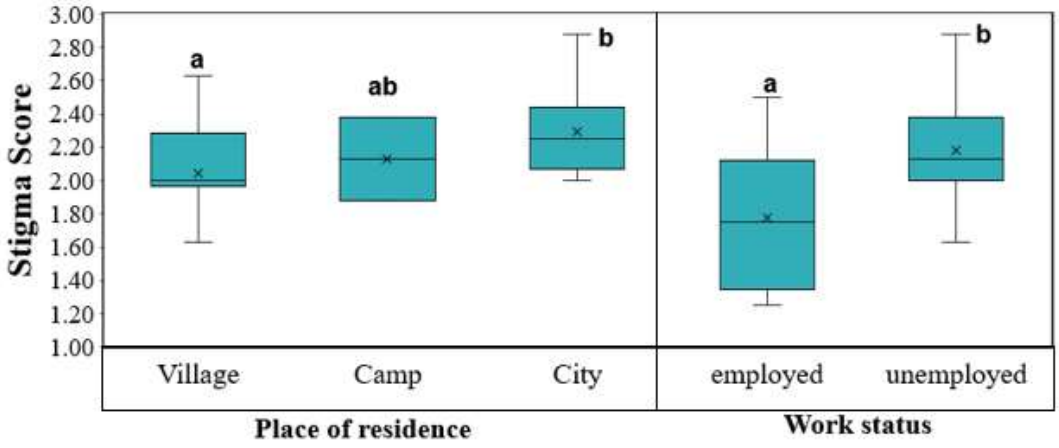

Figure 5.4: Mean and Standard Deviation of the Mean Score of Stigma in Children with CF due to Significant Factors; Different letters within the box plot indicate a significant difference

5.7 Assessment of Self-efficiency in Children with CF by Demographic Factors:

This section displays the result of the first and second main hypotheses which state:

1. **"There is no significant difference in the mean score of self-efficacy in children with CF due to the children's characteristics (gender, place of residence, age, education level, family income, have another chronic disease)"**
2. **"There is no significant difference in the mean score of self-efficacy in children with CF due to the parent's characteristics (level of mother education, level of father education, work status of the father, work status of the mother)"**

The result of the Mann–Whitney U-test in table 5.7 indicates that there is no statistically significant difference in the mean score of self-efficiency in children with CF due to gender (p=0.993) and chronic existence with CF (0.897). In addition, Kruskal–Wallis test

showed there are no statistically significant differences in the mean score of self-efficacy in children with CF due to place of residence (p=0.912), children's age (p=0.576), education level (p=0.502), and family income (p=0.138).

With Regard to differences due to parents' characteristics, Kruskal–Wallis test revealed that there are no statistically significant differences in the mean score of self-efficacy in children with CF due to the level of mothers' and fathers' educations (p=0.474 and 0.522 respectively). Furthermore, the results of the Mann–Whitney U-test indicate that there is no statistically significant difference in the mean score of self-efficiency in children with CF due to the work status of the mothers and fathers (p=0.664 and 0.885 respectively).

Table (5.7): Result of Main Differences in the Mean Score of Self-efficiency in Children with CF due to Children and Parents' Characteristics

Variables	Options	Mean	SD	Mean rank	Test statistic	Sig.
Gender	Male	2.49	0.52	26.98	-0.009‡	0.993
	Female	2.51	0.47	27.02		
Place of residence	City	2.47	0.43	26.47	0.184†	0.912
	Village	2.50	0.51	27.76		
	Camp	2.61	0.67	30.33		
Age	Less than 11 years	2.44	0.48	25.48	1.102†	0.576
	11– 15 years	2.52	0.40	30.38		
	16– 18 years	2.49	0.60	29.90		
Education level	Primary school	2.41	0.41	24.08	2.353†	0.502
	High school	2.61	0.54	30.32		
	Secondary school	2.50	0.53	31.22		
	Collage	2.33	0.00	25.00		
Family income	Less than 1000 NIS	0.00	0.00	0.00	3.964†	0.138
	1000-2000 NIS	2.27	0.47	20.90		
	2001-3000 NIS	2.51	0.49	26.57		
	More than 3000 NIS	2.69	0.49	33.56		
Other chronic dieses	Have	2.57	0.47	30.06	-0.129‡	0.897
	Don't have	2.49	0.49	26.99		
level of mother's education	Uneducated	2.70	0.74	31.20	4.721†	0.474
	Elementary	2.75	0.12	39.50		
	Preparatory	2.42	0.42	25.79		
	High school	2.44	0.73	27.42		
	Diploma	2.53	0.32	30.92		
	BA Graduate	3.33	.	52.50		

Variables	Options	Mean	SD	Mean rank	Test statistic	Sig.
	Master or Ph. D Degrees	0.00	0.00	0.00		
level of father's education	Uneducated	2.38	0.81	26.75	3.219†	0.522
	Elementary	2.47	0.36	27.67		
	Preparatory	2.47	0.48	26.79		
	High school	3.00	0.47	45.25		
	Diploma	2.61	0.35	35.00		
	BA Graduate	0.00	0.00	26.75		
	Master or Ph. D Degrees	0.00	0.00	0.00		
Work status of the mother	Work	2.53	0.41	30.83	-0.464‡	0.664
	Didn't work	2.49	0.49	27.65		
Work status of the father	Work	2.50	0.60	29.00	0.141‡	0.885
	Didn't work	2.49	0.47	27.88		

†: Result obtained by Kruskal–Wallis test a
‡: Result obtained by Mann–Whitney U-test

5.8 Assessment of Adherence to the Treatment in Children with CF by Demographic Factors:

This section displays the result of the fifth and sixth main hypotheses which state:

1. **"There is no significant difference in the mean score of adherences to the treatment in children with CF due to the children's characteristics (gender, place of residence, age, education level, family income, have another chronic disease)"**
2. **"There is no significant difference in the mean score of adherences to the treatment in children with CF due to the parent's characteristics (level of mother education, level of father education, work status of the father, work status of the mother)"**

The result in table 5.9 indicates that there is no statistically significant difference in the mean score of adherence to the treatment in children with CF due to children's characteristics that represent gender (p=0.716), chronic existence with CF (0.470), place of

residence (p=0.337), children's age (p=0.201), and family income (p=0.192), while the result indicates that there is a statistically significant difference in the mean score of adherence to the treatment in children with CF due children's level of education (p=0.069<0.10). In addition, the result indicates there is no statistically significant pairwise difference in the mean score of adherence to the treatment of children with different education levels (see appendix 4).

Furthermore, the result indicates that there are no statistically significant differences in the mean score of adherence to the treatment in children with CF due to the level of mothers' and fathers' educations (p=0.159 and 0.113 respectively), and there is no statistically significant difference in the mean score of adherence to the treatment of children with CF due to the work status of the mothers and fathers (p=0.939 and 0.973 respectively).

Table (5.8): Result of Main Differences in the Mean Score of Adherences to the Treatment in Children with CF due to Children and Parents' Characteristics

Variables	Options	Mean	SD	Mean rank	Test statistic	Sig.
Gender	Male	20.57	4.14	-	-0.366‡	0.716
	Female	20.97	3.82	-		
Place of residence	City	20.47	2.76	24.06	2.175†	0.337
	Village	21.35	4.09	29.84		
	Camp	18.33	7.51	20.50		
Age	Less than 11 years	21.85	3.13	32.08	3.210†	0.201
	11– 15 years	21.33	3.07	29.50		
	16– 18 years	18.87	5.08	22.33		
Education level	Primary school	22.25	3.12	32.52	7.086ɪ	0.069**
	High school	20.47	3.19	24.45		
	Secondary school	17.78	5.31	18.33		
	Collage	23.50	4.95	37.50		
Family income	Less than 1000 NIS	0.00	0.00	-	1.710†	0.192
	1000-2000 NIS	19.53	3.85	-		
	2001-3000 NIS	21.54	3.49	-		
	More than 3000 NIS	21.88	4.05	-		
Other chronic dieses	Have	21.38	3.64	30.94	-0.723‡	0.470
	Don't have	19.56	4.10	26.81		
level of	Uneducated	17.20	4.60	-	1.673ɪ	0.159

Variables	Options	Mean	SD	Mean rank	Test statistic	Sig.
mother's education	Elementary	18.50	2.12	-		
	Preparatory	21.49	3.37	-		
	High school	19.17	5.38	-		
	Diploma	21.67	3.61	-		
	BA Graduate	23.00	0.00	-		
	Master or Ph. D Degrees	0.00	0.00	-		
level of father's education	Uneducated	18.25	5.68	-	1.971ᒣ	0.113
	Elementary	18.83	1.47	-		
	Preparatory	21.13	3.76	-		
	High school	26.00	1.41	-		
	Diploma	20.00	4.00	-		
	BA Graduate	0.00	0.00	-		
	Master or Ph. D Degrees	0.00	0.00	-		
Work status of the mother	Work	20.67	3.88	-	-0.077‡	0.939
	Didn't work	20.80	3.89	-		
Work status of the father	Work	20.83	4.26	-	0.034‡	0.973
	Didn't work	20.78	3.85	-		

†: Result obtained by Kruskal–Wallis test a
‡: Result obtained by independent sample t-test
ᒣ: Result obtained by One-way analysis of variance tests
**and *: Result significant at 5% and 10% respectively.

5.8 Relationship Between Study Variables:

This section displays the result of the last third-main hypothesis which states

1. **There is no significant relationship between children's stigma score and self-efficacy score.**
2. **There is no significant relationship between children's stigma score and adherence to the treatment score.**
3. **There is no significant relationship between children's stigma score and adherence to the treatment score.**

In order to test these hypotheses, the Pearson correlation coefficient was applied, the result in table 5.12 indicates there is a significant negative relationship between children's stigma

score and self-efficacy score (r = -0.276, p =0.00), while there is no significant relationship between children's stigma score and adherence to the treatment score (r = -0.211, p =0.118), and there is no significant relationship between children's self-efficacy score and adherence to the treatment score (r = 0.124, p =0.363).

Table 5.9: Pearson correlation coefficient

	stigma	self-efficacy	adherence to the treatment
Stigma	1.00		
self-efficacy	-0.276**	1.00	
adherence to the treatment	-0.211	0.124	1.00

**: Result significant at 5%.

Chapter six:

Discussion and Limitations:

6.1 Discussion:

This chapter summarizes the study and conclusions drawn from the data analysis in chapter five. It also provides a discussion of the implications for actions and recommendations for further research. The focus of this research is to assess the self-efficacy of CF children, assess their adherence and assess the health related stigma on CF children in the West bank. It will discuss the relationship between self-efficacy, adherence and health related stigma among CF children in the West Bank. Furthermore, this section will discuss the relation of demographic data with self-efficacy, adherence and health related stigma among CF children in West Bank.

Stigma can be categorized to three different types depending on the severity of stigma based on adjusted stigma scale that has been used in this study. According to the adjusted stigma scale, stigma can be categorized to mild, moderate and severe. The scale has four answers strongly disagree 1, disagree 2, agree 3, and strongly agree 4. According to this scale, increase in the score of items indicate

more severity of perception about stigma. In this study, the average of answers was from 2 to 3 and this indicates moderate severity of stigma. The results of this study are similar when compared with literature about severity of stigma perception.

The findings in this study suggest that children who have CF has moderate level of stigma using the adjusted stigma scale. This was consistent with a study that was conducted by Pakhale, et. al. in 2014 to assess the severity of stigma among children who has CF using the adjusted stigma scale. The results were consistent with this study as the stigma severity was moderate in children who have CF.

This study suggests that children who have CF are careful when talking with other peers about their disease and this is consistent with another study that children with chronic diseases put boundaries in their relationships with other peers in the community (Kingod et al., 2017).

This study shows that children who have CF complain of fear from socializing with the community due to the characteristics of their illness. A study by Whitehead showed that parents were forced to change their place of living because their child couldn't communicate with others in community due to stigma of CF. (Whitehead, 2018).

The findings of study suggest that children who live in a village have lower stigma scale than children who live in the city. This may be due to the close relationships in village where people live around relatives and people who know each other and know what is the condition that the child faces. This makes children have less stigma score in that village than city. (Laurie & Richardson, 2021)

This study concludes that CF children whose parents have low financial income suffer from stigma more than other children whose parents have a good income. The income depends on the employment of the parents. Employed parents have high financial income more than unemployed ones so CF children who their parents have low income suffer from stigma more than CF children who their parents have good income, and this result was consistent with Kane et al. (2019) and Smythe et al. (2020).

In this study, the score of self-efficacies among children who have CF was moderate based on four Likert scale. According to Bravo et al. (2020), children who have chronic diseases have moderate self-efficacy to perform the activities that make them overcome the signs and symptoms of their illness. This study indicates that children have moderate self-efficacy to do ADL, performing actions that can decrease the doctor visits and medications adjustment. But when asked about emotional distress depending on the scale, it was a moderate result and the lowest one among all the items. This is because emotional distress occur when the child doesn't have the physical ability to do and perform a task (Rodriguez-Ayllon et al., 2018).

A study was conducted by Yigit et al, revealed that increase in stigma severity level decreases the self-efficacy and this yield to the in ability to perform the tasks that the child should do like ordinary peers in community (Yigit et al., 2020).

Adherence was one of the variables that has been assessed in this study and it is defined as the ability of the child to stick to the tasks and actions that must be done to achieve the goal of treatment. The findings revealed that children who have CF has moderate level of adherence to their condition and this is consistent with a systematic review conducted by (Gray et al., 2018).

Moreover, Gray et al. (2018) concluded that the awareness and the educational level of mothers affect the level of adherence to medications. This is consistent with the current study which found that the educational level plays an important role in adherence for Palestinian children with CF. Moreover, the item of missing some doses of medications that should the child take was scaled by low adherence. This is also consistent with Gray et al. (2018) where it is caused by denial and the medications don't impact signs and symptoms.

According to Kay et al. (2020) there association between stigma, self-efficacy and adherence to medications. The results revealed that decreased level of self-efficacy and increased level of stigma suggest less adherence to medications and medical condition responsibilities. This is in contrast with the current study which found that there is no relation between these three variables according to the data that has been analyzed in this study.

Conclusion:

children who have CF in west-banks has moderate level of health-related stigma, self-efficacy and treatment adherence. With no relation between these variables. Also, place of residency and economic state for child's parents paly and important role in perceived stigma, adherence to treatment and self-efficacy.

6.2 Limitations:

CF is a rare chronic disease affects children and due to the uniqueness of this illness and the low number of children who are allocated in different sites in the West Bank. The first limitation was the samples size which it was low. Second, the difficulty of accessibility for the children due to the different allocation of their living sites. Third, according to the literature review, there is not enough evidence-based researches that assess the level of stigma, adherence and self-

efficacy for children who have CF and this makes literature weak in demonstrating the relations also it makes difficulties in finding the proper tools to assess the relation-ships between health-related stigma, self-efficacy and adherence to treatment. But on the other side, this weakness considers one of the strengths for this study, because this study adds new information on literature about health-related stigma in children who have CF.

Forth, qualitative designs should be used instead on quantitative due to that this is the first study in Palestine, but quantitative designs used for the shortage of time and accessibility. Finally, presence of parents during questioner makes children shy from answering and this gives a bias for the results.

6.3 Recommendation:

Due to the lack of the evidence-based literature about assessing stigma, self-efficacy and adherence levels in children who have CF, a further study is recommended to assess these levels. Conducting new studies about the emotional and psychological state of children who have CF will enrich the literature with new suggestions and recommendations.

This study was the first study in Palestine that discusses the emotional and psychological aspect for children who have CF. A further study can be conducted in Palestine to assess psychological aspects for children who have CF, also this study can be a ground study that can benefit other studies.

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Appendices:

Appendix 1: Participant's responses distribution of items on stigma scale (S-S)

No	Items	Strongly disagree	Disagree	Agree	Strongly agree
1	I have been hurt by how people reacted to learning I have cystic fibrosis	4 (7.1)	41 (73.2)	11 (19.6)	0 (0.0)
2	I have stopped socializing with some people because of their reactions of my having cystic fibrosis	5 (8.9)	41 (73.2)	10 (17.9)	0 (0.0)
3	I have lost friends by telling them I have cystic fibrosis	5 (8.9)	42 (75.0)	9 (16.1)	0 (0.0)
4	I am very careful who I tell that I have cystic fibrosis	5 (8.9)	19 (33.9)	28 (50.0)	4 (7.1)
5	I worry that people who know I have cystic fibrosis will tell others	4 (7.1)	35 (62.5)	16 (28.6)	1 (1.8)
6	I feel that I am not as good a person as others because I have cystic fibrosis	4 (7.1)	41 (73.2)	11 (19.6)	0 (0.0)
7	Having cystic fibrosis makes me feel unclean	10 (17.9)	43 (76.8)	3 (5.4)	0 (0.0)
8	Having cystic fibrosis makes me feel that I'm a bad person	8 (14.3)	43 (76.8)	5 (8.9)	0 (0.0)

Appendix 2: Participant's responses distribution of items on the self-efficiency scale

No	Items	Not very confidant	Not confidant	Confidant	Very confidant
1	How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	2 (3.6)	31 (55.4)	21 (37.5)	2 (3.6)
2	How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	2 (3.6)	31 (55.4)	20 (35.7)	3 (5.4)
3	How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	3 (5.4)	34 (60.7)	18 (32.1)	1 (1.8)
4	How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	1 (1.8)	31 (55.4)	20 (35.7)	4 (7.1)
5	How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?	2 (3.6)	20 (35.7)	30 (53.6)	4 (7.1)
6	How confident are you that you can do things others than just taking medication to reduce how much your illness affects your everyday life?	0 (0.0)	25 (44.6)	27 (48.2)	4 (7.1)

Appendix 3: Participant's responses distribution of items on adherence to the treatment scale

No	Items	Never	Very low	Very low	Moderate	High
1	Do you always remember to take all your medications according to your doctor's instructions?	4 (7.1)	2 (3.6)	22 (39.3)	11 (19.6)	17 (30.4)
2	Do you find purchasing of the medications prescribed by your doctor a significant financial burden?	2 (3.6)	3 (5.4)	38 (67.9)	2 (3.6)	11 (19.6)
3	Do you happen to change the dosing of your medications without prior consultation with your doctor?	0 (0.0)	1 (1.8)	2 (14.3)	3 (10.7)	4 (73.2)
4	Do you adjust the dosing of your medications according to how you feel?	0 (0.0)	6 (10.7)	19 (33.9)	3 (5.4)	28 (50.0)
5	On the appearance of medication-related side effects (e.g. stomach pain, liver pain, rash, lack of appetite, oedema)	1 (1.8)	3 (5.4)	28 (50.0)	6 (10.7)	18 (32.1)
6	Do you find all your medications necessary for your health?	0 (0.0)	2 (3.6)	8 (14.3)	3 (5.4)	43 (76.8)
7	Does your doctor inquire about medication-related problems that you might possibly experience?	8 (14.3)	0 (0.0)	4 (7.1)	4 (7.1)	40 (71.4)
8	Do you always remember to take all your medications according to your doctor's instructions?	0 (0.0)	1 (1.8)	3 (5.4)	2 (3.6)	50 (89.3)

Appendix 4: the result of the pairwise test of mean score on adherence to the treatment scale due to children's education level

Pairwise groups	Test-statistic	Sig.
Secondary school- High school	6.114	1.000
Secondary school- Primary school	14.188	0.123
Secondary school- Collage	-19.167	0.705
High school- Primary school	8.073	0.559
High school- Collage	-13.053	1.000
Primary school- Collage	-4.979	1.000

Appendix 5: Questionnaire :

Cystic fibrosis stigma scale:

Question	Strongly disagree	disagree	agree	Strongly agree
1: I have been hurt by how people reacted to learning I have cystic fibrosis.				
2: I have stopped socializing with some people because of their reactions of my having cystic fibrosis.				
3: I have lost friends by telling them I have cystic fibrosis.				
4: I am very careful who I tell that I have cystic fibrosis.				
5: I worry that people who know I have cystic fibrosis will tell others.				
6: I feel that I am not as good a person as others because I have cystic fibrosis.				
7: Having cystic fibrosis makes me feel unclean				
8: Having cystic fibrosis makes me feel that I'm a bad person.				
9: Most people think that a person with cystic fibrosis is disgusting				
10: Most people with cystic fibrosis are rejected when others find out.				

Reference:

(Pakhale et al., 2014)

(Wright, Naar-King, Lam, Templin, & Frey, 2007)

Self-efficacy scale:

Question	**Strongly no confidant**	**No confidant**	**confidant**	**Strongly confidant**
1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?				
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?				
3: How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?				
4: How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?				
5: How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?				
6: How confident are you that you can do things others than just taking medication to reduce how much your illness affects your everyday life?				

(Freund, Gensichen, Goetz, Szecsenyi, & Mahler, 2013)

The Adherence Scale in Chronic Diseases

1. Do you always remember to take all your medications according to your doctor's instructions?

A. Always.

B. Almost always.

C. Sometimes.

D. Hardly ever.

E. Never.

2. Do you find purchasing of the medications prescribed by your doctor a significant financial burden?

A. No, it is insignificant.

B. It is burdensome, but acceptable.

C. It is financially cumbersome, but with some effort I can still afford to buy all my medications.

D. Occasionally I cannot afford to buy all my medications.

E. Frequently I cannot afford to buy all my medications.

3. Do you happen to change the dosing of your medications without prior consultation with your doctor?

A. Never.

B. Only occasionally.

C. Sometimes.

D. Frequently.

E. I do not adhere to my doctor's recommendations at all.

4. Do you adjust the dosing of your medications according to how you feel?

A. No, I strictly follow the prescribed dosing, no matter how I feel.

B. Yes, I reduce the dosage of some medications when I feel good.

C. Yes, I skip doses of some medications when I feel good.

D. Yes, I temporarily discontinue some medications when I feel good.

E. Yes, I discontinue all medications when I feel good.

5. On the appearance of medication-related side effects (e.g. stomach pain, liver pain, rash, lack of appetite, oedema):

A. I seek medical attention instantly.

B. I reduce the dosage of the medication and attempt to expedite the elective appointment with my doctor.

C. I discontinue the medication and attempt to expedite the elective appointment with my doctor.

D. I discontinue the medication and wait for the next elective appointment with my doctor.

E. I discontinue all my medications and wait for the next elective appointment with my doctor.

6. Do you find all your medications necessary for your health?

A. Yes, I do.

B. I find most of my medications to be beneficial for my health.

C. I find only some of my medications to be beneficial for my health.

D. I find some of my medications to be beneficial for my health, while the others to be harmful for me. E. I find the majority of my long-term medications to be harmful for me.

7. Does your doctor inquire about medication-related problems that you might possibly experience?

A. Yes, on every appointment.

B. Yes, he/she usually does.

C. Yes, but only sometimes.

D. Yes, but only occasionally.

E. No, never.

8. Do you tell truth when asked by your doctor about medication-related problems?

A. Yes, always.

B. Almost always.

C. I try to be honest, but sometimes it is hard to admit to non-compliance with doctor's recommendations

D. Sometimes yes, another time no.

E. No, I don't. I find it my own private business

(Buszko et al., 2016)

Appendix 6: الاستبانة

مقياس وصمة التليف الكيسي:

السؤال	غير موافق بشدة	غير موافق	موافق	موافق بشدة
1: لقد تأذيت من رد فعل الناس عندما عرفوا أنني مصاب/ة بالتليف الكيسي.				
2: لقد توقفت عن التواصل مع بعض الأشخاص بسبب ردود أفعالهم على إصابتي بالتليف الكيسي.				
3: ابتعد عني بعض الأصدقاء عندما أخبرتهم أنني مصاب/ة بالتليف الكيسي				
4: أنا حريص جدًا على انتقاء من أقول له إنني مصاب/ة بالتليف الكيسي				
5: أخشى من أن يخبر الأشخاص الذين يعرفون أنني مصاب/ة بالتليف الكيسي أشخاص آخرين.				
6: أشعر أنني لست كالآخرين لأنني مصاب/ة بالتليف الكيسي.				
7: تجعلني الإصابة بالتليف الكيسي أشعر بأنني غير نظيف/ة				
8: تجعلني الإصابة بالتليف الكيسي أشعر أنني شخص سيء.				
9: يعتقد معظم الناس أن الشخص المصاب بالتليف الكيسي مثير للاشمئزاز				
10: يبتعد الأشخاص عن معظم المصابين بالتليف عندما يكتشفون أنهم مصابين.				

المرجع:

(Pakhale et al., 2014)

(Wright, Naar-King, Lam, Templin, & Frey, 2007)

مقياس القدرة الذاتية:

السؤال	غير قادر بشدة	غير قادر	قادر	قادر بشدة
1. ما مدى قدرتك على السيطرة على التعب الذي يسببه مرضك لكي لا يمنعك من عمل الأمور التي تريد القيام بها؟				
2. ما مدى قدرتك على منع الألم الناتج عن مرضك من التأثير على الأمور التي تريد القيام بها؟				
3 :ما مدى قدرتك على منع الاضطراب العاطفي الذي يسببه مرضك من التأثير على الأمور التي تريد القيام بها؟				
4: ما مدى قدرتك على منع أي أعراض أو مشاكل صحية أخرى لديك من التأثير على الأمور التي تريد القيام بها؟				
5 :ما مدى قدرتك على أداء المهام والأنشطة المختلفة اللازمة لإدارة حالتك الصحية لتقليل حاجتك إلى زيارة الطبيب؟				
6 :ما مدى قدرتك على فعل أشياء أخرى غير تناول الأدوية لتقليل مدى تأثير مرضك على حياتك اليومية؟				

(Freund, Gensichen, Goetz, Szecsenyi, & Mahler, 2013)

مقياس الالتزام في حال وجود مرض مزمن

1. هل تتذكر دائمًا تناول جميع أدويتك وفقًا لتعليمات طبيبك؟

. أ دائما.

ب. تقريبا دائما.

ج. أحيانا.

د. نادرا.

ه. أبدا.

2. هل يعد شراء الأدوية التي وصفها لك الطبيب عبئًا ماليًا كبيرًا؟

أ. لا، أمرها لا يذكر

ب. أمر مرهق ولكنه مقبول

ج. يعتبر أمر مرهق من الناحية المالية، لكن مع بعض الجهد لا يزال بإمكاني شراء جميع الأدوية.

د. لا أستطيع شراء جميع الأدوية الخاصة بي في بعض الأحيان

ه. لا أستطيع شراء جميع الأدوية الخاصة بي في كثير من الأحيان

3. هل قمت بتغيير جرعات أدويتك دون استشارة طبيبك مسبقًا؟

أ. أبدا

ب. مرات قليلة

ج. في بعض الأحيان.

د. في كثير من الأحيان.

ه. لا ألتزم بتوصيات طبيبي على الإطلاق

4. هل تقوم بتعديل جرعات الأدوية الخاصة بك وفقًا لما تشعر به؟

أ: لا، أنا أتبع بدقة الجرعات الموصوفة، بغض النظر عن شعوري.

ب: نعم، أقوم بتقليل جرعة بعض الأدوية عندما أشعر أنني بحالة جيدة.

ج. نعم، أتخطى جرعات بعض الأدوية عندما أشعر أنني بحالة جيدة.

د. نعم، أوقف بعض الأدوية مؤقتًا عندما أشعر أنني بحالة جيدة.

ه. نعم، أتوقف عن تناول جميع الأدوية عندما أشعر أنني بحالة جيدة

5. عند ظهور الآثار الجانبية المرتبطة بالأدوية (مثل آلام المعدة، آلام الكبد، الطفح الجلدي، قلة الشهية، الوذمة "تجمع الماء بالجسم"):

أ: أطلب الرعاية الطبية فورا.

ب. أقلل جرعة الدواء وأحاول تقديم تاريخ الموعد المحدد مع طبيبي.

ج. أوقف الدواء وأحاول تقديم تاريخ الموعد المحدد مع طبيبي.

د. أوقف الدواء وانتظر الموعد المحدد التالي مع طبيبي.

ه. أوقف جميع الأدوية وانتظر الموعد المحدد مع طبيبي.

6. هل تعتقد أن كل أدويتك ضرورية لصحتك؟

أ: نعم، أعتقد ذلك.

ب. أعتقد أن معظم الأدوية التي أتناولها مفيدة لصحتي.

ج- أعتقد أن بعض الأدوية التي أتناولها فقط مفيدة لصحتي.

د- أعتقد أن بعض الأدوية التي أتناولها مفيدة لصحتي، في حين أن بعضها الآخر ضار بي.

هـ. أعتقد أن غالبية الأدوية طويلة الأمد تضر بي.

7. هل يسأل طبيبك عن المشكلات التي قد تواجهك بسبب الأدوية؟

أ: نعم، يسأل في كل موعد.

ب. نعم، عادة ما يفعل ذلك.

ج. نعم، ولكن في بعض الأحيان فقط.

د. نعم، ولكن في بعض الأحيان فقط.

ه. لا يسأل عن ذلك أبدا.

8. هل تجيب بصدق عندما يسأل طبيبك عن المشاكل المتعلقة بالأدوية؟

أ: نعم دائما.

ب. تقريبا دائما.

ج. أحاول أن أكون صادقًا، لكن في بعض الأحيان يصعب الاعتراف بأنني لا امتثل لتوصيات الطبيب

د. أحيانًا نعم، وأحيانا لا.

ه. لا، لأنني اعتقد أنها أمور خاصة بي

Appendix 7: Letter of Approval

Al Quds University
Faculty of Health Professions
Jerusalem –Abu Dis

جامعة القدس
كلية المهن الصحية
القدس – أبو ديس

Research Ethics Subcommittee of Faculty of Health Professions
Letter of approval

May 24, 2022
Ref. No.: RESC/2022-12

Dear Applicants, (**Dr. Kawther Alayasa, Dr. Salam Alkhatib, Ms. Fida Turkman**)
Program: **MSc Nursing Department**

The Research Ethics subcommittee of Faculty of Health Professions has recently reviewed your proposal entitled (**The adherence, self-efficacy, and stigma in children with cystic fibrosis in Palestine**) submitted by (**Dr. Kawther Alayasa, Dr. Salam Alkhatib**). Your proposal is deemed to meet the requirements of research ethics at Al-Quds University, but further assessment is required by the Central Research Ethics Committee of Al-Quds University. We wish you all best for the conduct of the project.

Hussein ALMasri
Research Ethics Subcommittee Chair
Faculty of Health Professions

Hussein ALMasri

CC: File
CC: Committee members

Tel. Fax: 02 2791243 Email: dean@hpro.alquds.edu تلفاكس: 02 2791243